

Errata

- p69 Para 2 - Delete 'infamous' to read: '... The Rosenhan (1973) study illustrated ...'
- p111 Para 2 - Change 'This study wanted' to 'The researcher wanted the opportunity ...'
- p246 Para 3 - Insert 'The' to 'The current government, in response to recent violent incidents in the community where it has been claimed that individuals have stopped their medication, is discussing the possibilities of compulsory drug treatment orders in the community.'
- p403 Line 4 - Change '... this thesis offers three advantages to previous research.' to '... this thesis offers three advances on previous research.'
- p404 Para 3 - Change 'This study wanted' to 'The researcher wanted to maximise the opportunity ...'
- p422 Insert in the 2nd para - after 'However, limitations were evident with the negative skew of the adherence data and so quantitative analyses could only be exploratory. Further, it was recognised that the medication adherence measure adopted in this study did not necessarily reflect an individual's autonomy to adhere or not adhere to medication. Outreach services provided by community psychiatric nursing staff were employed to ensure that some patients received their medication. The use of outreach services was not always consistent with patients and therefore, it was not possible to analyse the data according to those patients who were free to choose to take their medication and those who were not free to choose to take their medication. Freedom to choose to adhere to medication was also confounded by other influential factors such as the hostel policy that may insist that staff members accompany patients for their medication, follow-up phone calls or visits by clinic staff if a patient missed an appointment for their medication. For the same patient, such factors varied on each occasion that the depot medication was due according to the behaviour of the patient. Therefore, it is acknowledged that examining medication adherence solely as a quantitative variable (in terms of the proportion of doses of medication received divided by the total number of doses expected according to the prescribed regimen) was a further limitation to the interpretation of the study data.'
- p424 Insert as a new paragraph after '... In support of these findings and recommendations, Diamond (1985) published case studies of patients with schizophrenia illustrating how individual patient's priorities and preferences affected their attitudes to medication, their tolerance of adverse effects and their acceptance or rejection of treatment.'

'The results presented in this thesis in relation to adherence to depot antipsychotic

drug therapy may also be interpreted in light of the social cognition model: the health belief model (HBM) (for more details see Rosenstock, 1966; Becker, 1974; Sheeran and Abraham, 1996). Social cognition models are used to interpret health behaviours by describing the important cognitions and how these are related to the regulation of different types of behaviour (Conner and Norman, 1996:6). Other authors have used these models while researching the behaviour of patients with mental health problems (e.g. Kelly, 1987; Pan and Tantom, 1989).

The first and second constructs (*perceived susceptibility of an illness or health breakdown and the anticipated severity of the consequences of illness*) were reflected by the respondents' perceptions of their symptoms and problems both at the time of admission and at the interviews in the hospital and the community. Respondents discussed their perceived insight to their illness and their perceptions of the consequences of taking medication, not taking medication and the consequences of the illness itself in relation to their everyday life.

The perceived *benefits or efficacies of adhering to their depot medication* (third construct) were clearly of importance to the respondents. Qualitative data in response to open questions demonstrated the positive consequences of attending for their depot medication. Similarly, the perceived *costs of or barriers to adhering to medication* (fourth construct) were also illustrated through the responses to open questions about the experiences of medication. Respondents described both positive and negative aspects of their perceived illness careers, and their experiences of their illness and medication in controlling the symptoms of their illness. From the qualitative data, some respondents clearly described a risk-benefit analysis of the medication that informed their future use of medication.

Triggers contributing to adherent or non-adherent behaviour (*cues to action*) were demonstrated through the interview data. Internal factors were represented by the respondent's recognition of the onset of a psychotic episode, linking with insight to the illness and recognising the need to come into the hospital. External factors also contributed to medication taking behaviour such as advice from family and friends, different pathways of admission to the hospital and the involvement of outreach services in engaging patients in depot medication (e.g. home visits by the community psychiatric nurses).

Health motivation (the sixth construct) was less comprehensively represented. In some of the qualitative comments, respondents recognised the need for medication which may be interpreted as a readiness to be concerned about health matters. However, this construct would be dependent on the effectiveness of medication and the depth of insight respondents had into their illness.

While using social cognition models may be an alternative way of interpreting this

data, caution must be applied to the results. The questionnaire interview schedule used in this research was not based on the HBM. Therefore, the reliability and validity of the data in reflecting the six constructs of the HBM may not be determined. Also, there are general weaknesses of the HBM that have been recognised elsewhere (e.g. Sheeran and Abraham, 1996; Conner and Norman, 1996) such as the lack of explicit inclusion of the perception of control over the performance of the behaviour which could be an important omission with this data. Further the model does not distinguish between the motivation to be adherent to medication and the action phase where medication adherence may be planned, performed and maintained. Future research considering medication adherence with people with a diagnosis of schizophrenia may wish to be based on the HBM where a longitudinal method may take into account a motivational and action phase of behaviour.'

- p427 Line 5 - Change 'voluntary' to 'voluntarily'.
Line 6 - Change '... fewer medication' to '... fewer medications.'
- p431 Insert 'Becker, M.H. (1974) The health belief model and sick role behaviour. *Health Education Monographs* 2, 409-419.'
- p432 Insert 'Bowling, A. and Parkman, S. (1993) A study of the needs of users of the psychiatric services in City and Hackney, with particular reference to those with a diagnosis of schizophrenia. Health Needs Assessment Unit, St. Bartholomew's Hospital Medical College, London.'
- p434 Insert 'Conner, M. and Norman, P. (1996) The role of social cognition in health behaviours. In: Conner, M. and Norman, P. (Eds.) *Predicting health behaviour*, pp. 1-22. Buckingham: Open University Press.'
- p451 Insert 'Rosenstock, I.M. (1966) Why people use health services. *Millbank Memorial Fund Quarterly* 44, 94-124.'
- p451 Insert 'Sheeran, P. and Abraham, C. (1996) The health belief model. In: Conner, M. and Norman, P. (Eds.) *Predicting health behaviour*, pp. 23-61. Buckingham: Open University Press.'

Medication and quality of life: a study of people with a diagnosis of schizophrenia

Thesis submitted in accordance with the requirements of the
University of London for the degree of Doctor of Philosophy by

Sally-Anne Francis

University College London Medical School

April 1998

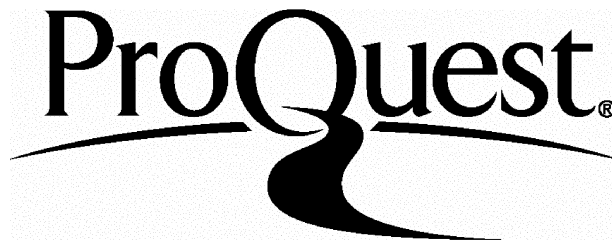
ProQuest Number: U644147

All rights reserved

INFORMATION TO ALL USERS

The quality of this reproduction is dependent upon the quality of the copy submitted.

In the unlikely event that the author did not send a complete manuscript and there are missing pages, these will be noted. Also, if material had to be removed, a note will indicate the deletion.



ProQuest U644147

Published by ProQuest LLC(2016). Copyright of the Dissertation is held by the Author.

All rights reserved.

This work is protected against unauthorized copying under Title 17, United States Code.
Microform Edition © ProQuest LLC.

ProQuest LLC
789 East Eisenhower Parkway
P.O. Box 1346
Ann Arbor, MI 48106-1346

In memory of my mother, Elizabeth Jane Francis

Abstract

Drug therapy is the most common form of treatment for schizophrenia. Few studies have focused on the measurement of the outcome of antipsychotic drug therapy on an individual's quality of life (QoL). The conceptual model of QoL adopted in this study was based on needs satisfaction and life satisfaction models. However, individuals can vary and therefore, including an assessment of the importance of areas of life to the individual is also valuable. These models were operationalised using adapted questions from the Schedule for the Evaluation of Quality of Life (SEIQoL) and the Lancashire Quality of Life Profile. Adults aged 18-64 years with a DSM-III-R diagnosis of schizophrenia and prescribed depot antipsychotic medication were interviewed in hospital and after discharge in the community.

The majority of the study sample were able to respond to the adapted SEIQoL approach. The areas of life generated questioned the content validity of the Lancashire Quality of Life Profile at an item-specific level. By combining approaches, the QoL data generated may be assured of reliability and permit comparable measurement but also with validity and relevance to the individual.

Qualitative data demonstrated the positive and negative effects of medication on respondents' QoL. Quantitatively, measures of subjective well-being did not predict the rate of medication adherence. Analysis of the data suggested that current QoL instruments are not sensitive enough to measure the outcomes of antipsychotic drug therapy.

Inductive analysis of the qualitative data identified different types of medication-taking behaviour that may be interpreted in relation to 'perceived coercion' and QoL. Future health care policies may focus on compulsory drug therapy in the community. While treatment orders may be justified for the care of the patient and those around them, the management of patients may be conducted so that individuals feel more involved in the process and less coerced.

Contents

List of tables	12
List of figures	18
Acknowledgements	19
Preface	20

PART ONE - INTRODUCTION

CHAPTER 1 - SCHIZOPHRENIA	23
1.1 Introduction	23
1.2 An overview of schizophrenia	23
1.2.1 Epidemiology of schizophrenia	23
1.2.2 Diagnosis of schizophrenia	25
1.2.3 Aetiology of schizophrenia	25
1.2.4 Signs and symptoms of schizophrenia	26
1.2.5 Prognosis of schizophrenia	26
1.3 Drug treatment of schizophrenia	27
1.3.1 Traditional antipsychotic drug therapy	29
1.3.2 Atypical antipsychotic drug therapy	31
1.3.3 Depot preparations of antipsychotic drug therapy	31
1.4 Mental health policy in the last decade	32
1.5 Living in the community with schizophrenia: issues and concepts relevant to quality of life	34
1.5.1 Social isolation	34
1.5.2 The stigma of schizophrenia	36
1.5.3 Insight and schizophrenia	38
1.5.3.1 Insight and patterns of service use	39
1.5.3.2 Insight and medication adherence	40
1.5.4 The role of medication	43
1.5.4.1 Medication taking behaviour and medication adherence	44
1.5.4.2 Subjective evaluation of medication	48
1.5.4.3 Medication and quality of life	50

CHAPTER 2 - QUALITY OF LIFE MEASUREMENT	54
2.1 Introduction	54
2.2 The conceptual debate of ‘quality of life’	55
2.2.1 Is quality of life about human needs or human wants?	57
2.2.2 Is quality of life more than we can measure?	60
2.2.3 Defining quality of life	62
2.3 The mental health perspective on quality of life	63
2.4 Assessment of quality of life	68
2.4.1 Who should measure quality of life?	68
2.4.2 Reliability and validity of reports by respondents who have mental health problems	69
2.4.3 How do we measure quality of life?	70
2.4.3.1 Respondent-led quality of life measurement	71
2.4.3.2 Qualitative approaches to the measurement of quality of life and changes in quality of life in schizophrenia	73
2.4.3.3 Popular quality of life measures used in outcome studies of schizophrenia	78
2.5 Summary	88

PART TWO - METHODOLOGY

CHAPTER 3-PILOT WORK	92
3.1 Pilot work: a study of psychiatric in-patients	92
3.2 Pilot work: semi-structured interviews with attenders of community psychiatric nurse ‘depot’ clinics	97
CHAPTER 4-THE MAIN STUDY PROPOSAL	110
4.1 Introduction	110
4.2 The aim of the study	110
4.3 The objectives of the study	112
4.4 The study method	113
4.5 The sample	115
4.5.1 Description of the sample	115

4.5.2	Determination of the sample size	115
4.6	Measurements used in the study	117
4.7	Limitations of the study	121
4.8	Methods of analysis	122

CHAPTER 5-PILOTING OF STUDY QUESTIONNAIRES AND ETHICAL

REVIEW	123

5.1	Pilot of community questionnaire at community psychiatric nurse ‘depot’ clinics	123
5.2	Decisions advised by the district research ethics committees	125

PART THREE - RESULTS

CHAPTER 6- RECRUITMENT INTERVIEW AND MEDICATION ISSUES

IN HOSPITAL		130
6.1	Introduction	130
6.2	Characteristics of the respondents	134
6.2.1	Socio-demographic characteristics	134
6.2.2	Admission details of the respondents	139
6.2.3	Diagnosis	142
6.3	Recruitment interview at hospital	142
6.3.1	Home circumstances	143
6.3.2	Relative support	144
6.3.3	Employment history	146
6.3.4	Insight	148
6.3.5	Symptoms and problems on admission and at time of recruitment interview	149
6.3.6	Severity of illness	156
6.3.7	Permission to contact general practitioners and significant others	157
6.4	Medication issues in hospital	159
6.4.1	Knowledge of medication	159
6.4.2	Effect of medication on symptoms	162
	6.4.2.1 Role of medication in managing symptoms	164
6.4.3	Unwanted effects of medication	166

6.4.3.1	Consequences of adhering to medication	169
6.4.3.2	Other / physical health problems that are potential medication-related effects	171
6.4.3.3	Mistrust of medication, hospital and its staff	171
6.4.4	Experience of non-adherence to medication	173
6.4.4.1	Consequences of illness	176
6.4.5	Behaviour of respondents in managing their medication	176
6.4.5.1	Behaviour influencers: hospital staff commanders	181
6.4.5.2	Behaviour influencers: community staff	182
6.4.6	Therapeutic information gaps expressed by respondents	182
6.4.7	Intentions of medication adherence after discharge	183

CHAPTER 7- COMMUNITY INTERVIEW AND MEDICATION ISSUES

IN THE COMMUNITY	188
7.1 Introduction	188
7.1.1 Medication characteristics of discharged sample	189
7.2 Community interview	190
7.2.1 Problems associated with the follow-up period	190
7.2.2 Insight	195
7.2.3 Informed	197
7.2.4 Stigma	198
7.2.5 Symptoms and problems at time of community interview	199
7.2.6 Severity of illness in the community	202
7.2.7 Contacting general practitioners in the community	205
7.2.8 Permission to contact significant others	205
7.3 Medication issues in the community	206
7.3.1 Medication adherence	206
7.3.2 Knowledge of medication	208
7.3.3 Effect of medication on symptoms	211
7.3.3.1 Role of medication in managing symptoms	214
7.3.4 Unwanted effects of medication	216
7.3.4.1 Consequences of adhering to medication	218

7.3.4.2 Other / physical health problems that are potential medication -related effects	220
7.3.3.3 Mistrust of medication and the community health staff	220
7.3.5 Experience of non-adherence to medication	221
7.3.5.1 Consequences of illness	223
7.3.6 Behaviour of respondents in managing their medication	224
7.3.6.1 Behaviour influencers: community staff commanders	228
7.3.7 Therapeutic information gaps expressed by respondents	230
7.3.8 Medication changes since discharge from hospital	231
7.3.9 Intentions of medication adherence after discharge from hospital and resulting medication adherence in the community	232
7.3.10 Non-attenders for depot medication	233
7.3.10.1 Reasons for stopping attendance for depot medication	233
7.3.10.2 Consequences of stopping depot medication	235
7.4 Summary	237
 CHAPTER 8-QUALITY OF LIFE IN THE COMMUNITY	 254
8.1 Respondent-defined quality of life	254
8.1.1 Introduction	254
8.1.2 Quality of life: five most important areas of life in rank order of importance ..	255
8.1.3 Current quality of life status	258
8.1.4 Quality of life: five most important areas of life affected by illness	260
8.2 Quality of life as measured by the Lancashire Quality of Life Profile	262
8.2.1 Introduction	262
8.2.2 Objective indicators of quality of life by domain	262
8.2.3 Subjective well-being	274
8.2.3.1 Perceived quality of life by domain	274
8.2.3.2 Subjective global well-being	283
8.2.3.3 Psychological well-being: the Affect-Balance Scale	286
8.2.3.4 Self-concept: the Self-Esteem Scale	290
8.2.3.5 Cantril's Ladder	294
8.2.3.6 Happiness: The Happiness Scale	295

8.3	Psychometric properties of the Lancashire Quality of Life Profile	297
8.3.1	Reliability	297
8.3.1.1	Test-retest reliability	297
8.3.1.2	Reliability of scale scores	299
8.3.2	Validity	300
8.3.2.1	Content validity	300
8.3.2.2	Construct validity	305
8.4	Summary	308
 CHAPTER 9-SOCIAL NETWORKS AND COMMUNITY CARE		330
9.1	Social networks	330
9.1.2	Social isolation (personal contacts and professional carers)	334
9.1.2.1	Personal contacts	335
9.1.2.2	Daily and weekly contacts	335
9.1.2.3	Satisfaction with contacts	336
9.1.3	Further analyses with social contacts	337
9.1.4	Summary	338
9.2	Care Programme Approach	339
9.2.1	Summary	346
9.3	Postal questionnaire to significant others	347
9.3.1	Medication issues	348
9.3.1.1	Effect of medication on respondents' symptoms of illness	348
9.3.1.2	Respondents' problems with the medication	350
9.3.1.3	Respondents' non-adherence with medication	352
9.3.1.4	Opinions of the respondents' medication	354
9.3.2	Respondents' social networks	358
9.3.3	Objective indicators of the Lancashire Quality of Life Profile	360
9.3.4	Items that would improve the respondents' quality of life	363
9.3.5	Summary	367
 CHAPTER 10-FURTHER ANALYSES OF MEDICATION ISSUES AND FURTHER ANALYSES OF QUALITY OF LIFE		369
10.1	Introduction	370

10.2 Chapter 10a: Further analyses of medication issues	370
10.2.1 Variations by sex	371
10.2.2 Variations by ethnic group	371
10.2.3 Variations by country of birth	371
10.2.4 Variations by Mental Health Act (1983) Status	371
10.2.5 Variations by severity of illness	372
10.2.6 Variations by depot attendance	373
10.2.7 Summary of bivariate relationships with medication issues	373
10.3 Multiple regression analysis of medication adherence	375
10.3.1 Model 1: General attendance rate for depot medication	375
10.3.2 Model 2: Attendance rate for depot medication on the expected day according to prescription	380
10.4 Chapter 10b: Further analyses of quality of life issues	385
10.4.1 Variations by sex	385
10.4.2 Variations by age	387
10.4.3 Variations by ethnic group	387
10.4.4 Variations by country of birth	388
10.4.5 Variations by Mental Health Act (1983) Status	389
10.4.6 Variations by severity of illness	392
10.4.7 Variations by depot attendance	392
10.4.8 Summary of bivariate relationships with quality of life issues	394
10.5 Multiple regression analysis of global well-being	396
10.5.1 Model 3: Global well-being	396

PART FOUR-CONCLUSIONS

CHAPTER 11-DISCUSSION AND CONCLUSIONS	402
11.1 Methodological difficulties experienced during the study	403
11.2 The limitations of the study	405
11.3 Quality of life measurement in schizophrenia research	407
11.4 How is antipsychotic medication related to the quality of life of people with schizophrenia?	417
11.5 Implications for the community care of people with schizophrenia	426

References	429
Appendices	i-xcviii
Appendix One	Popular quality of life (QoL) measures used in outcome studies of schizophrenia ii
Appendix Two	Requirements of a quality of life instrument xiii
Appendix Three	Letter of invitation for pilot work with attenders of community psychiatric nurse clinics xvi
Appendix Four	Semi-structured interview schedule for pilot work with attenders of community psychiatric nurse clinics xvii
Appendix Five	Patient consent form for main research study xviii
Appendix Six	Patient information leaflet for main research study xix
Appendix Seven	The recruitment questionnaire xxii
Appendix Eight	The community questionnaire xl
Appendix Nine	The carer questionnaire lxxi
Appendix Ten	Diagnosis of schizophrenia according to the Diagnostic and Statistical Manual of Mental Disorders (3 rd edn., revised) (DSM-III-R) (American Psychiatric Association, 1987) lxxxii
Appendix Eleven	Case reports of respondents followed-up greater than six months after discharge lxxxiii
Appendix Twelve	Five areas of life that contribute to quality of life generated using adapted Schedule for the Evaluation of Individual Quality of Life (SEIQoL) questions lxxxvi
Appendix Thirteen	Rating of current quality of life in relation to all areas of life named (ranks 1-5) xcvi

List of tables

Table 2.1	Summary of the most popular domains included in quality of life instruments used with respondents with schizophrenia	86
Table 2.2	Summary of the characteristics of the quality of life instruments used with respondents with schizophrenia	87
Table 3.1	In-patients' views of their medication	94
Table 3.2	Characteristics of the regular attenders interviewed at the four community psychiatric nurse depot clinics	99
Table 6.1	Recruitment phases and the number of patients recruited to the study by ward and consultant	130
Table 6.2	Socio-demographic characteristics of the respondents	135
Table 6.3	Personal histories of the respondents	138
Table 6.4	Psychiatric histories of the respondents taken from medical notes	139
Table 6.5	Admission details of the respondents taken from medical notes	141
Table 6.6	Accommodation details of the respondents	144
Table 6.7	Relative support expected after discharge from hospital	146
Table 6.8	Employment histories of the respondents	147
Table 6.9	Insight of the respondents	149
Table 6.10	Reasons for admission as reported by the respondents	150
Table 6.11	Symptoms on admission as reported by the respondents	151
Table 6.12	Current symptoms at the time of the recruitment interview as reported by the respondents	152
Table 6.13	Symptoms on admission taken from medical notes	153
Table 6.14	Problems on admission as reported by the respondents	154
Table 6.15	Current problems at the time of the recruitment interview as reported by the respondents	155
Table 6.16	Physical or other health problems reported by the respondents	156
Table 6.17	Global Assessment of Functioning Scale (GAF Scale) rating (severity of illness) of the respondents	158
Table 6.18	Respondents willing to name general practitioners and significant others for an interview	159
Table 6.19	Self-reported ability to name prescribed medication	160

Table 6.20	Details of prescribed medication as reported by the respondents	161
Table 6.21	Respondents' perceived effects of medication on symptoms	163
Table 6.22	Problems with medication as reported by the respondents	168
Table 6.23	The consequences of taking medication and the symptoms of illness as reported by the respondents	169
Table 6.24	Non-adherence to medication as reported by the respondents	174
Table 6.25	Intentions of medication adherence after discharge from hospital	184
Table 7.1	Length of stay in hospital	188
Table 7.2	Details of the medication prescribed at discharge taken from the medical notes	189
Table 7.3	Time from discharge to follow-up interviews in the community	190
Table 7.4	Total number of meetings required to complete the community interview	194
Table 7.5	Range of places for the community interviews	195
Table 7.6	Insight of the respondents	196
Table 7.7	Respondents' views of how informed they feel about the state of their health	197
Table 7.8	Respondents' views of the stigma associated with the state of their health	198
Table 7.9	Current symptoms reported when in-patients and at the time of the community interview	200
Table 7.10	Current problems reported when in-patients and at the time of the community interview	201
Table 7.11	Physical or other health problems reported when in-patients and at the time of the community interview	202
Table 7.12	Global Assessment of Functioning Scale (GAF Scale) rating (severity of illness) of the respondents	204
Table 7.13	Respondents willing to name significant others for an interview	205
Table 7.14	Medication adherence status after discharge from hospital	207
Table 7.15	The services responsible for the administration of the respondents' depot antipsychotic medication	207
Table 7.16	Type of service required for the administration of the depot	

	antipsychotic medication by depot attendance status	208
Table 7.17	Self-reported ability to name prescribed medication	209
Table 7.18	Details of prescribed medication as reported by the respondents	210
Table 7.19	Respondents' perceived effects of medication on symptoms	213
Table 7.20	Respondents' perceived symptom level since taking medication	214
Table 7.21	Problems with medication as reported by the respondents	217
Table 7.22	The consequences of taking medication and the symptoms of illness as reported by the respondents	218
Table 7.23	Non-adherence to medication as reported by the respondents	222
Table 7.24	Medication changes after discharge from hospital as reported by the respondents	231
Table 7.25	Intentions of medication adherence after discharge and resulting adherence status	232
Table 8.1	First to fifth most important areas of life named by the respondents . . .	257
Table 8.2	Feelings about life in relation to the most important areas of life named and life as a whole	259
Table 8.3	First to fifth most important areas of life affected by illness named by the respondents	261
Table 8.4	Activities of the respondents in the previous fortnight	263
Table 8.5	Current religion of the respondents	264
Table 8.6	Number of times the respondents attended religious service in the previous month	264
Table 8.7	Perceived-wealth of the respondents	267
Table 8.8	Living circumstances of the respondents	268
Table 8.9	The current marital status of respondents and their number of children	270
Table 8.10	Frequency of contact with a relative	270
Table 8.11	Respondents' perceived needs for social relations	273
Table 8.12	Age of respondents at their first admission to a psychiatric hospital or ward	272
Table 8.13	Health of the respondents during the last year	273
Table 8.14	Satisfaction with employment status	275
Table 8.15	Satisfaction with activities inside and outside the home	276

Table 8.16	Satisfaction with religion	276
Table 8.17	Satisfaction with finances	277
Table 8.18	Satisfaction with living situation	279
Table 8.19	Satisfaction with personal safety and the safety of the neighbourhood	280
Table 8.20	Satisfaction with family relations	281
Table 8.21	Satisfaction with social relations	282
Table 8.22	Satisfaction with health	283
Table 8.23	Do you feel different today?	284
Table 8.24	General well-being of respondents pre- (GWB-I) and post- (GWB-II) Lancashire Quality of Life Profile	286
Table 8.25	Respondents' psychological well-being	288
Table 8.26	Respondents' self-esteem	292
Table 8.27	Test-retest reliability measured using the general well-being ratings of the respondents pre- and post-Lancashire Quality of Life Profile . .	298
Table 8.28	Inter-item reliability for the three multi-item subjective well-being scales	299
Table 8.29	Areas of life that would improve quality of life as reported by the respondents	302
Table 8.30	Respondent-defined important areas of life compared with the domains of the Lancashire Quality of Life Profile and the free-response items at the end of the Lancashire Quality of Life Profile	303
Table 8.31	Spearman Inter-Correlations for Subjective Global Well-Being (GWB) Measures and Psychological Well-Being (PWB) Measures . . .	307
Table 8.32	Rank order of areas of life compared between the community sample with schizophrenia (this study), the British Omnibus Sample (total) and the British Omnibus Sample (mental illness) (from Bowling 1995)	313
Table 8.33	Inter-item reliability for three multi-item subjective well-being scales comparing this study data with published data (Oliver <i>et</i> <i>al.</i> 1996:70)	322
Table 8.34	Spearman Inter-Correlations for Subjective Global Well-Being (GWB) Measures and Psychological Well-Being (PWB) Measures:	

	Study data (in bold) and published data (Oliver <i>et al.</i> 1996:73)	326
Table 9.1	Number and frequency of contacts with others in the community	331
Table 9.2	Number and frequency of 'other' contacts in the community	332
Table 9.3	Number of and type of contacts in the community	334
Table 9.4	Number of respondents mixed or dissatisfied with perceived quality of life variables taken from the domains of living situation, family relations and social relations (Lancashire Quality of Life Profile)	336
Table 9.5	Care Programme Approach plans reported by the respondents	340
Table 9.6	Satisfaction with Care Plans	343
Table 9.7	Care Programme Approach plans wanted by the respondents	344
Table 9.8	Responders and non-responders of the significant other questionnaire	348
Table 9.9	A comparison of the perceived problems with the respondents' medication reported by the respondents and the significant others	351
Table 9.10	A comparison of the number of respondents' contacts reported by the respondents and the significant others	359
Table 9.11	Rate of agreement between the respondents and the significant others in reporting contact (or no contact) with others	360
Table 9.12	A comparison of the objective indicators of the Lancashire Quality of Life Profile reported by the respondents and the significant others .	362
Table 9.13	Rate of agreement between the respondents and the significant others in reporting the objective indicators of the Lancashire Quality of Life Profile	363
Table 10.1	Correlation matrix of general attendance rate for depot medication (medication adherence) with other variables of interest . . .	376
Table 10.2	Model 1: Regression of general attendance rate for depot medication (medication adherence) on severity of illness in hospital, Affect-Balance total score and total weekly income	379
Table 10.3	Model 2: Regression of depot attendance on expected day on knowledge of medication by name in hospital, level of educational and technical qualifications, problems making symptoms worse and ethnic group	382
Table 10.4	Variation of quality of life variables by sex	386

Table 10.5	Variation of quality of life variables by country of birth	389
Table 10.6	Variation of quality of life variables by Mental Health Act (1983) Status	391
Table 10.7	Variation of quality of life variables by depot attendance	394
Table 10.8	Model 3: Regression of global well-being on satisfaction with activities completed outside the home, Self-Esteem total score, satisfaction with the amount of independence at current residence and severity of illness in hospital	400

List of figures

Figure 6.1	Schematic representation of the outcome of the study population	132
Figure 7.1	Schematic representation of data collection period	193
Figure 8.1a	Positive affect sub-scores of the Affect-Balance Scale (n=41)	289
Figure 8.1b	Negative affect sub-scores of the Affect-Balance Scale (n=41)	289
Figure 8.1c	Total scores of the Affect-Balance Scale (n=41)	290
Figure 8.2a	Positive self-esteem sub-scores of the Self-Esteem Scale (n=38)	293
Figure 8.2b	Negative self-esteem sub-scores of the Self-Esteem Scale (n=39)	293
Figure 8.2c	Total scores of the Self-Esteem Scale (n=38)	294
Figure 8.3	Respondents' scores using Cantril's Ladder (n=37)	296
Figure 8.4	Respondents' scores on the Happiness Scale (n=36)	296
Figure 8.5	Mean changes in general well-being LSS ratings per respondent, pre- and post-profile (n=41)	298
Figure 8.6	Average satisfaction ratings for domain data of perceived QoL	316
Figure 8.7	Spearman correlations of global well-being with perceived QoL domain subscales and psychological well-being	327

Acknowledgements

My first acknowledgements of appreciation must go to my supervisors, Professor Ann Bowling and Dr Felicity Smith who helped me to obtain my funding and have supported me throughout my studentship and beyond. I continue to learn so much from them and feel extremely fortunate to have worked with them both. Also, I would like to thank Professor Bowling for the opportunities and sponsorship to present my work both at national and international conferences.

I greatly appreciate the opportunities afforded to me by the Department of Health Pharmacy Practice Research Enterprise Scheme and thank them for funding this PhD studentship.

Throughout the study, many people helped me to develop and carry out my research work and I would like to thank them all. In particular, I extend my appreciation to Dr Simon Fleminger and Dr Trevor Turner who were the named supporting consultant psychiatrists for the essential ethics committees applications and advised me throughout my data collection. Also I would like to thank the academics who gave me permission to use and adapt their questions and scales: Professor Ciaran O'Boyle, Dr Joseph Oliver, Professor Rachel Rosser and Professor John Wing.

During all phases of data collection, I was dependent on staff assistance and I would like to thank all the consultant, junior medical, nursing and managerial staff from Hackney, St. Bartholomew's, the Royal London and St. Clement's Hospitals who helped in the study. In particular Dr Vincent Kirschner who carried out the validation exercise using the DSM-III-R diagnostic criteria, and Mrs Beaver, Mrs Lagdon and Ms Kitty Price who helped to track down the medical notes. Again, during the community phase of data collection, many members of the community mental health teams and medical, social services and hostel staff provided help in following-up patients; I would like to thank them all. In particular, Dr Apenteng, Mr Paul Baker, Ms Danielle Barnes, Ms Rose Beck, SR Joyce Brown, Mr Eddie Davies, Mr Oliver Durkin, Mr Raoff Elahee, Mr Ben Hannigan, Mr Andrew Hartnett, Ms Annette Hastings, Irene, Mr Nigel Lempiere, Malcolm, Mr Billy Mathers, Mr Ian Miller, Ms Sandra Monero, Mr Alistair Morgan, Ms Rose Obembe, Mr Sanjeevee Ramsamy, Ms Margaret Sansom, Ms Janice Simmons, Mr Tom Smyth and Ms Tracy Uppex.

Ms Lee Marriott deserves a special vote of appreciation for accompanying me on home visits.

The purpose of this research was to help improve the measurement of quality of life for people with schizophrenia. I thank wholeheartedly all the participants of my research who were so willing to spend time with me and provide detailed information about the quality of their lives. It has been my priority to give justice to that precious time and data when analysing and disseminating my findings.

My final thanks are reserved for my closest friends and family who have not seen very much of me during the last few years; I greatly appreciate their support. Most sincerely, I thank Dr David Christopher Rees who has been so tolerant, patient and generous throughout the long haul!

Preface

The purpose of this thesis is to consider the value of a respondent-led measure of quality of life for people with a diagnosis of schizophrenia, and to compare its use with a population instrument. Further, this thesis investigates the relationship between the effects of antipsychotic medication and quality of life from the respondents' perspectives.

This thesis comprises four parts: part one (Chapters 1 and 2) introduces the thesis by reviewing the pertinent literature on schizophrenia and quality of life research, part two (Chapters 3-5) presents the pilot work and the main research proposal, part three (Chapters 6-10) presents the results and part four (Chapter 11) discusses the findings and concludes the thesis.

Chapter 1 reviews the disorder of schizophrenia and its drug treatment. This is followed by a summary of mental health policy from the last decade that has influenced care strategies. Subsequently, the chapter highlights issues of importance to people with schizophrenia living in the community, particularly those that potentially affect their quality of life. The medication compliance, adherence and concordance literature is reviewed and discussed throughout the thesis. The term compliance has been associated with an expectation of patients to be passive and 'follow doctor's orders'. Alternatively, concordance relates to the interaction between the prescriber and the patient and not the behaviour of individuals; as such, it is not the focus of this thesis. Therefore, the preferred term used in this thesis is medication adherence where the focus is on the behaviour of the individual and the ways that individuals interact with their medication. However, the original authors' terms have been retained when literature has been reviewed.

Chapter 2 reviews the quality of life literature, in particular that relevant to mental health. The concept, definition and measurement issues are discussed and available population tools for measuring quality of life in schizophrenia are summarised. It is acknowledged that the terms quality of life and health-related quality of life are not synonymous. The preferred term in this thesis is quality of life because in relation to people with schizophrenia living in the community, their quality of life encompasses wider issues such as the effects of safety,

financial status, living situation on their lives and social roles, and not solely areas of life affected by their illness. However, again, authors' terms have been retained when discussing their research papers.

Chapter 3 presents the pilot work carried out both with hospital in-patients and out-patients attending community psychiatric nurse clinics to receive their medication. This work provided the foundation for the main study proposal detailed in Chapter 4. Chapter 5 states the amendments made to the study methods and instruments as a result of further pilot work and requests made by the ethics committees.

Chapters 6 and 7 present the results relating to medication issues in the hospital and the community respectively. For ease of identification and to retain anonymity, respondents in both settings are referred to as patients (in-patient/recruitment sample and community sample respectively) and case numbers will represent individuals.

The quality of life research is presented in Chapter 8. Separate sections of the chapter focus on the respondent-led approach and the population instrument. Both methods are compared and contrasted in the discussion chapter (Chapter 11). The social networks of the respondents, community care (Care Programme Approach) and the results of the postal questionnaire to significant others are presented in Chapter 9.

Chapter 10 details further analyses of medication issues and further analyses of aspects of quality of life. The chapter concludes with exploratory modelling work of medication adherence and global well-being.

The final chapter (Chapter 11) first discusses the methodological difficulties and limitations of the study. Subsequently, the quality of life measures used in this study are reviewed and recommendations for future measurement are made. This is followed by a discussion of the relationship between antipsychotic medication and quality of life. Chapter 11 closes with the implications of this work for the community care of people with schizophrenia.

PART ONE - INTRODUCTION

CHAPTER 1 SCHIZOPHRENIA

1.1 Introduction

The purpose of Chapter 1 is to highlight issues of concern that may affect the quality of life of people with schizophrenia living in the community and as such, will not be a comprehensive appraisal of schizophrenia research. Sections 1.2 and 1.3 present a brief overview of the disorder of schizophrenia and its drug treatment (Sections 1.2-1.3). Section 1.4 summarises recent mental health policies and guidance documents that have focused on the delivery of community care. Section 1.5 reviews the literature on living in the community with schizophrenia from the sufferer's perspective. In particular, the section focuses on issues that may affect quality of life in the community such as social isolation, stigma, insight and medication.

1.2 An overview of schizophrenia

The annual cost of schizophrenia to health and social services is about £1 billion (Clinical Standards Advisory Group, 1995). The annual cost to the National Health Service (NHS) has been calculated as £397 million (1.6% of the total health care budget); three-quarters of which are spent on hospital and community-based residential care, while 5% represents drug costs. The direct lifetime cost of treating schizophrenia has been estimated to range from £1,700 to £316,000 per person (Davies and Drummond, 1994). To achieve reductions in direct costs, Kmietowicz (1997) states that the treatment outcome of schizophrenia must be improved for sufferers to be able to live more independent lives, without becoming a risk to society.

1.2.1 Epidemiology of schizophrenia

The lifetime prevalence rate of schizophrenia is nearly 1%, and is thought to be generally stable across temporal and geographical boundaries. Point prevalence rates range from 0.6 to 8.3 cases per 1000 population worldwide (Wing, 1975; Freeman and Alpert, 1986; Shur,

1988; Cooper, 1991; Reynolds, 1992). The average UK general practitioner cares for 10-20 patients with schizophrenia, depending on the location of the practice, although Davies (1997) suggests that approximately 10,000 people with schizophrenia in the UK are not registered with a general practitioner.

The World Health Organisation studies established incidence rates of schizophrenia across 10 disparate countries (12 centres) (Jablensky *et al.* 1992). Using a broad definition of schizophrenia, they reported rates that ranged between 1.5 and 4.2 per 100,000 of the population. However, when they used a narrow definition of schizophrenia (based on Schneiderian first-rank symptoms (Schneider, 1959)), the incidence rates ranged from 0.7 to 1.4 per 100,000 of the population. These values were not significantly different between centres, providing evidence for similar incidence rates in different cultures (Jablensky *et al.* 1992).

A number of studies have reported high incidence rates of schizophrenia among the African-Caribbean population resident in the UK compared with the resident white population (Harrison *et al.* 1988; Wessely *et al.* 1991). In early studies, researchers questioned the accuracy and appropriateness of the diagnosis of schizophrenia among black populations (e.g. Littlewood and Lipsedge, 1981). However, more recent studies using clear diagnostic criteria provide little evidence that schizophrenia is 'over diagnosed' in black populations (Lewis *et al.* 1990; Littlewood, 1992; McGovern *et al.* 1994). Bhugra *et al.* (1996) examined incidence rates for schizophrenia in the non-migrant population of two geographical catchment areas of Trinidad during a one year prospective study. The incidence rates for 'broad schizophrenia' were similar to the WHO incidence studies, and much lower than incidence rates in London among the African-Caribbean population. The authors explored different explanations for the high rate in UK-resident African-Caribbeans such as genetic factors and selective migration. The authors concluded that a genetic explanation was unlikely and called for further comparative studies concerning the social environment of UK and Caribbean African-Caribbean populations. The role of environmental factors in the causation of psychotic illness in immigrant populations requires further exploration.

Overall, schizophrenia has equal prevalence in men and women. Nevertheless, gender-

related differences exist with respect to age of onset (women presenting, on average, about four years later), course and likelihood of response to treatment (Jablensky *et al.* 1992; Awad *et al.* 1997a). Evidence regarding a better outcome for women remains controversial. It is unknown whether women have a more benign form of illness or whether factors such as better compliance with treatment and an increased likelihood of help-seeking behaviour confound the relationship (Johnstone and Lang, 1994).

1.2.2 Diagnosis of schizophrenia

The characteristic features of 'schizophrenia' are based on early descriptions by Kraepelin (1896) (who focused solely on the course and outcome of the illness), Bleuler (1913) (who conceptualised the fundamental symptoms) and Schneider (1959) (who developed an operational definition) (Malmberg and Wessely, 1994; Warner, 1994). Currently, schizophrenia is diagnosed according to a description of behaviour, mental state and history, but no assumption about aetiology or outcome is made (Cooper, 1991) (see Section 1.2.4). It is a heterogeneous disorder for which there are no objective physiological or biochemical markers (Reynolds, 1992; Turner, 1997).

At the time of this study, the International Classification of Disease (ICD) (10th edition) (World Health Organisation, 1990) was in preparation and therefore, the most recent version of the Diagnostic and Statistical Manual of Mental Disorders (3rd edition, revised) (DSM-III-R) (American Psychiatric Association, 1987) was used (see Chapter 4). One important difference between the ICD-10 and DSM-III-R is the symptomatic period required for the diagnosis of schizophrenia; ICD-10 requires one-month while the DSM-III-R requires 6-months, thereby excluding more acute disorders.

1.2.3 Aetiology of schizophrenia

The aetiology of schizophrenia is not yet fully established. However, the literature reports a range of factors thought to increase one's vulnerability and influence the manifestation of illness. Four main aetiological theories are currently described: biochemical theories, genetic influences, brain abnormalities and environmental factors (e.g. obstetric complications,

prenatal influenza). Evidence is not conclusive and more research is required with more advanced analytical techniques. (Due to the limits of this thesis, this vast literature will not be discussed but reviews can be found in Owen and Cross, 1992; Jernigan, 1992; Read *et al.* 1992; Bebbington and Kuipers, 1992; Kennedy, 1994; Johnstone, 1994; Warner, 1994).

1.2.4 Signs and symptoms of schizophrenia

Depending on the stage of the illness, a wide range of signs and symptoms may present which may be classified as positive and negative. Characteristically, positive signs and symptoms are a result of disordered brain functioning. Patients may present with signs of poor concentration, thought block, hallucinations (false perceptions) or delusions (false beliefs). Typically, patients experience thought withdrawal, thought insertion, and thought broadcast (Davies, 1997; Turner, 1997).

Negative symptoms present as a loss of personal attributes such as initiative, motivation, interest in others, and the sense of enjoyment (anhedonia). Emotions are blunted (flat affect) and there is poverty of speech. Negative symptoms are more often associated with identifiable abnormalities of brain structure (Reynolds, 1992; Turner, 1997).

1.2.5 Prognosis of schizophrenia

The presentation of the disorder, response to treatment and quality of after care can all affect the prognosis of schizophrenia. For the majority, a reduction of long term morbidity and a decreased number of hospitalisations are dependent on early and continued medication (Marder, 1996a). Contrary to media attention aggression towards others is relatively rare (Turner, 1997). Mortality has been calculated to be at least twice that of the general population, and approximately 10-15% of sufferers (mainly younger patients) will commit suicide (Leach and Scherer, 1992; Davies and Drummond, 1994; Meltzer and Okayli, 1995).

The course of schizophrenia is quite variable: about 20% of sufferers will require long term, highly dependent, structured care (possibly in locked or secure conditions); about 50% of sufferers will live relatively independent lives with varying levels of support and continued

medication; and about 30% of sufferers will be independent, working full-time and raising families (Turner, 1997). Continued debate surrounds this latter type of brief psychotic episode from which people generally recover. 'Revolving-door patients' are identified as individuals who experience repeating cycles of acute admission to hospital and discharge to the community. Turner (1997) suggested that a key feature of the revolving door syndrome is the failure to adhere to medication.

The literature includes a range of well-established factors and indicators associated with the prognosis, course and outcome experienced by people with schizophrenia. Specific premorbid factors and features of the illness affect the prognosis such as family history of schizophrenia, personality type, intelligence, insight, age of onset, known precipitating cause, acute/insidious onset, prominent affective symptoms, prompt/delayed treatment and response to low doses of drugs (Cooper, 1991; Turner, 1997). Other features of the condition include drug abuse, stressful life events, stressful family environment, labelling and stigma, social isolation or reintegration, social role rehabilitation and patterns of institutional care can also affect the course and outcome of schizophrenia (Warner, 1994:19). Soni *et al.* (1994) in their study of schizophrenic patients receiving depot antipsychotic medication found that higher rehospitalisation rates were more likely with patients experiencing a more severe form of illness. Severe illness was indicated by an early age of onset, greater severity of positive and affective symptoms, higher antipsychotic dose and higher total AIMS score (Abnormal Involuntary Movement Score).

1.3 Drug treatment of schizophrenia

The management of schizophrenia depends on the stage of the illness and may comprise pharmacological, psychological and social approaches. This section focuses on the pharmacological approach, i.e. the drug treatment of schizophrenia (Section 1.3.1). Hirsch (1993) reported that drug therapy has the largest impact on schizophrenia while psychosocial treatment, in combination with medication, has a time limited effect on the risk of a relapse.

Antipsychotic drug therapy may be broadly dichotomized into 'traditional' and the newer 'atypical' drugs. It is well established that traditional antipsychotic drugs contribute

substantial benefits to the management of schizophrenia during the acute phase, medium-term treatment and in long-term maintenance therapy for the prevention of relapse (Marder and May, 1986). However, drug therapy does not affect patients consistently and to date, predictors of response to antipsychotic treatment have not been clearly identified (Shalev *et al.* 1993). Therefore, clinicians have been unable to identify those patients who could discontinue their medication indefinitely (Davis *et al.* 1980; Kane, 1987a; Lydiard and Laird, 1988; Awad, 1989; Johnstone, 1993; Johnstone and Geddes, 1994).

The efficacy of traditional antipsychotic medication in acute episodes is well established. However, in acute treatment trials, approximately 30% of patients showed limited improvement (Davis, 1976) and about 7% of patients showed no improvement, even after long-term treatment (MacMillan *et al.* 1986a). Additionally, for those who respond to traditional drug therapy, response is usually measured by reduction in the severity of psychotic symptoms. However, only about 40% achieve a good recovery in social functioning and most patients will experience some drug-related adverse effects (Van Putten, 1974; Marder and May, 1986; Tarrier *et al.* 1993; Meltzer, 1996). In long-term follow-up, it has been shown that positive symptoms are related to the number of hospitalisations but overall, the social course of schizophrenia is more closely associated with negative symptoms (Fenton and McGlashan, 1991).

Maintenance therapy aims to preserve the gains achieved during treatment of the acute phase and to reduce the risk of relapse or readmission to hospital, or at least to postpone such episodes since maintenance medication (oral or depot) can only reduce the likelihood of relapse and not eliminate it completely (Leff and Wing, 1971; Hirsch *et al.* 1973; Davis, 1975; Hogarty *et al.* 1979). About 40% of patients will relapse within one year (compared with 30-80% given placebo or drug-discontinued patients). For those who are relapse free within the first year, the relapse rate will average at 15% for the subsequent year (compared with about 65% of placebo-substituted or drug-discontinued patients) (Hogarty, 1984; Kane, 1987a; Hirsch, 1993; Kane and McGlashan, 1995).

Different strategies have been attempted to reduce doses of antipsychotic medication to protect against the experience of adverse effects (Marder *et al.* 1984; Marder *et al.* 1986;

Kane, 1987a; Hirsch, 1991; Burnett *et al.* 1993). Studies have shown many benefits of low-dose therapy including a reduction in early tardive dyskinesia, an improvement in social well-being and patients have more affect, spontaneity, are less blunted and less withdrawn (Kane, 1987b). However, patients who are chronically ill and are on the higher doses initially, are more likely to relapse when their dose of antipsychotic drug is reduced (Johnstone and Lang, 1994).

Antipsychotic medication has also been associated with compromised social and occupational roles (MacMillan *et al.* 1986b). Beyond recurrent or residual symptoms, many patients will also have to cope with social difficulties and unemployment (Johnstone and Lang, 1994). Additional approaches to drug therapy such as family therapy, psychological approaches and social-skills training have been employed to reduce symptoms and relapse rates. Moderate success has been shown in some cases but it remains unproven whether such approaches can benefit long term outcome (Tarrier and Barrowclough, 1990; Hirsch, 1993; Goldstein and Kern, 1994).

1.3.1 Traditional antipsychotic drug therapy

Clinically, all traditional antipsychotic drugs are perceived to be equally efficacious but differ in potency, available formulations and side effect profiles. The traditional drugs may be differentiated by their antidepressant effects. For example, chlorpromazine, thioridazine and flupenthixol can have an additional antidepressant effect while others, such as fluphenazine, pimozide and pipothiazine may exacerbate depression (British Medical Association and Royal Pharmaceutical Society of Great Britain, 1997:161).

It is thought that antipsychotic drugs act by blocking dopamine receptors. However, one major disadvantage of all of these drugs is that they are non-selective in their blocking action of a number of other brain receptors (e.g. cholinergic, alpha-adrenergic, histaminergic, and serotonergic) resulting in a wide array of adverse effects which can be disabling, distressing and a disincentive to take medication (Van Putten, 1974). The clinical management of patients receiving these drugs requires weighing up the potential benefits and risks (Barnes, 1992). Adverse effects include sedation, hypotension, dry mouth, blurred vision,

constipation, urinary retention, memory dysfunction and reflex tachycardia. Traditional antipsychotic drugs can lower the seizure threshold (Cowen, 1991) and cause hypersalivation (Hirsch, 1991). All traditional drugs can cause gastro-intestinal and hepatic adverse effects, as well as increasing prolactin levels which are associated with sexual dysfunction, sedation, weight gain, galactorrhoea (spontaneous breast milk production that can occur in men as well as women) and oligomenorrhoea (abnormal menstrual cycle) (Marder, 1996a).

The traditional antipsychotic drugs can affect motor functioning (Awad *et al.* 1997a). Most adverse effects are discrete conditions, dose-dependent and reversible on the discontinuation of therapy. However, tardive dyskinesia, an irreversible neurological adverse effect, questions the continuation of drug therapy. The drug-induced movement disorders (also known as extra pyramidal side-effects (EPSE)) include acute dystonia¹, acute akathisia², parkinsonism³, tardive dyskinesia⁴ and neuroleptic malignant syndrome⁵. Reported incidences of EPSE are between 2.3%-40%, depending on the accuracy of assessment and the dose of the drug prescribed (Marder, 1996a). EPSE has been estimated to cause 40-65% of out-patients with schizophrenia to discontinue oral antipsychotic medication within the first six weeks of therapy (Morrison, 1996). Further, the motor phenomena can be misinterpreted as signs and symptoms of psychiatric illness and thus confound clinical assessment of the mental state (Barnes, 1992).

¹ *Acute dystonic movements* are abnormal postures or involuntary muscle spasms primarily affecting the neck (torticollis), jaw, face and tongue.

² *Akathisia* is a subjective feeling of restlessness where patients have a constant urge to move and an inability to keep still.

³ The *parkinsonian syndrome* presents with the patient exhibiting a 'mask-like' face, a tremor at rest, rigidity, shuffling gait and bradykinesia.

⁴ *Tardive dyskinesia* presents with repeated involuntary movements affecting the face and the limbs.

⁵ *Neuroleptic malignant syndrome (NMS)* is a rare but potentially fatal condition that can occur with any dopamine-receptor antagonist, despite the dose. NMS presents with fever and muscle rigidity and with two or more of the following: confusion and impaired consciousness, excessive sweating, dysphagia, altered blood pressure, tachycardia, tremor, incontinence, mutism, leucocytosis and indicators of muscle injury (e.g. myoglobinuria or a grossly raised serum creatinine kinase) (Launer, 1996; Pathare and Paton, 1997).

1.3.2 Atypical antipsychotic drug therapy

Two factors drive the search for new antipsychotic drugs: the first is the need for an effective treatment without the disabling adverse effects and the second factor is that approximately 30% of all patients are poor responders to traditional drugs (Lydiard and Laird, 1988; Kane, 1990; Reynolds, 1992; Awad *et al.* 1997a). The atypical drugs have been prescribed in clinical practice since about 1990 when clozapine was reintroduced for the indication of treatment-resistant schizophrenia. The superior efficacy of clozapine compared with traditional antipsychotic drugs in treating 30-60% of patients who are poor-responders is well established (Pickar, 1995). Clozapine has been shown to reduce positive and negative symptoms, reduce anxiety and aggression and facilitate discharge and social reintegration (Pickar *et al.* 1992; Meltzer, 1992; Clozapine Study Group, 1993; Goldberg *et al.* 1993).

While clozapine is associated with fewer extra pyramidal side-effects (EPSE), many other adverse effects may develop such as hypersalivation, drowsiness, tachycardia, weight gain, dizziness and constipation (Clozapine Study Group, 1993; Marder, 1996b). Patients prescribed clozapine must agree to haematological monitoring due to the risk of agranulocytosis (2-4%) which decreases over subsequent years of treatment. The risk of dose-dependent seizures induced by clozapine exceeds the risk associated with traditional antipsychotic drugs (Pickar, 1995). Clozapine does not significantly increase prolactin levels, so associated adverse effects such as galactorrhoea are avoided (Kane *et al.* 1981).

Currently, most empirical studies of the atypical antipsychotics have occurred with clozapine. Limited information (beyond drug company data) is available on the more recent drugs (e.g. olanzapine, risperidone, sertindole, quetiapine and amisulpride).

1.3.3 Depot preparations of antipsychotic drug therapy

Currently, the atypical antipsychotic drugs are available only as oral preparations while many traditional drugs are available as both oral medication and as an intramuscular long-acting 'depot' injection. (The first atypical antipsychotic drug available for intramuscular use (ziprasidone) is expected to be launched mid-1998). Depot injections provide a slow release

of the drug over a 1-4 week period. Most patients (70%) who receive depot medication achieve relief from their symptoms. However, depot antipsychotic preparations do not provide any additional therapeutic effects or risk of side-effects compared with oral preparations (Johnson, 1984; Cowen, 1991; Pathare and Paton, 1997). Pharmacokinetic differences obviously exist since depot administration avoids first-pass metabolism and therefore a higher concentration of unaltered free drug is available to the brain (Johnson, 1984; Barnes, 1991; Hirsch, 1993). However, a recent study found that there was marked intra-individual variability in pharmacokinetic data during long-term depot administration (Tuninger and Levander, 1996). The authors recommended that because plasma levels did not correlate with the clinical assessment of symptoms or adverse effects, plasma levels should not be used to determine the most appropriate maintenance dose.

In Europe, 20-60% of people with schizophrenia are treated with depot preparations (Gerlach and Casey, 1994). It has been suggested that depot medication is a way of improving antipsychotic therapy, particularly for those with poor medication adherence and a lack of insight into their illness. Further advantages are the reduced opportunity for overdose or abuse of drug therapy and the indirect benefit of facilitating regular contact of the patient and/or their carers with a mental health professional allowing an opportunity for monitoring and identifying early signs of relapse (Johnson, 1984; Barnes, 1991; Hirsch, 1993). A disadvantage described by some patients is that they felt 'controlled' on depot medication (Gerlach, 1994).

1.4 Mental health policy in the last decade

The shift of care for people with mental health problems from large institutions to the community has been ongoing for about the last 50 years. Lelliott *et al.* (1997:34-35) suggested that there have been five influential factors: the less restrictive social climate of the 1960s and 1970s, the exposure of poor conditions and standards of care in some of the large institutions, social psychiatry and the impact of psychosocial interventions, the advent of drug therapy and 'the (mistaken) political assumption that community care would be cheaper'.

The policies and guidance documents of the last decade have been aimed at improving the community care received by people with mental health problems.

- Both the white paper '*Caring for People: Community Care in the Next Decade and Beyond*' (Department of Health, 1989) and the *National Health Service and Community Care Act* (House of Commons, 1990) focused on the provision and coordination of local services designed to meet the identified needs of its population. Local authorities were made responsible for providing services that would promote people to live in their own homes.
- The *Care Programme Approach* (Department of Health, 1990) specified that all users of the specialist mental health services, including all in-patients, must have a comprehensive assessment of their health and social care needs. Each patient should have an individual care plan formulated and a key worker appointed to coordinate its implementation. It is expected that most patients should be discharged from hospitals on satisfactory completion of the care plan. The aim of the approach has been to reduce the risk of people losing contact with services.
- The *Health of the Nation: a strategy for health in England* (Department of Health, 1992) nominated mental illness as one of its key areas. The main targets were to improve significantly the health and social functioning of mentally ill people, to decrease the overall suicide rate by at least 15% by the year 2000 and to reduce the suicide rate for the severely mentally ill by at least 33% by the year 2000.
- In 1994, supervision registers were introduced to ensure patients receive the care they need (e.g. patients at significant risk of suicide, of doing serious harm to others, or of serious self-neglect) (Department of Health, 1994). All health districts are required to maintain registers of patients who are considered to be at risk. The 'revolving door' patients who may fail to comply with treatment after discharge from hospital and therefore pose a serious risk to themselves or others are often included on the register (White *et al.* 1997).
- In 1994, in response to the influential report of the inquiry into the care and treatment of Christopher Clunis (Ritchie *et al.* 1994), the Department of Health issued further guidance concerning the discharge of people with mental illness from hospitals into the community (NHS Executive, 1994). They reinforced the requirement that those responsible for discharging patients into the community must be satisfied of the patient's ability to live safely in the community and that the required care and services were available for that patient.

However, little research exists that considers the extent to which these policies and documents have made a difference to the risk of suicide, violent acts or readmission rates to hospitals. When the Care Programme Approach was first introduced, critics debated whether the scheme provided more support to an individual or whether it was just a paper exercise. Others criticised the supervision registers for the vague inclusion criteria and the ill-thought legal consequences of those included on or excluded from the register. The basis of the criticisms of the recent reforms was that an increased demand was being placed on services without an adequate increase in resources (Caldicott, 1994). Anecdotally, clinicians have claimed that because of these policies, services have been focused on the more needy patients and have improved the quality of care and supervision of patients in the community (Ramsay and Fahy, 1995).

1.5 Living in the community with schizophrenia: issues and concepts relevant to quality of life

Consistently, patients and their relatives have been shown to prefer community to hospital care (Marks, 1992; Okin and Pearsall, 1992). Although a disadvantage identified by patients is the absence of social contacts that had been previously available to them in the larger long-stay hospitals (Goldie, 1988). Other issues such as coping with the potential stigma of mental illness and acknowledging their illness are also of pertinence to individuals living in the community. Drug therapy is the most common form of treatment of schizophrenia in the community and such patients have to cope with managing their medication and the potentially quite disabling adverse effects (see Section 1.3.1). Consequently current providers of community care have been challenged to develop suitable housing and social projects in the community to address such concerns. These are key issues associated with the quality of life of people with schizophrenia living in the community and are discussed below.

1.5.1 Social isolation

Many studies have illustrated the social isolation experienced by people with schizophrenia living in the community and the subsequent association with a poor outcome (e.g. Strauss and Carpenter, 1972). In a long-term follow-up study of 46 people with schizophrenia,

McEvoy *et al.* (1989a) found that patients who were supported by people with an interest in the patients' treatment were more likely to take their medication.

Most people with schizophrenia experience disintegration of family relationships but greatest effects are evident with other social contacts. People with schizophrenia have been shown to have smaller primary networks (personal and informal relationships) with a third to a fifth less close contacts compared with the average for 'normal' members of society. A third of people with schizophrenia have been reported as having no friends at all. Network size has been shown to be negatively related with the number of readmissions to hospital. Family and relatives are depended upon for the majority of emotional and practical support (Cohen and Sokolovsky, 1978; Pattison and Pattison, 1981; Lipton *et al.* 1981; Cresswell *et al.* 1992; Neeleman and Power, 1994). Interestingly, these findings were consistent in both the British and American studies and included a wide range of participant and comparator groups (e.g. day patients with schizophrenia, out-patients with schizophrenia, referred patients with depression, parasuicide patients and non-psychiatric controls). However, details were inconsistent regarding participant selection and so limited extrapolation may be made to a general population with schizophrenia.

Paradoxically, too much support has also been shown to have a negative impact on outcome because of its arousing effects (Wing, 1978). Psychosocial stressors such as expressed emotion (Brown *et al.* 1958; Brown 1959) (a measure of emotional atmosphere in the home: hostility, critical comments, emotional over involvement, excessive demands, a reluctance to leave the adult relative to be alone) has a strong positive relationship with relapse rate (Hirsch, 1993).

Neeleman and Power (1994) compared aspects of social support between groups of chronic schizophrenic, depressed and parasuicide patients with a group of medical controls. They highlighted a dilemma with their research sample of people with schizophrenia. Their sample had small primary networks and reported that they did not want more social support. However, they also reported feelings of loneliness. Such dilemmas illustrate the complexity and thought required in the design of community-based strategies to meet the unmet social needs of clients. There were limitations to this research study due to the small sample size

of 21 respondents with schizophrenia (7 of whom were recruited from the day hospital and the remaining 14 were recruited from a depot clinic). Diagnoses were not standardized and therefore comparisons between the groups on the basis of diagnosis could have been misleading as the authors suspected a degree of diagnostic overlap. As a cross-sectional study, the links between social support and diagnoses could not be established in causality terms.

Cresswell *et al.* (1992) studied 40 long-term day-patients with primary diagnoses of schizophrenia attending a district rehabilitation service. They found that professionals seemed to provide an important function at times of stress for people with schizophrenia. They concluded that ‘... given their emotional distance, professionals are often well-placed to provide the combination of problem-solving and low-level emotional support that may be best suited to the needs of most of this group.’ However, these findings need to be considered in light of all the participants having established contact with professionals through their attendance at the day hospital.

1.5.2 The stigma of schizophrenia

In recent years, there has been wide media attention of events in the UK where people with schizophrenia or other chronic mental illnesses have committed public acts of violence, crime or ‘deviant’ behaviour. For example, Christopher Clunis killed Jonathan Zito at Finsbury Park Station; Ben Silcock climbed into the lion’s den at London Zoo. Such incidents have questioned the success of community care and instigated crucial reviews and recommendations concerning the care of people with mental health problems in the community (e.g. Ritchie *et al.* 1994). However, sensationalist publicity can reinforce negative attitudes towards people with chronic mental illness and enhance the stigma experienced by sufferers. The lay person’s perception of schizophrenia may be anchored by the articles they read or documentaries they see, while being ignorant of the rare incidence of such events. Rarely do published newspaper articles or screened television documentaries focus on the successful community living of people with schizophrenia.

Stigma is an aspect of a patient’s self-conception represented by feelings that other people

think less of them, avoid them or feel uneasy with them because of their illness (Hyman, 1971). Society defines stigma by imposing its values of what is deemed acceptable or deviant and such criteria of stigma may vary over time and between cultures.

‘...the disgrace associated with certain conditions, attributes, traits, or forms of behaviour. Precisely which of the latter are publicly regarded as signs or marks of disgrace and to what degree, has of course varied historically and continues to vary between cultures.’

(Scambler, 1984:203)

Today, the culture of psychiatric illness continues to have a negative image which must impact greatly on people being discharged from hospital to live in the community.

‘Stigma is thus a social phenomenon that implies a person, an audience, and a set of powerful negative images that connect the two. There is no measurement procedure ...that allows one to establish stigma and differentiate it from social undesirability.’

(Fabrega, 1990:290)

Although Goffman (1963) suggested that discharge from hospital may remove an initial ‘schizophrenic’ label, it still promotes the individual as having a psychiatric history and therefore not ‘normal’. Equally, sufferers in the community who are socially isolated and do not have the opportunity for social intercourse with others, have limited means by which to rationalise feelings of suspicion, hostility and anxiety that may develop. Alternatively, it has been said that the stigmatized person can use the label to their benefit by adopting it as an explanation for their misfortunes in life, hence protecting themselves from social responsibilities (Goffman, 1963:20-24).

Wahl and Harman (1989) reported the results from a postal questionnaire survey with a self help and advocacy organisation of families of individuals with mental illnesses. Over three-quarters of the respondents (77%) reported that the stigma of mental illness affected their ill relative, where stigma had the dictionary definition of “a mark of disgrace or infamy, a stain or reproach, as on one’s reputation.” The three most unfavourable consequences were to self-esteem, ability to make and keep friends and success in acquiring a job. Perceived contributors to the stigma of mental illness were most commonly reported as movies about mentally ill killers, news coverage of tragedies caused by mentally ill people and violence by mentally ill people. The study’s findings were limited by the self-selecting sample of a self-help group, a low response rate of 35% (n=487) and the survey questions deliberately

focused on the negative consequences of (an assumed existence of) stigma for families. However, Wahl and Harman (1989) concluded that there was consistent evidence that stigma was an enormous burden for the families of people with schizophrenia as well as the sufferer him or herself.

Ultimately, living in the community does not only present the problem of the stigma for the individual with schizophrenia but also their family. Furthermore, it challenges the community to address its stereotypes of what is normal and acceptable within society.

1.5.3 Insight and schizophrenia

Marková and Berrios (1992) reported that while insight is included as part of the standard mental state examination, no guidelines exist on its definition or measurement. Resulting categories of no insight, partial insight and good insight disclose little about ‘insight’ itself. In 1934, Lewis in his essay on the psychopathology of insight highlighted the very complex nature of insight. He proffered a ‘temporary’ definition of insight as “a correct attitude to a morbid change in oneself” and explained in great detail the respective definitions of correct, attitude, morbid and change in oneself. It has been suggested that for people with schizophrenia who have disturbed functioning, it is impossible for the patient to consider and rate himself/herself objectively, in the same way that removed ‘healthy’ outsiders can. However, Lewis (1934) presented excerpts from clinical interviews illustrating that people with psychotic disorders can rationally present data about themselves indicative of insight:

‘It is, moreover, the common experience of psychiatrists, that, at the onset of the disorder, the insight of the patient is sometimes considerable and is associated with a struggle against the illness that is tragic.’

In their review of ‘insight’ literature, Heinrichs *et al.* (1985) provided evidence that people with schizophrenia do not uniformly lack insight. Lewis (1934) also drew attention to the unstable nature of ‘insight’ and that within the same interview with a person with schizophrenia, the objective rationing of their illness could first be evident and then lost.

Heinrichs *et al.* (1985) reported that insight ‘...refers to the patient’s awareness that he or she is suffering from a mental illness’. In a retrospective study of out-patient case notes of

people with schizophrenia (n=38), measures of prognosis, severity of illness and severity of episode were not significantly different for insightful and noninsightful patients. The judgement of insight ('the patient's ability, during the early phase of a decompensation, to recognize that he or she is beginning to suffer a relapse of his or her psychotic illnesses') was extracted from case notes and validated with discussions with the relevant clinicians. This limits the findings to a function of the accuracy of the case notes and the memories of the clinicians. Further limitations of this study relate to the all-or-nothing definition of insight and the respondents belonged to a group of patients who attended an out-patient research clinic.

Early definitions of insight created an all-or-nothing variable; people either had insight or they lacked insight. 'Complete insight' was a vague term used in clinical practice. It reflected a verbal agreement between the patient and clinician of the approximate notion of '...the patient's sanity of judgment, or common sense attitude towards his illness' (Lewis, 1934). Later research dismissed this approach (David, 1990; David, 1992; Perkins and Moodley, 1993) and conceptualised insight as a multidimensional phenomenon that was present in degrees.

David (1990) suggested that insight has at least three dimensions: awareness of illness, the capacity to re-label psychotic experiences as abnormal and treatment compliance. According to this model, the amalgamation of all three dimensions results in 'complete insight into illness and psychotic phenomena, and with full and informed consent to treatment'. Marková and Berrios (1992) cautioned against David's approach of distinguishing between an awareness of illness and the judgment of its significance since it suggested that there was an active process in the mind involved in making a judgment of the illness affecting it. David provided little empirical evidence to support his approach.

1.5.3.1 Insight and patterns of service use

Lewis (1934) suggested that insight may be an important predictor for a patient's willingness to accept admission to a hospital. Dawson (1972) in his study of reasons for compulsory admission to hospital found that those patients who denied that they were ill were more likely

to be formally admitted to hospital using the Mental Health Act (1959) than those who accepted that they were ill. Denial was assessed on a 3-point scale (minimal, moderate, marked) and determined during the interview with the patient and using behavioural accounts given by other informants. However, no data were presented to support the reliability or validity of the denial rating scale.

Perkins and Moodley (1993) defined a lack of insight as ‘the failure to acknowledge illness and the need for treatment’. They postulated that a lack of insight was likely to affect patterns of help-seeking behaviour and may lead to different pathways to psychiatric services, i.e. police involvement and compulsory admissions to hospital as opposed to referral through the general/primary care practitioner. They studied 52 consecutive admissions to two acute wards in an inner London area: 48% of patients were white and 42% were African-Caribbean. Approximately 40% of the sample had some form of schizophrenia. Within one week of admission they interviewed respondents about their problems on admission. They categorised these into psychiatric, social, physical or no reported problems. The schizophrenia sub-sample was most likely to admit that they had psychiatric problems (41.7%), a third reported physical or social problems (33.3%) and a quarter denied experiencing any problems (25%). The white respondents who denied experiencing psychiatric problems were most likely to report ‘physical or social problems’, while black respondents in denial were most likely to report ‘no problems’. This study illustrated a potential cultural component to insight and the presentation of psychiatric problems.

1.5.3.2 Insight and medication adherence

A problem with David’s (1990) multidimensional approach to conceptualising insight is that it did not acknowledge patients’ abilities to make rational choices according to their subjective experiences of the medication. It promoted a paternalistic view to the prescription and taking of medicines. If patients found that the medication they were taking did not resolve their symptoms and in addition they were experiencing unwanted adverse effects from their medication, then according to this model their choice to stop their medication would be indicative of a lack of insight. Alternatively, it may be indicative of ‘intelligent nonadherence’. In 1934, Lewis rejected the assumption that those with greater insight were

more likely to accept treatment. He suggested that a lack of insight may be indicative of a negative view of ill health or disease that may be an advantage in treatment. However, he did not provide any empirical evidence to support his theory.

Lin *et al.* (1979) operationally defined insight as ‘a recognition of existence of problems and the need for medical intervention’. This study investigated the role of insight in the medication adherence of people with schizophrenia (n=100). They concluded that medication adherence increased with the presence of insight and a perception that benefit was gained from medication. Methodological concerns with this study include the methods used for measuring insight and medication adherence. ‘Insight’ was said to be present if patients answered ‘yes’ to one of three items: do you think you had to be in hospital/had to see a psychiatrist/had to see a doctor? Insight was therefore, a dichotomous variable: present or absent. Qualitative information supporting their answers was not collected and therefore limited interpretation can be afforded to the study. None of the items asked about the need for medication. Respondents were asked directly about their medication-taking behaviour which was confirmed by the case worker or a family member. Adherence was arbitrarily dichotomized to adherer or nonadherer where adherers were respondents who ‘admitted to faithfully taking their medication’ corroborated by an external report. This is an oversimplification of medication adherence and does not take into account the varying degrees of adherence which may be reflected by rational choices concerning medication where symptoms are not alleviated and debilitating adverse effects are experienced (‘intelligent non-adherence’). If people were taking more than one medication, they may be more adherent for one than the other; they may take some medications ‘when required’.

McEvoy *et al.* (1989b) demonstrated an inconsistent relationship between changes in the psychopathology of people with schizophrenia and the degree of insight (n=52). The authors reported that a lack of insight was often defined as ‘schizophrenic patients failure to acknowledge their illness and need for treatment’ but they found that insight had little correlation with in-patient medication adherence. The authors reflected that their measure of in-patient medication adherence more immediately reflected the expected behaviour associated with the environment rather than a clear need for treatment. They postulated that insight may have a greater degree of influence on out-patient medication adherence.

However, in a long-term follow-up study of 46 people with schizophrenia, McEvoy *et al.* (1989a) found that patients who were supported by people with an interest in the patients' treatment were more likely to be medication adherent whether or not they had insight, i.e. whether they saw themselves as ill or not. Insight was measured using a semi-structured questionnaire which was based on questions relating to patients' attitudes towards admission, medication and the need for follow-up. The authors reported that '...patients with insight judge some of their perceptual experiences, cognitive processes, emotions, or behaviours to be pathological in a manner that is congruent with the judgment of involved mental health professionals, and that these patients believe that they need mental health treatment, at times including hospitalization and pharmacotherapy.' According to this definition, the focus is on the agreement between patient and staff report, rather than awareness of self-change, i.e. 'insight is defined as a social acquiescence' (Marková and Berrios, 1992).

Many of the studies reported suffered from methodological inconsistencies in their definition and measurement of both insight and medication adherence. This lends little value to the comparison of results and the extrapolation of a relationship between insight and medication adherence.

'Whatever the nature of insight, from a clinical management point of view one can still ask - does it matter? Does it make any difference to patients' prognoses whether they only parrot the description of their illness or whether they have a deep understanding of it? With more understanding of what is happening to them, greater patient compliance with treatment could be achieved. Perhaps there are protective devices which play a part in limiting the amount or areas of insight held, and these devices may be in operation not only in relation to mental disorders, but also to non-psychiatric physical diseases.'

(David, 1990)

It seems important to consider the amount of information that people with schizophrenia receive both about their illness and their medication. David (1990) considered the fundamental question of whether insight is a 'good thing'? He suggested that sufficient insight confirming the need for treatment would be a positive contribution to the health care of people with psychosis. However, he warned against the facilitation of so much insight that people would lament over their severity of illness.

1.5.4 The role of medication

Antipsychotic medication suppresses the illness by controlling or preventing symptoms rather than treating the illness at an aetiological level (Hirsch, 1991). The role of maintenance medication is best understood as postponing rather than preventing a relapse in patients with recurrent or chronic schizophrenia (Hirsch, 1993). Therefore, due consideration must be given to the risks and benefits of long-term treatment from the perspective of the individual taking the medication.

Marder and May (1986) reported that more than half of people with schizophrenia experience clinically significant depression during maintenance drug treatment while a similar proportion will experience anxiety. Adverse effects of drug therapy such as akathisia and akinesia can also contribute to the negative feelings experienced by patients (Van Putten, 1974). The risk of a relapse must be weighed against the risk of adverse effects and tardive dyskinesia associated with maintenance drug treatment. Relapses can be severe, difficult to treat, disastrous on long-term functioning and consequently patients may require a higher dose of drugs than previously required as maintenance therapy (Hogarty *et al.* 1974). Due to the heterogeneity of the disorder, patients may present with widely different symptoms and may experience different outcomes despite the treatment prescribed. Therefore, treatment programmes must be individualised for patients to receive the most appropriate care (Kane, 1990).

Marder and May (1986) also warn that ‘not relapsing’ is a poor indicator of functioning well in the community. Many patients experience severe impairment in the community due to personality and environmental influences which reflect the need for other therapeutic approaches (e.g. psychotherapy, vocational rehabilitation, family therapy, social skills training) alongside drug therapy. They recommend that drugs should only be used where they are demonstrably effective for an individual and at the minimum effective dose. Psychosocial and pharmacological approaches used together have shown to have cumulative effects (Marder and May, 1986; Kane, 1990).

1.5.4.1 Medication taking behaviour and medication adherence

It has been estimated that up to 50% of patients are non-adherent with their oral medication within a few months of discharge from hospital (Van Putten, 1974; Appelbaum and Gutheil, 1980a; Weiden and Olfson, 1995). A double-blind controlled study also showed that patients who defaulted on oral medication were also very likely to default on depot (intramuscular injections) medication and that both forms of maintenance medication had similar rates of relapse (Falloon *et al.* 1978).

Van Putten (1974) studied the reasons why patients were intentionally non-adherent with drug therapy. Between 24-63% of out-patients took less antipsychotic drug than prescribed. This study identified a relationship between drug reluctance and drug-induced extra-pyramidal side-effects (EPSE). He suggested that in-patients had a greater tolerance of EPSE compared with out-patients due to the greater impact on functioning in the community.

‘... an akinesia may cost a clerk typist her job; an oculogyric crisis may imperil the life of a man who needs to drive; or a tremor can be socially incapacitating to a self-conscious woman’.

Van Putten (1974)

Thirty-five per cent of patients being treated with antipsychotic medication will relapse annually due to a lack of efficacy (Lecrubier and Meltzer, 1993). One of the most common reasons cited was a high incidence of EPSE. Sexual disturbance and weight gain have also been reported as important predictors of patients discontinuing their medication (Young *et al.* 1986; Buchanan, 1992). Paradoxically, not all literature supports a relationship between the presence of adverse effects and noncompliance (Willcox *et al.* 1965; McEvoy *et al.* 1989a). Other studies have found that mild side-effects were not associated with non-adherent behaviour (Hogan *et al.* 1983; Pan and Tantam, 1989). Therefore, simply substituting atypical antipsychotic drugs, whose side-effect profiles are improved, will not be sufficient to lead to complete adherence with drug therapy (Hale, 1993).

Factors associated with drug non-adherence have been identified to be not only a function of the medication (e.g. form type, regimen, adverse effects) but also a function of the patient, the illness, the health care professionals, the patient’s environment, the therapeutic setting or a combination of the above (Babiker, 1986; Flieschhacker *et al.* 1994a; Kissling, 1994;

Gerlach, 1994). Studies have shown that poor adherence with antipsychotic medication is related to personal variables such as culture and ethnic group, patient's experiences, severity of illness, attitudes to treatment, insight into illness, poor relationship between patient and professionals, compulsory admission to hospital and a lack of social support (Appelbaum and Gutheil, 1980b; Marder *et al.* 1983; Kelly *et al.* 1987; Bartkó *et al.* 1988; Pan and Tantam, 1989; Buchanan, 1992; Sellwood and Tarrier, 1994; Lecrubier and Meltzer, 1993).

Diamond (1983) reported a management strategy for enhancing a patient's medication adherence:

- Medication should be put into the context of the patient's life.
- Compliance should be of interest and concern to the professional and there should be an opportunity for constructive dialogue with the patient.
- The patients and all their significant contacts should be well informed about the medication.
- The patient's extended support system should be involved in enhancing compliance.
- The patient should be involved as much as possible in their medication.
- Health care professionals should be assertive in encouraging compliance.
- Contact should be maintained with the active drug defaulter to enhance opportunity for future cooperation and compliance.

Such a strategy highlights the level of involvement the health care professional should take. Non-adherence does not only represent a patient that resists or lacks the motivation to accept the medication or treatment plan that a clinician offers. Non-adherence may also represent the failure of the clinician to offer an appropriate clinical intervention that allows a better therapeutic outcome for that individual (Cohen, 1993). Non-adherence can be an expression of independence and a judgement about the utility of an intervention.

'The quality of one's life is a personally defined concept and so too are the reasons why a patient refuses to do what is recommended. Appropriate health behavior should be thought of as a behavior that meets the person's goals and achieves some mutually definable outcome.'

(Liang, 1989)

Kane (1987a) called for patients and their carers to be more involved in their drug therapy. The role of antipsychotic medication and the goals of treatment, especially during the acute

phase of the illness and long-term maintenance therapy should be understood. Similarly, the limitations of drug therapy should be clearly explained, i.e. that they do not cure the illness and they do not necessarily alleviate psychosocial and interpersonal difficulties.

Szabadi (1996) suggested that predicted adverse effects can promote medication adherence since it reassures the patient that the medication is working. Flieschhacker *et al.* (1994b) showed that noncompliance with haloperidol and clozapine drug therapy was not predicted by the incidence of parkinsonian symptoms in the first four-weeks of treatment. They explained this finding in relation to their approach to treatment. They devoted time to the provision of information and discussion about adverse effects with their patients, as well as the early treatment of adverse effects through dose reduction, concomitant drug therapy and change of antipsychotic medication. This study highlighted the potential importance of information exchange and an open relationship between the prescriber and patient. Flieschhacker *et al.* (1994b) concluded that a positive relationship between the physician and patient is not only an opportunity for information provision to the patient but also an opportunity to correct any misinformation in the patient's health belief system.

Promising results have been obtained with behavioural and educational intervention programmes. For example, Boczkowski *et al.* (1985) carried out a controlled study comparing behavioural-tailoring (BT) and a psychoeducational intervention (PE) with people with chronic schizophrenia taking antipsychotic medication. BT focused on making the medication highly visible, pairing the medication regime with specific activities and providing a self-monitoring calendar. PE was an educational approach that centred on information about the illness and the needs for medication. BT participants were found to be significantly more adherent than either the PE or control group. Limitations of the study included the low correlation between the three measures of compliance: self-report, ratings by significant others and pill counts (pill counts were taken as the criterion measure) and also the short follow-up period of three months.

Kissling (1994) showed in a prospective study of people with schizophrenia in Germany, a 30% improvement in compliance and 20% decrease in readmission in the first year through a series of 8 psychoeducational sessions. He concluded that it is neither ethical nor

economically defensible to prescribe maintenance medication without compliance enhancing strategies such as psychoeducational interventions.

In another controlled study, Kemp *et al.* (1996) helped acutely psychotic in-patients to change their medication-taking behaviour using an active therapeutic approach with guided problem solving and an education component ('compliance therapy'). Consecutively admitted patients (69% response rate) were randomly assigned to compliance therapy (n=25) or control treatment (supportive counselling with no discussion of treatment) (n=22). Four from each group were lost to follow-up. Compliance therapy showed an improvement in insight, attitudes and compliance in the short term (6 months). However, improvement in functioning was not obtained when a minimum standard of 50 on the Global Assessment Scale (Endicott *et al.* 1976) was analysed. A stepwise linear regression model explained 62.5% of the variance in compliance using detention under the Mental Health Act, extra pyramidal side-effects (EPSE) and attitudes to treatment as the explanatory variables. Caution has to be applied to the results due to the small numbers and because the observer (who rated functioning and compliance initially and at 3-months) was not blinded to the treatment group. Nevertheless ratings at 6-months were carried out by an independent assessor who was blinded.

Huxley and Warner (1992) reported reduced readmission rates due to enhanced medication adherence encouraged by patients receiving their welfare benefits simultaneously with their medication, assertive outreach and by close monitoring by case managers with small case loads.

A recent report 'From compliance to concordance: achieving shared goals in medicine taking' suggested that the term 'concordance' should replace the terms compliance and adherence (Royal Pharmaceutical Society of Great Britain and Merck Sharp and Dohme, 1997). Compliance was criticised for its paternalistic approach suggesting that a patient's behaviour (as a passive receiver) should follow the 'doctor's orders'. The authors acknowledged that adherence suggested negotiation between the prescriber and the patient and that the patient had a choice but they still criticised adherence for the same 'semantic overtones' as compliance. The authors of the report justified the new term 'concordance'

because it described the negotiated agreement between the prescriber and the patient and it did not focus on the behaviour of either party.

‘Concordance is based on the notion that the work of the prescriber and patient in the consultation is a negotiation between equals and that therefore the aim is a therapeutic alliance between them. This alliance, may in the end, include an agreement to differ. Its strength lies in a new assumption of respect for the patient’s agenda and the creation of openness in the relationship, so that both doctor and patient together can proceed on the basis of reality and not of misunderstanding, distrust or concealment.’

(Royal Pharmaceutical Society of Great Britain and Merck Sharp and Dohme, 1997:8)

Limitations of this model include the assumption that all patients wish to negotiate as equals with the prescriber; this may not always be the case. Patients and their clinicians may be concordant in the consultation in relation to their views about medication but this does not infer that the patient will be adherent to the advice or treatment after leaving the consultation.

Other critics suggest that there are instances where the model of concordance does not apply (Milburn and Cochrane, 1997). They provided three examples: (1) clinical trials where incomplete compliance and adherence would lead to inconclusive results, (2) research into the human behaviour of medicine-taking and (3) the ethical considerations of allowing someone to decide which and how many medications to take when they have a fatal and infectious disease such as tuberculosis. Clearly, having the patient as the decision maker requires caution in situations where medication taking behaviour has implications beyond the treatment of an individual (Milburn and Cochrane, 1997). So, how appropriate is the model of ‘concordance’ with mental health patients? In this thesis the author (SAF) has continued to use the term adherence because the research focuses on the medication-taking behaviour of the respondents with their depot antipsychotic medication. However, the discussion (Chapter 11) will address the application of the concordance model with this patient group.

1.5.4.2 Subjective evaluation of medication

Although many studies have demonstrated the value of patients’ self-reports on their symptoms and the adverse effects of medication, differentiating between subjective evaluations of some adverse effects and symptoms of illness is difficult (Diamond, 1985).

Van Putten *et al.* (1984) demonstrated moderate agreement between patients' self-reports and clinicians' ratings of symptoms and adverse effects. Significant positive correlations were achieved with patients' self-reports of akinesia and akathisia and with nurses' assessments (Michaels and Mumford, 1989). However, there is poorer agreement between clinicians and patients when the 'bothersomeness' of some symptoms and adverse effects are judged (Finn *et al.* 1990). For example, psychiatrists overestimated the negative consequences of experiencing dystonias and somatic hallucinations and underestimated the negative consequences of constipation, thought disorder and thought blocking when compared with patients.

Hogan *et al.* (1983) in their study of people with schizophrenia found that subjective experience of medication largely contributed to determining adherence. Subsequently, Hogan *et al.* (1985) showed that early subjective response predicted short-term outcome (three weeks) to traditional antipsychotic drugs in patients with schizophrenia, confirming earlier studies. Further, they suggested that those patients who experienced a less favourable subjective response to their medication were more likely to default with their medication. By implication, the authors suggested that early subjective response may be used to identify potential drug defaulters. They conclude that their paper '... underscores the good medical practice of asking our patients how medications agree with them, and paying more attention to their self-reports'. Awad and Hogan (1994) also found that how patients felt and functioned on medication largely contributed to adherence with the therapeutic regime. A negative subjective response did not relate to the plasma levels of the antipsychotic drug, to the severity of symptoms nor to the emergence of side-effects (Van Putten *et al.* 1980; Awad and Hogan, 1994).

A 'subjective well-being on neuroleptics' scale (SWN) was designed for the measurement of the subjective effects of antipsychotic medication (Naber *et al.* 1994; Naber, 1995). When tested, 28 patients taking clozapine were reported to score significantly better than 38 patients on traditional antipsychotic drugs. Four-to six months after discharge from hospital, 14 noncompliant patients scored significantly worse on the total score compared to 34 compliant patients. Caution must be applied to the results because of the small numbers and compliance was determined by the psychiatrists answering 'Does your patient regularly take

his/her neuroleptic drug?'. Objective rating symptom scales were applied at discharge and these did not differentiate between the compliant and noncompliant patient groups. Naber *et al.* (1994) conclude that the main difference between subjective and observer measures are that some parts of the affective state are immeasurable by an expert, therefore confirming the relevance of subjective ratings. The SWN was developed in Germany by selecting the most commonly reported subjective effects from the literature.

1.5.4.3 Medication and quality of life

Personal factors such as life events and cohabiting with over-involved relatives or family (high expressed emotion) can hamper the effectiveness of antipsychotic medication (as reported earlier in Section 1.5.1). The success of medication therefore depends on environmental factors associated with the patient and social influences (Hirsch, 1991). The wider impact of medication on people's lives in the community and the perceived need for medication by community dwellers must be addressed.

Barham and Hayward (1991) asked patients who had been in hospital with mental health problems and were now settled in the community, about their medication. Most people did not object to medication and found it to be beneficial, at least in the short term. However, people wanted an increased understanding of the place medication held within their lives in the community. Medication was recognised as a contributory factor enabling people to live in the community but it also had immense implications on their everyday lives. Respondents of this survey expressed a need for more explanation about their illness, medication and side-effects. They requested adjunctive therapeutic approaches as they perceived medication as controlling and not aiding them to deal with their problems. Respondents requested '... purposive activity; ... direction in their lives; ... to do something more than passing the day or filling time.' Similarly, a study of psychiatric in-patients illustrated that medication was 'quite helpful' but was not foremost on the respondents' agendas. 'Talking' therapy was valued as the most helpful aspect of care (McIntyre *et al.* 1989).

Gerlach and Casey (1994) claimed that the subjective experience and quality of life of the patients are important in measuring the outcome of antipsychotic drug therapy. The United

Kingdom Clinical Pharmacy Association (UKCPA) (1996), in their statement of pharmaceutical care, also emphasised the importance of the outcome of treatment on quality of life (QoL):

‘In order to be meaningful to patients, the outcomes of treatment should be expressed in terms of their own quality of life. In practice, it is necessary for pharmacists to strive to improve that quality of life, whether it is gauged objectively or purely subjectively.’

Traditionally, clinical trials have used measures of the incidence and severity of symptoms and side-effects to evaluate the efficacy of new antipsychotic medication. However, Collins *et al.* (1991) suggested that treatment effectiveness can be obscured when only unidimensional and symptom-based measures are used. Measures of adverse effects alone do not indicate how desirable a treatment is for an individual or how one set of adverse effects would compare with another (Tantam, 1988). A patient’s subjective response to medication and subsequently the patient’s psychosocial functioning in everyday life must also be included. It cannot be assumed that a patient free of major symptoms and side effects will be sociable and self-sufficient (Awad, 1992). Gerlach and Casey (1994) implored that rating scales based upon the patient’s own experience of disease and treatment should be included in clinical trials of new antipsychotic drugs (e.g. Hogan *et al.* 1983; Hogan and Awad 1992).

One example has been the work by Meltzer *et al.* (1990; 1993). Meltzer *et al.* (1990) reported significant improvements in QoL, measured using the Quality of Life Scale (QLS) (Heinrichs *et al.* 1984) in 38 hospitalized patients diagnosed with schizophrenia and treated for 6-months with clozapine. The QLS measures four major factors: intrapsychic foundations, interpersonal relations, instrumental role functioning and common objects and activities. An improvement of $\geq 50\%$ in QLS score was recorded for 22 (58%) patients and $> 100\%$ improvement occurred for 16 (42%) patients. However, caution must be applied to these results since the raters were not blind to the treatment and clozapine (due to its intensive monitoring) would facilitate regular contact with services. At a two-year follow-up the treatment-resistant patients with schizophrenia who continued taking clozapine ($n=37$) compared with those who dropped-out ($n=10$) had a significantly higher quality of life according to the Quality of Life Scale. Another caution must be applied to these results due to the small number in the comparison group who were found to be significantly more likely

to be women. A further limitation to these studies is the choice of quality of life scale. The Quality of Life Scale (QLS) (Heinrichs *et al.* 1984) is a clinician administered instrument that is also rated by the clinician. However, most of the quality of life literature supports subjective measurement of quality of life by the study population (see Chapter 2 for further discussion about who should measure quality of life and Appendix One provides more details on the instrument).

Research in Germany demonstrated a relationship between the subjective well-being associated with antipsychotic drugs and quality of life. The SWN scale (subjective well-being with neuroleptics) (Naber *et al.* 1994) produced significant positive correlations with the mean score and many of the sub-domain scores of a German QoL measure (n=38) (Bullinger, 1993; Naber, 1995). However as described earlier the SWN scale was developed from the most commonly reported subjective effects from the literature and therefore similar research using anglicised instruments, testing for validity and cultural equivalence needs to be completed in the UK.

Recently, a conceptual model was proposed for measuring the QoL of people with schizophrenia taking antipsychotic medication (Awad, 1992; Awad and Hogan 1994). The authors suggested three major determinants of the model: symptoms of schizophrenia and their severity, side effects and psychosocial performance. Three other variables that they thought modified the outcome to antipsychotic medication were subjective response, premorbid characteristics and psychosocial adjustment. This model underlines the need to measure the side-effects and the subjective response to medication as part of QoL determination.

Although there is a range of QoL measures available for use with people with severe mental illness (see Chapter 2), none has systematically been used in clinical drug trials (Awad, 1992). The only published attempts were Meltzer's work described earlier (Meltzer *et al.* 1990; Meltzer *et al.* 1993). Therefore, Awad (1992) makes several suggestions for an appropriate QoL scale to be used in clinical drug trials:

- The scale must tap multidimensional issues, including illness and treatment-related issues.

- The scale should provide profile and index (weighted) measurement - the former to provide separate measures of the various dimensions and the second to permit comparisons between treatment groups.
- The scale should be sensitive enough to measure relatively small changes in functional performance, questioning the need to include domains of life that are unlikely to be affected by drug treatment.
- The scale must include patients' perceptions of their QoL and their subjective feelings about their medicated state.

In conclusion, the benefits of antipsychotic medication in terms of symptom alleviation and the risks in terms of the adverse effects have been described earlier (see Section 1.3). Theoretically, adverse effects such as shaking, restlessness, drowsiness, lip smacking and repeated involuntary movements would be expected to affect one's quality of life. Case studies of people living in the community while taking antipsychotic medication have illustrated the potential effects of antipsychotic medication on quality of life.

'Although undoubtedly the beneficial effect, from a clinical viewpoint, of taking Prolixin probably outweighs the negative side effects, it is still hell taking Prolixin. My immediate worries, aside from my long-term fears of tardive dyskinesia, are how to stop shaking in front of everyone all the time. The amantadine and Artane just don't do the trick entirely. They don't even make it comfortable in the least bit for me ... probably the hardest side effect for me to live with... is that it drains my energy. While not taking Prolixin I can bounce around with almost free perpetual motion... I don't feel human when taking Prolixin... I take Prolixin now... because I can't make a living if I don't take the drug.'

(Diamond, 1985:32)

'Cyril is an ex-weaver in his mid-fifties who, since his wife died some years ago, now cares single-handedly for his severely handicapped sister-in-law... Yet despite the pressures on his time, he also succeeds in generating a source of income - he has a knitting machine on which he knits hats and scarves and the previous week, for example, he sold six sets of scarves and hats for £2 each. Just as the moment, however, he is unable to knit. The change in his medication... as well as making him drowsy, has produced a tremor which affects his writing and also the 'fiddly bits' in his knitting.'

(Barham and Hayward, 1991:65, 116)

Antipsychotic medication, therefore, can affect an individual's quality of life and research is required to establish the most appropriate methods of routinely measuring the outcome of medication in clinical practice.

CHAPTER 2 QUALITY OF LIFE MEASUREMENT

2.1 Introduction

Advancement in the therapeutic management of people with schizophrenia has shifted the focus of care from institutional settings to the community. As discussed in Chapter 1, symptom alleviation alone is no longer a satisfactory outcome measure for the treatment of people with schizophrenia. Due consideration must be given to whether a treatment leads to a life worth living; does treatment improve, or at the very least not decrease, the ‘quality of life’ of people with a diagnosis of schizophrenia?

For people with chronic schizophrenia, it is unlikely that many will achieve high levels of rehabilitation, return to competitive employment or attain a high level of social functioning (Baker and Intagliata, 1982). Measurement of such objective terms therefore provides little information about the client and their achievements in the community. As an outcome variable, quality of life (QoL) can reflect an increase in domain-specific life satisfaction within a realistic set of goals. The multidimensional structure provides a framework for considering the client as a whole instead of focussing narrowly just on pathology (Malm *et al.* 1981; Baker and Intagliata, 1982). QoL measurement also facilitates the assessment of the combined effects of a complex multidisciplinary rehabilitation care programme (Baker and Intagliata, 1982, Oliver *et al.* 1996).

‘The extent to which mental health services can have a positive impact on the lifestyle of long-term clients and maximise their quality of life is an important test of the success of the new services in translating their policy objectives into practice.’

(Barry *et al.* 1993)

Within mental health care, as for health care as a whole, ‘consumerism’ and patient autonomy have increasing involvement through advocacy services and the active participation of carers and families. QoL assessment can provide evidence to determine the contribution of therapeutic interventions and programmes of care to life satisfaction, or overall happiness (Baker and Intagliata, 1982). Throughout their work, Oliver *et al.* (1996) found that respondents and their relatives regarded QoL measures positively and in general, demonstrated their support of its measurement with high response rates.

This chapter introduces and briefly discusses the concept of ‘quality of life’ (QoL) (Section 2.2) focussing on the mental health perspective (Section 2.3). Methods for assessing QoL in schizophrenia research will be reviewed in Section 2.4. A summary of the most common instruments used in psychiatric outcome research for patients with schizophrenia will be reported. It is not the intention of this thesis to include a comprehensive account of the development and uses of all generic and condition-specific (including disease-specific) health outcome measures. Detailed commentaries have been published that focus on measuring health, disease, health status, health policy and quality of life (e.g. McDowell and Newell (1987); Teeling-Smith (1988); Streiner and Norman, (1989); Bowling (1991); Bowling, (1995); Patrick and Erickson (1993)). Finally, the Chapter will close with the strategy adopted in this research study for measuring the quality of life (QoL) of people with schizophrenia (Section 2.5).

2.2 The conceptual debate of ‘quality of life’

Quality of life (QoL) is a multidimensional concept, of which health status is one component. Some researchers do not make this conceptual distinction explicit and inappropriately discuss health status synonymously with QoL. QoL, *per se*, is a broader concept including other life dimensions (e.g. life satisfaction, morale, socioeconomic status). This section will first discuss health status as an outcome indicator and will then relate this to the broader concept of QoL.

The health outcome debate is a concern, not only for theoretical researchers but also for clinicians, health care managers and health care policy makers. The measurement of health outcomes has become increasingly important in allocating scarce resources, informing clinical decision-making and facilitating patients’ autonomy (Häyry, 1991). Traditional outcome criteria focus on morbidity and mortality statistics, service utilization data and an individual’s return to optimal functioning. Determinants of the success of treatment include symptom alleviation, biological and physiological functioning and role performance, such as the ability to go to work (Hunt and McKenna, 1993). However, it has been recognised that self-assessment is the best approach to determining whether a treatment or medical intervention facilitates a patient to meet their needs or expectations. Nevertheless, medical

information databases continue to exclude patients' self-assessments of their health status (Ware, 1995). Little attention is usually afforded to patients' outcome criteria such as ability to fulfil household duties, levels of interest and energy and the ability to enjoy themselves (Hunt and McKenna, 1993).

Negative measures of health such as mortality statistics and life expectancy data have been used to measure *quantity* of life for some time, or more accurately the quantity of ill health. However, the World Health Organisation's (1948) definition of health including physical, mental and social dimensions gave impetus to the concept of positive health and well-being.

'Health is a state of complete physical, mental and social well-being, and not merely the absence of disease and infirmity.'

(World Health Organisation, 1948)

Criticisms of this definition focus on its lack of clarity. The definition excludes physiological states, does not define what health-states are preferable to others nor the boundaries of social well-being in relation to health (Patrick and Erickson, 1993:20). A more recent definition of health compounds the criticism that health is unrealistically represented as an ideal state.

'Health also connotes completeness - nothing is missing from the person - and proper function - all is working efficiently.'

(Ware, 1995)

While there is no agreement on a single definition of health, these definitions introduced the concept of positive health which one author has reported as a group of distinct components requiring individual measurement and interpretation. Ability to cope with stressful events, the maintenance of a strong social support system, integration in the community, high morale and life satisfaction, psychological well-being and physical health and fitness are among the main components thought to contribute to positive health (Bowling, 1991:7).

The wider definitions of health incorporating concepts such as positive health are often an important basis for defining many health-related concepts including the multidimensional concept of quality of life (QoL). Representing health as an absolute state (e.g. see definitions above) is unhelpful for clarifying these related terms. Defining health, and therefore the quality of one's health or life, as a relative concept is more useful and practical. There is no absolute state that may be attained to represent the best/highest QoL, or standard against

which one may assess QoL. Some authors comment that QoL can be lost. However, QoL is not an all-or-nothing concept. Quality of life is represented by a continuum that ranges from a positive quality of life to a negative quality of life and so there is always a degree of quality of life, although it may be very poor (McCall, 1975; Meeberg, 1993).

‘Quality of life’ (QoL) is a much broader concept than health including standards of living, quality of housing, job satisfaction and other factors (Campbell *et al.* 1976). QoL has two conceptual issues (McCall, 1975).

- *Quality*, in its non-evaluative status, is a character or attribute. Parkerson *et al.* (1992) defined QoL as an attribute of multiple components, drawing specific attention to the importance of functional health.
Quality, in its evaluative status, is ‘multi-criterial’ (i.e. dependent on the presence or absence of coexisting factors) and ‘type-dependent’ (i.e. dependent on what is being described as having ‘quality’).
- *Life* also requires clarification. It depends upon whose ‘life’ is referred to, e.g. society’s, a group of people, or an individual.

2.2.1 Is quality of life about human needs or human wants?

The conceptualisation of QoL has been perceived from a human ‘needs-approach’ and a human ‘wants-approach’ (Häyry, 1991). The first perspective emphasized that QoL lies in the satisfaction of human needs. Well-being is represented by a continuum of positive to negative feelings associated with the degree of human unmet need (McCall, 1975; Schuessler and Fisher, 1985; Häyry, 1991). The identified human needs form objective criteria that can be used for the evaluation of QoL and permit comparisons between individuals, groups and different societies at different times and places (McCall, 1975).

Maslow’s (1970) hierarchy of human basic needs have been used to illustrate the needs-approach: physiological needs (1st); safety needs (2nd); belongingness and love needs - passive and active (3rd); esteem needs - passive and active (4th); need for self-actualisation (5th). Most of the needs in Maslow’s hierarchy have psychological endpoints and much work is still required to construct a list of causal factors (physical, interpersonal and social) that can

predict these end states if we want to use these needs as objective indicators of QoL (McCall, 1975). Also, within this framework, 'met needs' require clarification, e.g. what is adequate shelter? (Michalos, 1974). However, an advantage to the poorly defined framework is that transfer between cultures and settings is more likely to be possible (McCall, 1975).

Hunt (1997) criticised the needs-approach for the lack of empirical evidence to support the assumption that QoL is associated with needs satisfaction. Other criticisms of the needs-approach are that by ignoring the subjective and psychological aspects of human life, determinants of people's happiness and contentment are not accounted for. The meeting of basic human needs does not predict life satisfaction (Häyry, 1991). Browne *et al.* (1997) criticised the needs-approach as an inadequate model of the nature of QoL at the individual level. Beyond a basic standard of living, only the individual may define what constitutes a good or bad QoL. Definition, evaluation criteria and relative importance of life domains differ for different people.

Alternatively, the human 'wants-approach' (Häyry, 1991) introduced a psychological state to the measurement. The individual approach to QoL measurement asks people themselves to define the components of QoL pertinent to them.

'.. like health, a concept as broad as quality of life cannot be closely defined or measured. Being intrinsically both subjective and situational, it can be truly defined only individually in the relative terms and in the historical perspective that refer to an individual's subjective experience of and overall satisfaction with life.'

(Sullivan, 1992)

It is unlikely, by adopting this approach, that people will respond by naming met needs. Only people who have unmet needs are acutely aware of their importance (Flannagan, 1978). Calman (1984) developed his QoL definition from this perspective based on the gap between current status and expectations:

'A good quality of life can be said to be present when the hopes of an individual are matched and fulfilled by experience.'

Calman (1984)

Cribb (1985) congratulated this definition because it promoted QoL improvement for the individual, but he also criticised it because of the inability to compare between individuals, groups and societies due to its subjective nature. Calman (1985) suggested that an external

validator may be required to ensure hopes and expectations were realistic. However, involving the opinions of external judges of different value systems or levels of ignorance introduce inherent difficulties. Häyry (1991) commented that by using an external validation process, QoL may be met equally by diminishing an individual's goals or by helping in their attainment. Considering Maslow's (1970) hierarchy of 'needs' it is said that thwarting of esteem needs can lead to feelings of inferiority, weakness and helplessness that lead to basic discouragement or else 'compensatory or neurotic trends'. The definition of wants and needs must therefore be explicit; otherwise, by reducing individuals' expectations to a 'realistic' level through external validation, one could be decreasing self-esteem instead of improving QoL. A final criticism of the wants-approach to QoL, is the underlying assumption that individuals wish to have all their aspirations satisfied, when in reality, goal setting/aspirations may be an important component of life for some people (Cribb, 1985).

Many of the quality of life scales in psychiatry adopted the conceptual models of needs satisfaction and satisfaction with life (e.g. Lehman's Quality of Life Interview, 1988) with the relative concepts of need and satisfaction being dependent on the values and perceptions of the individual. The notion of 19th century utilitarianism, which sought to maximise happiness for the greatest number, underpins the life satisfaction model. Ideally, society was portrayed as a collection of individuals trying to make the most of what they had by using their social relationships, ultimately aiming for the greatest good for the greatest number. The dimension of well-being was introduced and defined as 'the difference in value between the sum of all pleasures of all sorts and the sum of pains of all sorts which a man experienced in a given period of time.' (Bentham, 1834/1983). Bentham attempted to illustrate how utilitarianism may be developed into an analysis of pleasures by which the effects of actions could be judged, and the right policy would thus be identified. Subsequently, it was expected that utilitarianism would provide a rational foundation for social and legal policy (Bowling, 1995).

The utilitarian desired state of obtaining excesses of pleasure over pain was derived from the translation of Aristotle's desired ethical goal of human behaviour, the concept of *eudaemonia*. The focus of the translation was on pleasure and happiness (rather than virtue and excellence) and shaped the subsequent studies of psychological well-being (e.g. Gurin

et al. 1960) (Oliver *et al.* 1996:19-20). However, contemporary utilitarianism focuses more on satisfaction than happiness as the relevant outcome (Bowling, 1995). Thus, current measures of quality of life and health-related quality of life in psychiatry demonstrate this philosophical influence by including questions about feelings of happiness and satisfaction with various areas of life and functioning.

2.2.2 Is quality of life more than we can measure?

Rosenberg (1992) presented a thoughtful philosophical discussion of the QoL concept. He acknowledged that to establish and refine the psychometric properties of a QoL measure, immense scientific effort is required and therefore, this alone could represent a worthy concept of QoL. However, he questioned the concept as something more than the reliable and valid measurement of its relative components. He also questioned the ability of the empirical researcher to accept that there is an existential status to QoL that cannot be met through epistemological enquiry. Hunt (1997) claimed that the meaning of QoL lies singularly within moral philosophy and to claim that psychometric enquiry alone represents the QoL concept, which is ‘such an essential aspect of human life’, was ethically unjust.

Conversely, Fitzpatrick *et al.* (1992) suggested that the philosophical approach to QoL is misleading. Driving their argument from the empiricist’s perspective, they suggest that in medical contexts there is no attempt to include indicators such as life satisfaction or living standards, and approaches to QoL should concentrate on experiences related to health and health care. They avoided the conceptual issue by stating that QoL ‘... is inherently subjective and definitions vary.’ Patrick and Erickson (1993:21) suggested that due to the global nature of QoL, a list of domains should be requested to clarify the term when used. Therefore, this view also dismisses the philosophical debate by suggesting that the concept of QoL is nothing more than the domains used to measure the concept.

The health economist’s approach to QoL attempts to quantify the concept as a single index by combining quantity and quality of life, but rarely is ‘quality’ defined (Torrance, 1987; Patrick and Erickson, 1993:21). More often ‘quality’ is indirectly assumed by the items selected for inclusion in measures. Weinstein and Stason (1976) introduced quality-adjusted

life years (QALYs) as a measurement of health outcomes in cost-utility studies. However, Hunt (1997:207) criticised the method for its lack of philosophical awareness. The method employs subjective judgements that may be used to make policy decisions, thereby introducing the potential for an individual to be discriminated against if their preferences were not accounted for in the measurement process. Hunt (1997) also suggested that the method had not established any relationship between disability/distress and quality of life, and did not take into account how individuals may adapt their lives to their illness. A description of health state utilities and methods used for the measurement of health state utilities is beyond the scope of this thesis and the reader is referred to other texts (e.g. Kaplan and Bush, 1982; Kind *et al.* 1982; Williams, 1985; Torrance, 1987; Drummond, 1987; Karlsson, 1992; Patrick and Erickson, 1993).

2.2.2 Defining quality of life

Quality of life (QoL) is a multidimensional concept that is not only used synonymously with health status, but also with health-related quality of life (HRQoL). Many authors fail to state explicit definitions of the terms when they quote QoL in publications. Torrance (1987) defined HRQoL, distinct from QoL, as only those factors that are part of, and directly affect, an individual's health such as physical and emotional functioning. Physical and emotional functioning are measures of health status, and it is the impact of health status on life and social roles that constitutes health-related quality of life. For example, the WHOQOL Group (1993) (World Health Organisation Quality of Life Group) published their definition of HRQoL that underpins the development of their QoL instrument for use in different settings.

'Quality of life is defined as an individual's perception of their position in life in the context of culture and value systems in which they live and in relation to their goals, expectations, standards and concerns. It is a broad ranging concept affected in a complex way by the person's physical health, psychological state, level of independence, social relationships, and their relationships to salient features of their environment.'

(WHOQOL Group, 1993)

Bowling (1995) added that HRQoL is '... a double-sided concept, incorporating positive as well as negative aspects of well-being and life'.

‘... HRQoL is defined here as optimum levels of mental, physical, role (e.g. work, parent, carer, etc.) and social functioning, including relationships, and perceptions of health, fitness, life satisfaction and well-being. It should also include some assessment of the patient’s level of satisfaction with treatment, outcome and health status and with future prospects. It is distinct from quality of life as a whole, which would also include adequacy of housing, income and perceptions of immediate environment.’

(Bowling, 1995)

However, in this thesis the wider term quality of life is used because of its relevance to people with mental health problems. Quality of life for people with schizophrenia will include areas of life such as the adequacy of housing, financial status and feelings of safety.

QoL has been defined as an all-inclusive concept incorporating all factors that influence an individual’s life (Torrance, 1987). However, global definitions, such as this, are unhelpful in guiding the operationalisation of the concept of QoL. Bowling (1991:9) provided one of the most comprehensive definitions that included the physical, mental and social dimensions of the World Health Organisation’s (1948) definition of health.

‘... quality of life is recognised as a concept representing individual responses to the physical, mental and social effects of illness on daily living which influence the extent to which personal satisfaction with life circumstances can be achieved. It encompasses more than adequate physical well-being, it includes perceptions of well-being, a basic level of satisfaction and a general sense of self-worth. It is an abstract and complex concept comprising diverse areas, all of which contribute to the whole, personal satisfaction and self-esteem.’

(Bowling, 1991:9)

Clark and Bowling (1989) considered the quality of everyday life for the residents of a nursing home and a long-stay ward for the elderly. In their review of institutionalised care, they referred to QoL as ‘not limited to functional ability, level of activity, mental state and longevity, but encompasses the concepts of privacy, freedom, respect for the individual, freedom of choice, emotional well-being and maintenance of dignity’.

Farquhar (1995) published findings of an empirical study that focused on elderly people living in their own homes. In-depth unstructured interviews were used to find out what the term ‘QoL’ meant to respondents. Farquhar found that respondents could discuss QoL and defined it in terms of the good and bad aspects of their lives. QoL for this group included family relationships, other social contacts, activities, material circumstances, independence,

as well as general health and functional status.

Hunt (1997) criticised those who claim that a consensus has been reached in the definition of QoL. She stated this to be untrue which is illustrated by the number of existing models that do not agree over the structure of the concept. Campbell *et al.* (1976) claimed that ‘quality of life is a vague and ethereal entity, something that many people talk about, but which nobody clearly knows what to do about’. In the 1990s, QoL remains a vague term. Others claim that attempting to define QoL is unrealistic and efforts would be better focussed on formulating “... valuable and practical indicators and components of ‘quality of life’” (Cribb, 1985). However, Hunt (1997) suggested that to measure a construct that does not have a conceptual model is irresponsible, especially when the measurement of such issues as HRQoL are being used to inform decisions of resource allocation and clinical decisions that affect people’s lives. In one review of 75 QoL articles, only 15% conceptually defined QoL (Gill and Feinstein, 1994).

2.3 The mental health perspective on quality of life

Contrary to most authors in the mental health field, Awad (1997) specifically called for the measurement of HRQoL in research on the clinical outcomes of schizophrenia. He argued that the broad concept of QoL included too many life dimensions that were not related to health such as job, family, environment. QoL, he claimed, was useless as a health outcome measure. Lehman *et al.* (1982) acknowledged that health care could not address all aspects of individuals’ lives. However, they defended the broader QoL approach by commending that a wide knowledge of an individual’s life circumstances and the subsequent impact of ill health, can inform the most appropriate care for improving their lives. Oliver (1991) endorsed the broader conceptualisation by explaining that QoL is both total health and welfare. The development of the Lancashire Quality of Life Profile (Oliver, 1991) was in response to Governmental changes in the provision of services for people with mental health problems (e.g. NHS and Community Care Act, 1990 (House of Commons, 1990)). Instruments were required to evaluate these changes and to interpret the impact on the QoL of people living in the community. ‘Community care’ for the chronically mentally ill has two components: health and ‘social’ care, where social care includes needs beyond health care

(Oliver, 1991).

The range of conceptual approaches and methods used to measure QoL illustrates the variation in the importance of different dimensions of QoL for people with schizophrenia. Much work has been completed exploring the conceptualisation and measurement of QoL. However, there is still no universal acceptance of one model or standard instrument for the measurement of QoL. Limiting the concept to HRQoL has aided the development of definitions and measurement in some instances. However, this approach has also presented restrictions: can respondents with mental health problems differentiate health-related factors from all of life factors when asked to make global ratings about their QoL?

The development of QoL measurement has its origins with the large scale American surveys of life satisfaction and social indicator research (Gurin *et al.* 1960; Andrews and Withey, 1976; Campbell *et al.* 1976). Subsequently, approaches to the measurement of QoL were developed, such as global well-being and satisfaction in specific life domains, incorporating both objective indicators (non-experiential e.g. income, housing) and subjective indicators (experiential e.g. satisfaction) (Barry *et al.* 1993). QoL scales do not only focus on health factors in a general, global sense but also related items such as safety and life circumstances. Measuring QoL in psychiatry requires three essential considerations: patient's own subjective view, degree of patient satisfaction, i.e. her/his opinion about well-being, and evaluation of the situation beyond basic and general needs (Dencker, 1992).

Defining the QoL of people with schizophrenia living in the community solely using objective indicators is impractical and unrealistic. Undoubtedly, respondents' scores would cluster at low ratings of QoL since respondents are often unemployed with poor financial standing and an unstable or nonexistent family life (Franklin *et al.* 1986). Similarly, defining QoL purely in subjective terms for people with schizophrenia also receives criticism. It assumes that assessments of happiness and dissatisfaction are not associated with pathology, therefore ignoring the impact of mental ill health. However, the instability of the overall mood of respondents can affect the measurement of happiness. Furthermore, subjective assessment '.. does not differentiate the privileged from the disadvantaged' and therefore sanctions inactive behaviour (Malm *et al.* 1981). For these reasons, these authors supported

the combination of objective (factors concerning the material and social environments) and subjective factors.

Many authors agree that the combined objective and subjective assessment of QoL for the chronic mentally ill is the most appropriate approach. Zautra and Goodhart (1979) defined QoL as the 'goodness of life' and called for both objective and subjective indicators; '... this 'goodness' resides in the quality of the life experience, both as subjectively evaluated and as objectively determined by an assessment of external conditions.' The employment of both objective indicators plus subjective assessments of specific life domains have been more useful in determining individual differences (Zautra and Goodhart, 1979; Najman and Levine, 1981).

Relationships between objective and subjective indicators have been tested empirically but there is little agreement on the nature of the relationship. Lehman *et al.* (1982) demonstrated low correlations between each type of indicator. The authors used this finding to justify the inclusion of both types of indicators as each were measuring different aspects of QoL. However, Bigelow *et al.* (1991) stated that the relationship between the two types of indicators was unknown. In their evaluation of a resettlement programme for the chronically mentally ill, Barry *et al.* (1993) found an absence of significant correlations between objective and subjective indicators in each domain of an adapted version of the Quality of Life Interview (Lehman *et al.* 1982). They then raised some questions: how do objective indicators of different life areas relate to their subjective evaluation? Do states of well-being have a discrete objective component? For example, does the frequency of social contact determine satisfaction with social relations?

Baker and Intagliata (1982) recognised the theoretical insufficiencies and definitional ambiguity in QoL research. They called for '... more open-ended interviews and other kinds of exploratory data gathering so that we can have a better understanding of what the relevant dimensions of quality of life are with particular populations'. Using psychological indicators, they discussed two major approaches of operationalising perceived QoL:

- global well-being, happiness or satisfaction is used as a criterion and a variety of more specific measures are studied as they relate to it;

- specific life domains are identified conceptually or empirically, and QoL is determined in relation to an individual's reaction to these specific life areas.

Subsequently they proposed a conceptual model of QoL '... that represents relationships between the external environments (objective indicators), individual experiences/perceptions, individual health status (one's needs, desires, knowledge, beliefs, values and attitudes) and quality of life responses (behavioural outcomes of the person's encounters with various environmental situations)'. This was the model on which they based their instrument 'Satisfaction with Life Domains' and they claimed to confirm its content using open-ended interviews with a sub-sample of 20 respondents. However, Baker and Intagliata (1982) reported few details.

Franklin *et al.* (1986) suggested a three component model of QoL for the chronic mentally ill: '...objective indicators of life situations, satisfaction with these situations and adaptation to life situations'. The authors defend their inclusion of an adaptive component since it is precisely this aspect of QoL that mental health professionals can have the greatest influence compared with objective indicators (e.g. income) or subjective indicators (e.g. satisfaction with living conditions). However, this may also be perceived as a disadvantage of this model since it infers that what is important to QoL is only what providers of services can act upon and measure. The authors tested their model by evaluating an intervention programme for 220 clients (56% with a diagnosis of schizophrenia) in the USA (Franklin *et al.* 1986). The six objective indicators were selected by identifying those needs that the programme intervention could address. A 5-point Likert scale was used to measure satisfaction with each of the objective indicators. Measurements of activities of daily living (ADL), the Affect-Balance Scale (Bradburn, 1969) and the Self-Esteem Scale (Rosenberg, 1965) operationalised the dimension of adaptation. A 6-item scale was used to represent ADL. A 5-point continuum was used for self-assessment of the successful completion of each activity during the past month.

The adaptation component was highly correlated to the subjective component, which questioned whether each were measuring the same construct and whether measurement error caused the non-perfect correlation (Franklin *et al.* 1986). However, the authors concluded that satisfaction and adaptation varied according to the amount of change respondents

perceived in their life situations, i.e. the greater the perceived change, the smaller the association between the subjective and adaptation components. The measurement model used was not psychometrically tested.

Through testing this model, low associations between objective indicators and the subjective (and adaptation) dimensions were reported. This supported similar findings from previous studies as already discussed (Campbell *et al.* 1976; Zautra and Goodhart, 1979; Najman and Levine 1981; Lehman *et al.* 1982).

Lehman (1988) published an alternative three component conceptual model of QoL: ‘... the experience of general well-being as a product of personal characteristics, objective life conditions in various life domains, and satisfaction with life conditions in these various domains’. Lehman (1988) and Oliver (1991) tested this model empirically and both supported its formulation.

QoL has also been modelled as a subjective feeling affected by personal characteristics and welfare that in turn were affected by standard of living (e.g. housing, education, relationships) i.e. objective indicators (Skantze *et al.* 1990). Empirically, the authors showed, with a sample of outpatients with schizophrenia (n=61), that standard of living was not a direct determinant of an individual’s QoL.

Bigelow *et al.* (1991) adopted an alternative approach and defined QoL from the two theoretical perspectives of need and role. They developed the popular Oregon Quality of Life Interview from this conceptual base.

‘Quality of life, as we view it, comes out of a social contract- fulfilment of *needs* in exchange for meeting of *demands* which society places upon its members. Needs are fulfilled through *opportunities* presented by the social environment. Demands are met through the exercise of basic psychological *abilities*-cognition, affect, perception and motor. For example, a work role demands concentration and stress tolerance while it provides opportunities for meeting self-esteem, social affiliation, and basic needs. Abilities compromised by mental illness deprive a person of the satisfaction of his or her needs due to impairment of the person’s participation in the normal opportunity structure. Mental health services address that deprivation by moderating social demands (advocacy), supplementing opportunities (brokerage and sheltered work), and restoring abilities (rehabilitation and medication).’

[Note: Authors italicising retained]

(Bigelow *et al.* 1991)

2.4 Assessment of quality of life

The QoL concept is often reduced to the methodologically difficult (and philosophically trivial) enquiry of psychometric testing of various existing scales and to discussions of appropriate future measures (Rosenberg, 1992). For a detailed account of general issues concerning the measurement of QoL, the reader is referred to the books referenced in Section 2.1. The aim of this section is to review the available methods for assessing QoL in schizophrenia outcome research.

Section 2.4.1 discusses who is most appropriate to measure QoL and then focuses on an individual approach to QoL measurement in Sections 2.4.2 and Section 2.4.3. Section 2.4.4 summarises the available QoL measures for people with schizophrenia. It is not the intention for QoL measurement to substitute traditional outcome measures or clinical judgement. Its purpose is to contribute information to the clinical setting that is pertinent to an individual's or population's perspective of their health care or treatment, facilitating patient involvement (Hunt and McKenna, 1993; Fitzpatrick *et al.* 1992). Although, Goodare (1992) questions the extent to which clinicians involve patients in clinical decisions.

2.4.1 Who should measure quality of life?

The perspective taken at the time of defining and measuring QoL can severely affect the interpretation and flexibility of the concept. Outcome research can be organised from the viewpoint of the patient, provider, support system or society. The outcomes derived from each of these participant groups may not be consistent (McGlynn *et al.* 1988). Skantze *et al.* (1990) reported that only an individual can define and assess a 'good life' and individuals differ on their criteria. Joyce (1994) agreed that QoL is a matter for the individual, rather than the social group and that objective measures or judgements of functioning do not take precedence over an individual's assessment and perception of that functioning. Häyry (1991) criticised the use of health professionals or informed lay people to determine an individual's QoL since it contradicts today's ethos of patient autonomy. There are dangers in assuming that the values of the raters are the same as the values of the respondents (Littlewood and Lipsedge, 1989). Where individuals are capable to make such judgements, and wish to do

so, then judgement by others is not required.

Studies have compared ratings between patients and clinicians concerning assessments of care, treatment and QoL in a range of specialties. Poor levels of agreement were shown in all studies (Orth-Gomer *et al.* 1979; Jachuk *et al.* 1982; Slevin *et al.* 1988; Rothwell *et al.* 1997). Such disagreement can be useful as a focus of negotiation between clinician and patient for improvements in care (Hunt and McKenna, 1993). However, lack of agreement between patients' and professionals' assessments should not be dismissed as inadequacies on the parts of the patients (Babiker and Thorne, 1993). Strauss *et al.* (1978) found that there was no evidence to suggest that patient reported information was any less valid than data from other sources, e.g. relatives or clinical records.

2.4.2 Reliability and validity of reports by respondents who have mental health problems

All respondents provide sources of error in interview data, irrespective of health status. However, respondents who have mental health problems may provide an additional source of error due to the nature of their illnesses (Dworkin, 1992). Zautra and Goodhart (1979) questioned subjective assessments by people with mental health problems because of the unknown influence of their psychiatric symptoms. In the case of psychological illness, people's responses may be unreliable due to brain damage, dementia or severe psychotic symptoms. On these occasions, using proxy measures may be useful. However, often patient and/or relative accounts are used to inform clinicians' diagnoses and monitor improvements in illness. Paradoxically, clinician-led information is used to evaluate the outcome of treatment in terms of symptom alleviation and assessment of side-effects. Patients' reports on the wider impacts of treatment on well-being are more often dismissed due to assumptions about poor reliability and validity of patient-report (Hunt and McKenna, 1993; Awad *et al.* 1997a). The infamous Rosenhan (1973) study illustrated this point when 'healthy' people ensured their admissions to a mental hospital and then could not persuade staff of their sanity.

Bowling (1995:66) reported that interviewing people with mental health problems for subjective ratings is an essential component when assessing the outcome of psychiatric

treatment. Multiple methods (triangulation) are suggested to guard against distorted reporting due to mental ill health: corroborating a patient report with carer and staff ratings, using open-ended interview techniques with additional probing and interviewer coding (Bowling, 1991). Psychiatric research should consider including assessments of the patient, the carer and the people with whom they live. Not only as sources of validation but benefits of treatments that directly improve the QoL of the patient may also have an indirect benefit on the carer's well-being (Hunt and McKenna, 1993). Dworkin (1992) acknowledged that multi-method approaches are necessary when researching the mentally ill but also warns against the dilemma of contradiction between data sources.

'It cannot be assumed that one data source is a priori preferred over another. In the absence of gold standards, the researcher needs to generate strategies to referee differences.'

(Dworkin, 1992:75)

Schizophrenia with active psychotic symptoms can affect respondent-reporting. Oliver (1991) suggested that because QoL itself is related to well-being, then if ill health affects well-being, it is reasonable to assume that it would affect QoL. Rapport may be difficult between the respondent and the researcher; respondents may deny the existence of illness, suffer time distortions and may have a limited attention span (Dworkin, 1992). Attention should also be given to the type of medication people are taking. Some adverse effects of medications used for the treatment of schizophrenia (see Chapter 1) can interfere with the research interview, e.g. restlessness, drowsiness. However, published studies provide evidence that people with psychoses can reliably and consistently report information about their satisfaction and feelings (Davidhizar, 1985; Brewin, 1992; Hogan and Awad, 1992). Lehman (1988) illustrated that while life satisfaction was negatively associated with symptoms of anxiety and depression, it was not associated with thought disorder.

2.4.3 How do we measure quality of life?

An abundance of scales exist for the measurement of QoL, including measures of functional ability (ability to perform social roles), health status (subjective perceptions of physical, mental and social health and well-being), psychological well-being, social networks and social support, and emotional well-being (life satisfaction and self-esteem) (see Bowling, 1991 for a full review). Standardised instruments have been developed for use as generic or

condition-specific measures. It has been recommended that in some instances, both generic and condition-specific measures should be used together. However, Hyland (1992a) commented that it was misguided to use both a generic health scale and a condition-specific scale. Although the generic health scale asks about generic health issues, the respondent may reply to that scale from the perspective of their disease because the respondent may associate any health problems or issues with their disease. Care must therefore be taken at the degree of overlap between instruments so that the same issues are not measured twice. Other authors have recommended using the most appropriate valid tool according to the purpose of the study and where necessary, adding supplementary items (Fletcher *et al.* 1992). Joyce (1994:49) expressed caution in adding deficient items to a general questionnaire due to the effect on the validity of the original instrument. Another suggestion has been to randomise patients to different instruments with a common core set of items. However, large numbers of respondents are required and if several outcomes are being investigated, it is recommended that p-values are adjusted (Bulpitt, 1992). A further approach becoming widely accepted is to supplement generic health measures with symptom checklists (Croog *et al.* 1986). Alternatively, some authors have suggested a respondent-led approach to measuring QoL (Chambers, 1993; Joyce, 1994; O'Boyle, 1994)

2.4.3.1 Respondent-led quality of life measurement

Individual patient-perceived QoL is a respondent-led method of defining and measuring QoL, where QoL is '... what the patient tells him- or herself it is' (Joyce, 1994:47). According to O'Boyle (1995) subjective health assessment can provide information about individual QoL: the capabilities¹ and the welfare² of individuals. However, he warns that if 'welfare' assessment is allowed to dominate, experiences and unrealistic expectations could affect measurement (O'Boyle, 1995).

¹ *Capabilities* - performance and possible attainment in areas of mental and physical health. 'Objective assessment' of individuals' functioning allows for comparisons between individuals.

² *Welfare* - domain-specific health and life satisfaction. Welfare assessment allows for individual preferences to take precedence.

These criticisms were highlighted earlier in the ‘wants-approach’ to QoL (Section 2.2.1). Calman (1984) suggested that an external validator could ensure the appropriateness of expectations, therefore enhancing QoL through ‘thwarting’ an individual’s expectations! O’Boyle (1995) suggested alternative solutions through further examination of the welfare approach:

- Information about the way individuals make their judgements should be explored.
- The reliability and validity of individuals’ judgements and the experiences that influence them should be examined.
- The ways in which individuals adapt the activities upon which they judge the impact of their illness should be studied.

Other authors agree that components of QoL differ for each individual and therefore measurement of QoL should reflect the preferences and priorities of the individual. By allowing individuals to choose the life domains of most concern to them, the question of the appropriateness of the instrument becomes invalid and researchers are unlikely to make any inappropriate measures (Goodare, 1992).

Some authors have recommended the use of a respondent-led approach in clinical trials since measurement of items reported by respondents have an increased sensitivity to change that allows a smaller sample size to be employed compared with standardised tools (Tugwell *et al.* 1990; Chambers, 1993). Similarly, QoL measurements taken from clinical trial data should not automatically be generalised to other populations. A risk-benefit analysis of treatment, weighing the positive effects of the medication (in terms of treating the disease) against the toxicity of the treatment, is an individual judgement and levels of acceptable toxicity are likely to vary between individuals (Fayers, 1992).

It is acknowledged that by adopting a respondent-led approach, cross-sectional data will vary between individuals but the responsiveness of individual measurement is likely to be greater when considering the effects of different interventions and detecting unexpected or iatrogenic effects. However, problems can occur when respondent-led items reported at a follow-up interview are not related to those items reported at baseline. On such occasions, respondents could be asked to re-prioritise baseline items also.

Cairns (1996) argued that people with essentially the same health status may score differently on QoL instruments and changes in their scores could occur without any underlying change in health status. However, most researchers agree that by measuring QoL, an individual's perception of life quality and life satisfaction is being assessed that includes judgements on more aspects of life than health status. Hunt (1997) also reflected that individuals have different coping abilities and will make different adjustments to their lives in response to various health states. Gill and Feinstein (1994) added that individuals' values and preferences distinguish QoL from other measures of health.

Rosenberg (1992) supported the adoption of subjective methods by suggesting the use of the hermeneutic approach of philosophy to broaden the naturalistic enquiry of human life. Validation criteria should be applied to individual assessed QoL such as '.. consistency, meaningful connections, clarification of concepts and the development of comprehensive theories.'. Rosenberg (1995) also warned against taking a radical hermeneutic approach, that abandons the objective solely for the subjective because disease and health are a matter for the whole of society. He recommended taking a hybrid approach using both objective and subjective forms of enquiry; integrating philosophical reflection of health and disease issues with the psychometric measurement of QoL.

The argument against the use of individual measurement of QoL and condition-specific measurement is that such measurement cannot inform resource allocation decisions because there is limited potential for comparison between individuals, groups, or societies with different diseases (Cairns, 1996). However, the reason for measuring QoL is of paramount importance to the choice of method. It is unlikely that the same method appropriate for one purpose may be transferred to another setting and remain as effective.

2.4.3.2 Qualitative approaches to the measurement of quality of life and changes in quality of life in schizophrenia

Joyce (1994:51) on reviewing the assessment of individual QoL, questioned whether studies asked what was meaningful change for an individual. He claimed that individually measured QoL and change may be a more useful tool for clinicians in their outcome assessments of

treatment. Involving the perspective of the individual in the assessment of change in QoL has been reviewed elsewhere (O'Boyle *et al.* 1994). However, few studies have considered using a qualitative approach when measuring the QoL of people with schizophrenia. Reasons may include issues of reliability as discussed in Section 2.4.2. Initially, this section will comment on studies that have incorporated open-ended questions of QoL with people with mental health problems. The focus will then move to reviewing the Schedule for the Evaluation of Individual Quality of Life (SEIQoL) (O'Boyle, 1994). This approach is still being developed and tested and has not yet been employed with people with schizophrenia. However, consideration will be given to its applicability with this group of the population as an alternative method to the standardised instruments reviewed in Section 2.4.3.3. As the literature reviewed below illustrates, there are practical difficulties in interviewing patients with severe mental illness.

Jones *et al.* (1986) carried out a pilot project on patients who had been discharged from three York mental hospitals. Patients had either been long-stay in-patients (continuously in hospital for over one year) or belonged to an elderly confused group (n=132). Over half of the sample had a diagnosis of schizophrenia. In-depth interviews were carried out (ranging from 1-3 hours) based on checklists and a detailed case study per respondent. However, few respondents were capable of answering the questions and most of the information had to be gathered from significant others such as relatives, landlords, hostel wardens and hospital staff who did not always know the relevant information.

A study by Barry *et al.* (1993) evaluated the resettlement of long-stay patients from a North Wales hospital (n=62). An adapted version of Lehman's (1988) Quality of Life Interview was used, supplemented with a number of open ended questions. These were included 'to explore individual perceptions of significant life events and experiences, aspirations and attitude to discharge'. The data gathered from the open-ended questions were subject to content analysis. However, investigation of the qualitative data suggested that respondents had some difficulty responding to open-ended format questions.

The qualitative data supported the inclusion of domains such as family, social relations and leisure in the standardised instrument (Barry *et al.* 1993). However, excluded from current

instruments were those items pertinent to an individual's QoL e.g. cigarettes, coffee. The authors suggested that the importance of such items to an individual's judgement of their QoL requires further examination. They called for the exploration of the processes that contribute to self-assessed QoL to inform the factors that influence individual well-being. Improvements in QoL are dependent on an individual's perspective and therefore, the development of an appropriate means of eliciting and including a personal perspective in QoL assessment is essential to provide relevant care packages (Barry *et al.* 1993). They suggest that combining exploratory qualitative approaches with standardised instruments may offer the best method of exploring the more individualistic determinants of life. The authors proposed that the use of a novel approach such as the Schedule for the Evaluation of Quality of Life (SEIQoL) (O'Boyle, 1994) method may reveal interesting new perspectives in the assessment of QoL for psychiatric patients.

The SEIQoL approach (O'Boyle, 1994) was developed in response to the question of relevance of standardised instruments where an external value system is imposed on respondents. It was also recognised that the relative importance of aspects of life will vary between respondents and for individual respondents over time or throughout the course of an illness. It would appear more crucial to focus interventions on areas of life that are important to people than those areas of life that are less important. However, lives which are subjectively highly rated but are objectively poorly rated do not dismiss the need for care agencies to work at improving the objective aspects (O'Boyle, 1994). The subjectivity of QoL and its multidimensional nature have been reported earlier in this Chapter. While the debate of the appropriateness of QoL or HRQoL as an outcome measure continues between researchers, O'Boyle *et al.* (1992) published empirical evidence involving patients undergoing hip replacement surgery illustrating that 50% of respondents (n=20) did not name health in their top 5 life areas that contributed to their overall QoL. This questions the underlying assumption to HRQoL measurement whose frame of reference is based on a 'disease' model, focussing on the impact of illness and treatment on QoL (O'Boyle, 1994). O'Boyle (1994) suggests that individuals should be afforded the opportunity to specify those areas of life that are important to him/her, to judge their progress in those areas of life and the contribution that each makes to their overall QoL.

The SEIQoL has three stages (O'Boyle *et al.* 1993):

- The first stage elicits 5 areas of life (*cues*) that are crucial to the individual's QoL by means of a structured interview.
- The second stage requires the respondents to judge their current functioning or satisfaction with each cue by drawing a vertical bar to represent his/her functioning or satisfaction for each area. Each extremity is labelled 'as good as could possibly be' and 'as bad as could possibly be'. The height of each bar represents the score for each of the life areas (*cue levels*) which are independent, continuous data ranging from 0-100. The SEIQoL does not prescribe the dimensions by which respondents should judge their QoL, but encourage the individual respondents to use their own evaluative criteria.
- The third stage derives the relative weight the individual allocates to each aspect in relation to the importance to overall QoL (*cue weights*). The relative importance of each area of life to the individual and therefore its relative weight may be derived using one of two methods: judgement analysis or a direct weighting procedure.

A SEIQoL index for global QoL may be derived for group comparisons by summing the product of each cue level and its weight.

The authors of the SEIQoL originally used judgement analysis which 'externalises the manner in which a person makes a judgment or decision-his or her "judgment policy" by using statistical methods to derive an algebraic model of the judgement process. The goal of judgement analysis is 'to quantify the relationships between a person's judgment and the information, "cues", used to make that judgement' (O'Boyle, 1994:12). Thirty randomly generated hypothetical cases are presented to each respondent (labelled with their five cues derived at stage one). Respondents are asked to rate the global QoL of each case using a horizontal visual analogue scale, anchored by 'best life imaginable' and 'worst life imaginable'. Multiple regression analysis is performed on the 30 cases and the respondents' judgments determine the relative weight of each area of life (*cue*). The weights are dependent on each other and total 1.0. Psychometric data in the form of internal validity and internal reliability have been published for this method (O'Boyle, 1994).

The direct weighting procedure for deriving the *cue weights* use a layered coloured disc

(O'Boyle, 1994). The disc consists of five stacked, centrally mounted, interlocking laminated discs. Each disc is a different colour and is labelled by the interviewer with one of the areas of life (cues) named by the respondent. The coloured discs can be rotated over each other to produce a dynamic pie chart where the relative size of each coloured 'area of life' represents the weight the respondents attaches to that area. The circumference of the disc has a 100-point scale so that the proportion of each coloured area may be scored to produce the individual weighting of the importance the individual attaches to each area of life. This technique enables the most important areas of life to the individual to be incorporated within their scoring. This method has the added advantage of the respondents being able to visually revise their judgements. The method has been shown to be reproducible and have high criterion validity in healthy volunteers. This method has successfully been employed in a study determining the QoL of patients with HIV/AIDS (Hickey *et al.* 1996).

The relative merits of each method for deriving cue weights were compared using a convenience sample of 40 healthy volunteers (Browne *et al.* 1997). Judgement analysis required 10-60 minutes for explanation and administration to the respondents. This suggests that it has limited utility in routine clinical practice or where frequent measurement is required. The authors discuss the 'compensatory decision making purposes' required for this weighting process. Respondents must have the ability to make an overall judgement by distinguishing the individual merits of weighted information, rather than a summed approach of all information. Essential to this process is the cognitive status of the respondents and more work is required to examine the impact of varying levels of cognition. An advantage to this process is the decreased probability of social desirability bias, and the possibility of gaining measures of internal reliability and validity for individual interviews.

Alternatively, the direct weighting procedure disc is shorter and cognitively less demanding. However, further work is required with respondents who are cognitively impaired and to document the psychometric properties in clinical settings. Attention was drawn to the differences in the type of weight set each system was eliciting (Browne *et al.* 1997) and therefore, the appropriateness of comparing the two methods. Judgement analysis was designed to access implicit knowledge (unconscious thought), whereas the direct weighting procedure accesses explicit knowledge (conscious thought). It is unknown if QoL

preferences are dependent on implicit knowledge structures or information directly accessible to the individual. The authors suggested that if individuals are induced to think about their current circumstances and the interaction these have with their QoL preferences, then valid weights are more likely to be directly accessed as conscious thought (Browne *et al.* 1997).

Measurement models such as those of Lehman's (1988) and Oliver's (1991) have drawn attention to the fact that irrespective of objective measurement, it is important to know the respondent's level of satisfaction or dissatisfaction as this is likely to indicate the level of motivation a respondent would commit to improving an area of life. An added advantage of the SEIQoL approach (O'Boyle, 1994) is that patients are asked to weight life areas, therefore indicating which areas of life may take precedence in rehabilitation programmes. Where respondents have unlimited needs, limited resources can be focussed not only on those areas of life that respondents are dissatisfied with but those areas of life that are important to clients. Standardised instruments which only measure dissatisfaction without a weighting system, could assume that dissatisfaction is associated with importance. However, this could be subject to response bias such as dissatisfied feelings that respondents are expected to have when unemployed.

2.4.3.3 Popular quality of life measures used in outcome studies of schizophrenia

Advantages to administering condition-specific measures include a decreased patient burden and enhanced acceptability, due to the relevance of the domains. It is thought more likely that small but clinically important changes are detected also (Vickrey, 1993). Disadvantages are that such tools cannot be used for comparing between disease-states and obviously they do not measure effects in excluded domains (determination of unexpected or iatrogenic effects). Therefore, if exploratory work is required, Fletcher *et al.* (1992) recommend that additional items should be used and preliminary psychometric testing should be performed.

Simmons (1994) identified four features essential to the assessment of QoL of people with long term mental illness:

- Self-reports should include some element of the person's global satisfaction with life in general, and specific life domain features.

- A semi-structured interview format should guide the assessment but not hinder the respondent's opportunities to include their preferences and priorities for important areas of life.
- Respondent information should be transformed into scores or recorded verbatim and analysed qualitatively using content analysis.
- Objective measures of the person's welfare (as opposed to satisfaction with life) should also be included.

Future studies of QoL also need to establish the stability of subjective indicators over time and their sensitivity to objective life changes (Baker and Intagliata, 1992).

This section summarises the available measures of QoL for people with schizophrenia living in community settings. General outcome measures in mental health which focus on a limited set of QoL domains such as the Index of Health-Related Quality of Life (IHQL) (Rosser *et al.* 1992; Rosser *et al.* 1993) and the Health of the Nation Outcome Scales (HoNOS) (Wing *et al.* 1996a; Wing *et al.* 1996b; and Wing *et al.* 1996c) have not been reviewed. Currently, no information has been published to demonstrate specifically their application with people with schizophrenia.

Instruments specific to resettlement programmes of care where community services have been specially designed to cope with patients from institutional settings, (e.g. TAPS measures (Leff, 1993)) have not been reviewed since the focus of this research is on QoL measurement in the community. The respondents for this research are those who are routinely admitted to and discharged from hospital settings because of changes in their mental health status.

Two measures that are currently undergoing testing for use with a schizophrenia population are the Quality of Life Enjoyment and Satisfaction Questionnaire (Endicott *et al.* 1993) and a WHOQoL module in schizophrenia to supplement the WHOQoL-100 (Medical Outcomes Trust, 1997:21). However, no data have been published to support their performance with people with schizophrenia and are therefore not reviewed.

To date, very few generic instruments have been tested with a schizophrenic population. The SF-36 health survey (McHorney *et al.* 1994) has been tested with people with symptomatic

depression but no information has yet been reported with its use in schizophrenia outcome research (Awad *et al.* 1997a). The McMaster Health Index Questionnaire (Chambers, 1993) has been tested with a medical and a psychiatric outpatient population, but the information was unavailable as to whether the sample included patients with schizophrenia.

The following eight instruments were chosen for review because they are called quality of life (QoL) instruments focusing on the respondent's perspective and have been tested or piloted on people with schizophrenia. They are reviewed in more detail in Appendix One and are summarised here. (See Appendix Two for a review of instrument attributes to evaluate the strengths and weaknesses of an instrument).

1. Quality of Life Checklist (QoLC) (Malm *et al.* 1981)
2. Satisfaction with Life Domains Scale (SLDS) (Baker and Intagliata, 1982)
3. Quality of Life Scale (QLS) (Heinrichs *et al.* 1984)
4. The Oregon Quality of Life Questionnaire (OQLQ) (Bigelow *et al.* 1990)
5. Quality of Life Interview (QLI) (Lehman, 1983; Lehman, 1988)
6. The Quality of Life Self-report (QLS-100) (Skantze *et al.* 1990)
7. The Lancashire Quality of Life Profile (LQoLP) (Oliver, 1991)
8. Quality of Life Index for Mental Health (QLI-MH: client questionnaire) (Becker *et al.* 1993)

Table 2.1 summarises the domains included in the eight instruments under review. Only those domains included in two or more instruments were listed. The advantage of domain-specific measures is that they may indicate those areas of life that reflects people's satisfaction or dissatisfaction and they have increased discrimination power for intervention studies. Consensus regarding inclusion was greatest for employment/work/day programme, leisure/participation, living situation and relationships with others (e.g. family, friends). Mental health/psychological well-being was represented in all but the Satisfaction with Life Domains Scale (Baker and Intagliata, 1982) However, this instrument does include an item that asks about health in general. Less common were domains such as dependency, neighbourhood/environment, safety and knowledge/education which were represented in only three of the eight instruments. Only one of the instruments permitted individual respondents

to weight the items according to their preferences (Quality of Life Index for Mental Health: client questionnaire (Becker *et al.* 1993).

Some of the instruments focused solely on subjective indicators (e.g. Satisfaction with Life Domains Scale - Baker and Intagliata, 1982) where as others combined both objective and subjective indicators (e.g. Quality of Life Interview - Lehman, 1988; the Lancashire Quality of Life Profile - Oliver, 1991). Objective indicators of QoL (e.g. income, educational status) are considered insensitive measures and have limited application in guiding social policy. Represented by social statistics and consumer goods, they are indicators of societal QoL (Farquhar, 1995). Najman and Levine (1981) list four principal weaknesses that they believe have compromised the utilities of objective indicators: lack of clarity defining low/high QoL; lack of a consensus about the relevant indicators; deficiency relating inputs to outputs; and the inability to understand the association between the objective indicators of life and the subjective perception of these conditions. Subjective QoL research has produced more consistent results in social indicator research (Najman and Levine, 1981). It is well known that 'illness' better determines the behaviour of an individual than disease, i.e. the individual's perception of how they 'feel' has greater influence on behaviour than the presence or absence of medical signs or symptoms of disease. As stated earlier, QoL is also best assigned by the individual (MacKeigan and Pathak, 1992). Subjective health status, therefore, has become an important aspect of health services research and clinical practice because objective health measurements do not always represent patients' perceived health, satisfaction or well-being (O'Boyle, 1995). Some researchers place the value on combining both objective and subjective indicators (e.g. 'Quality of life relates both to the adequacy of material circumstances and to people's feelings about these circumstances.' - McDowell and Newell, 1987:204) though there has been little work to justify this approach theoretically.

The measures ranged from simple provider-led checklists that had not had any psychometric testing (e.g. Quality of Life Checklist - Malm *et al.* 1981) to comprehensive measures of QoL that had undergone extensive psychometric testing (e.g. Quality of Life Interview (Lehman, 1988); the Lancashire Quality of Life Profile (Oliver, 1991)). However, no one instrument has been universally adopted throughout the field of outcome research in schizophrenia. Furthermore, little information was reported on the content validity of any of the instruments.

Although there was moderate agreement on the minimum content at domain-level (Table 2.1), most authors cited previous work commonly dating back to the 1960s and 1970s. Often publications and measures were based on North American studies.

Few of the QoL instruments routinely included items relating to medication. The Oregon Quality of Life Questionnaire (Bigelow *et al.* 1982; Bigelow *et al.* 1990; Bigelow *et al.* 1991) included items about psychiatric medication, but mainly in relation to drug use problems. The self-report version asks about the use of ‘... drugs or medications, of any kind’. It asks about problems such as controlling the use of drugs, controlling behaviour because of the use of drugs, problems with feelings like guilt, anger or depression because of drugs, problems with health, parents, friends, spouse, children, job or school, other activities, because of drug use. The interviewer-rated version asks about the type of prescribed psychiatric medication, asks the respondents about their adherence (interviewers rate medication taking on a 4-point scale ranging from very irregularly to very regularly), finally the interviewer rates whether the respondents are adequately medicated at the current time (ranging on a 4-point scale from very inadequately to adequately). Concurrent judgements between 6 raters determining whether medication was adequate for respondents resulted in this item being ranked as having one of the poorest inter-rater reliability coefficients; $r=0.65$ (Bigelow *et al.* 1990). Alternatively, the Quality of Life Index for Mental Health: client questionnaire (Becker *et al.* 1993) includes 4 items concerning psychiatric medications including adherence, side-effects, control of symptoms and satisfaction with taking them.

Table 2.2 summarises information about the questionnaire length, administration, ratings, scoring options and the main country of development and testing. The number of items ranged from 15 (Satisfaction with Life Domains Scale - Baker and Intagliata, 1982) to 263 (Oregon Quality of Life Questionnaire: self-report version - Bigelow *et al.* 1991). Shorter instruments are likely to be less sensitive.

Almost all of the instruments were interviewer-administered. Interviewer-administered instruments introduce the potential of rater-bias into the assessment process. However, depending on the target population, interviewers may be essential in studies of patients with reading or cognitive difficulties that preclude the use of some self-administered instruments

(Vickrey *et al.* 1993). Interviewers must be as objective as possible and it is preferred that they are not the staff responsible for the health or social care of the respondents. This can help guard against respondents wishing to give desirable answers. Although Oppenheim (1992:139) reported that interview methods do not always encourage respondents to present themselves in a bias way. Interviewer-administered instruments also have the potential advantages of boosting response numbers, giving participants the opportunity to clarify issues or ambiguous questions, helping motivate respondents to complete the interview and if sufficient rapport is developed, can lead to increased reliability in the reporting.

The instruments that were self-administered had a surprisingly high number of items (92-113) (Quality of Life Checklist - Malm *et al.* 1981, Quality of Life Self-Report-100 - Skantze *et al.* 1990 and the Quality of Life Index for Mental Health: client questionnaire - Becker *et al.* 1993). Disadvantages associated with self-administered measures include failure of memory, misunderstanding the question and differences in internal standards or evaluations of an issue (Hays *et al.* 1993). However, each of the self-administered instruments allowed respondents to have help completing the instrument if required or the scales were followed by a semi-structured interview.

Most of the questionnaires had client-rated versions except for the Quality of Life Scale which depended on clinician-ratings (Heinrichs *et al.* 1984). The Oregon Quality of Life Questionnaire: self-report version (Bigelow *et al.* 1990) reported requiring rigorous training and monitoring to preserve the collection of quality data. Respondents have reported difficulty answering the questions, perhaps due to problems with understanding reality, abstract thinking and making choices (Simmons, 1994).

Four of the instruments used single item scores (Quality of Life Checklist - Malm *et al.* 1981; Satisfaction with Life Domains Scale - Baker and Intagliata, 1982; Quality of Life Scale - Heinrichs *et al.* 1984; Oregon Quality of Life Questionnaire: self-report version - Bigelow *et al.* 1990). However, single item scores can be limited since they are unlikely to provide comprehensive information about QoL and are likely to have low sensitivity.

Two of the instruments reviewed derived a QoL profile (Quality of Life Interview - Lehman,

1988; Lancashire Quality of Life Profile - Oliver 1991). The profile method of scoring provides a score for each individual dimension and does not aggregate the scores into summary scores. Profile scores are more comprehensive and meaningful about QoL. However, the disadvantage to this method of scoring is the limited utility in comparative studies.

Four of the instruments gave the option to calculate a total score which may be useful for economic evaluations (Satisfaction with Life Domains Scale - Baker and Intagliata, 1982, Oregon Quality of Life Questionnaire: self-report version - Bigelow *et al.* 1991, Quality of Life Self-Report-100 - Skantze *et al.* 1990 and the Quality of Life Index for Mental Health: client questionnaire - Becker *et al.* 1993). However, only the Quality of Life Index for Mental Health: client questionnaire (Becker *et al.* 1993) weighted the individual components before summing. Two of the instruments also gave the option to calculate summary scores for each section/subscale of the questionnaire which are useful for descriptive detail and are more sensitive than the disaggregated total score (Quality of Life Self-Report-100 - Skantze *et al.* 1990 and the Quality of Life Index for Mental Health: client questionnaire - Becker *et al.* 1993). Choice of instrument will depend on the purpose of the study. Of all the eight instruments reviewed, the only instrument developed and tested in the UK was the LQoLP (Oliver, 1991).

In Chapter 1, several suggestions for the choice of an appropriate QoL scale for used in clinical drug trials were reported (Awad, 1992):

- The scale must tap multidimensional issues, including illness and treatment-related issues.
- The scale should provide profile and index (weighted) measurement - the former to provide separate measures of the various dimensions and the second to permit comparisons between treatment groups.
- The scale should be sensitive enough to measure relatively small changes in functional performance, questioning the need to include domains of life that are unlikely to be affected by drug treatment.
- The scale must include patients' perceptions of their QoL and their subjective feelings about their medicated state.

As discussed above, only two of the eight instruments included treatment-related issues (Oregon Quality of Life Questionnaire: self-report version (Bigelow *et al.* 1990) and the Quality of Life Index in Mental Health: client questionnaire (Becker *et al.* 1993)). No individual scale provided both profile and index (weighted) measurement (see Table 2.2). None of the instruments have explicitly published information relating to its sensitivity to functional performance. All instruments except the Quality of Life Scale by Heinrichs *et al.* (1984) included patients' perceptions of their QoL. The only QoL studies published that considers antipsychotic medication are the clozapine studies by Meltzer *et al.* (1990; 1993) which used the Quality of Life Scale by Heinrichs *et al.* (1984), i.e. clinician-rated QoL.

Oliver *et al.* (1996:143) piloted the Lancashire Quality of Life Profile with a sample of social services department clients (n=422) and analysis considered those who were and were not in receipt of medication. Neither diagnosis, symptoms nor type of medication were detailed. Receipt of medication was self-reported by the respondents and was found to not be related to any measures of subjective well-being, including mental health. The authors did not report any data to validate the self-report of 'in receipt of medication'. Further, the authors did not clarify whether 'in receipt of medication' was synonymous with medication adherence.

Table 2.1 Summary of the most popular domains included in quality of life instruments used with respondents with schizophrenia

	QoLC	SLDS	QLS	OQLQ	QLI	QLS-100	LQoLP	QLI-MH
Employment / Work / Day programme	•	•	•	•	•	•	•	•
Leisure / Participation	•	•	•	•	•	•	•	•
Living situation	•	•	•	•	•	•	•	•
Relationships with others (e.g. family, friends)	•	•	•	•	•	•	•	•
Mental health / Psychological well-being	•		•	•	•	•	•	•
Finances		•		•	•	•	•	•
Basic needs / Self-care (e.g. food, clothing)	•	•		•		•		
Physical health	•			•		•		•
Religion	•				•	•	•	
General health		•			•		•	
Dependency	•			•		•		
Neighbourhood / Environment	•	•				•		
Safety	•				•		•	
Knowledge and education	•					•		

Notes: Only those domains included in two or more instruments are listed.

QoLC = Quality of Life Checklist (Malm *et al.* 1981); SLDS = Satisfaction with Life Domains Scale (Baker and Intagliata, 1982); QLS = Quality of Life Scale (Heinrichs *et al.* 1984); OQLQ = The Oregon Quality of Life Questionnaire (self-report) (Bigelow *et al.* 1991); QLI = Quality of Life Interview (Lehman, 1983; Lehman, 1988); QLS-100 = The Quality of Life Self-report (Skantze *et al.* 1990); LQoLP = The Lancashire Quality of Life Profile (Oliver, 1991); QLI-MH = Quality of Life Index for Mental Health: client questionnaire (Becker *et al.* 1993)

Table 2.2 Summary of the characteristics of the quality of life instruments used with respondents with schizophrenia

	QoLC	SLDS	QLS	OQLQ	QLI	QLS-100	LQoLP	QLI-MH
Number of items	92	15	21	263	143	100	100	113
Administered by: S = self, I = interviewer	S, I	I	I	I	I	S	I	S
Ratings by: C = clients, I = interviewer	C, I	C	I	C	C	C	C	C
Scoring options: I=item ratings, P=profile, SS=summary scores, SI=single index	I	I, SI	I	I, SI	P	SS, SI	P	SS, SI
Place of development and testing	Sweden	USA	USA	USA	USA	Sweden	UK	USA

QoLC = Quality of Life Checklist (Malm *et al.* 1981); SLDS = Satisfaction with Life Domains Scale (Baker and Intagliata, 1982); QLS = Quality of Life Scale (Heinrichs *et al.* 1984); OQLQ = The Oregon Quality of Life Questionnaire (self-report) (Bigelow *et al.* 1991); QLI = Quality of Life Interview (Lehman, 1983; Lehman, 1988); QLS-100 = The Quality of Life Self-report (Skantze *et al.* 1990); LQoLP = The Lancashire Quality of Life Profile (Oliver, 1991); QLI-MH = Quality of Life Index for Mental Health: client questionnaire (Becker *et al.* 1993)

2.5 Summary

The literature suggests that the definition of quality of life (QoL) is dependent on an individuals' perceptions and interpretations of what is important to them. However, scale measurement is criticised for reducing the individual to Mr. and Mrs. Average (Hunt, 1997). Limited work has been published that has used both individual approaches and scale measurement of QoL concomitantly with the same sample of people with schizophrenia.

The individual approach to QoL assessment developed by O'Boyle and colleagues, the Schedule for the Evaluation of Individual Quality of Life (O'Boyle, 1994) has not been used with people with schizophrenia. The cue weighting approaches (judgment analysis and the direct weighting procedure) are still being tested and have limited evidence for use with mentally ill respondents with unknown cognitive abilities. Other studies have reported some difficulties of using open questions with respondents with mental health problems. Jones *et al.* (1986) and Barry *et al.* (1993) both involved respondents who had experienced long stays in hospital and were being supported in the community. The acceptability and utility of open-ended questions with 'revolving-door' patients, i.e. patients who experience repeated short hospital admissions but live in the community otherwise, is unknown.

The QoL studies that have been completed with people with schizophrenia have mostly used disease-specific instruments. However, many QoL studies are flawed because of deficiencies in the choice of the most appropriate instrument for the purposes of that study. While the psychometric properties may influence choice, rarely are the conditions of the psychometric analysis repeated during routine use of the instrument. Is the measure being used with the same patient group and in the same setting as those by which it was tested? Few studies go to the lengths of retesting instruments for their particular subjects and environment (Sauer and Warland, 1982). Not only is this irresponsible in terms of using an instrument that may be inappropriate but also there is a missed opportunity for contributing to the body of evidence that supports the use of an instrument across different patient groups and settings.

A combination of both structured and semi-structured, quantitative and qualitative methods, and objective and subjective ratings have been reported to be the most comprehensive

approach to QoL measurement (Simmons, 1994). Few studies have combined qualitative individual approaches to measuring QoL with scale measurement. How do respondents with schizophrenia respond to an open approach to QoL assessment? Do individuals nominate the same items or domains as scale measures or do the different methods provide complementary information on the QoL of respondents? Does antipsychotic medication have a role in defining respondent-led QoL? Does either approach provide information about the role of antipsychotic medication in the QoL of people with a diagnosis of schizophrenia?

Therefore, it was decided that an adapted version of the SEIQoL (with permission) would be employed in this research study to determine its acceptability to a population with schizophrenia and to provide evidence of content validity for the Lancashire Quality of Life Profile (Oliver, 1991). (Content validity was poorly supported by claims of literary consensus and the use of previously developed instruments). This research study used only the first question of the SEIQoL which asks respondents to generate the five most important life areas (cues) that contribute to their overall QoL. The respondents continued by prioritising these five life areas and then rated each as they contributed to their overall QoL using a 7-point Delighted-Terrible Faces' Scale (Andrews and Withey, 1976) (see Chapter 4). Cue levels and cue weights were not employed due to the unknown cognitive difficulties that respondents would have. Cognition was unable to be assessed by the researcher due to no psychology training.

The researcher selected the Lancashire Quality of Life Profile (Oliver, 1991) for a number of reasons. The first was that it had been developed and tested with UK chronic mentally ill populations living in the community (see Appendix One); the only instrument out of the eight reviewed. Secondly, it was based on other well-tested scales such as the Quality of Life Interview (Lehman, 1988), the Self-Esteem Scale (Rosenberg, 1965), the Affect-Balance Scale (Bradburn, 1969), the Delighted-Terrible Response Scale (Andrews and Withey, 1976) and Cantril's Ladder (Cantril, 1965). The authors of the Lancashire Quality of Life Profile based the measure on the life satisfaction model and explicitly state the conceptual model of quality of life which comprises three components: personal characteristics, objective life conditions in various life domains and the satisfaction with life conditions in these various domains. Oliver (1991) reported good acceptability with clients and provided evidence that

is was a useful data collection tool that could be used routinely in various settings. The generation of a profile was attractive because of the detail this method would supply in terms of interpretation of findings in relation to medication factors. Finally, administration of the instrument did not require a clinician or extensive training.

A model of broader quality of life, rather than the more limited term of health-related quality of life was adopted in this study because of the global impact of mental illness on all aspect's of an individual's life. Quality of life, in this study, was based on the needs satisfaction and life satisfaction models. These models are based on the level of QoL achieved by an individual based on a common set of values defining one's needs, wants and desires. However, individuals can vary and therefore, including an assessment of the importance of areas of life to the individual is also important. These models were operationalised in this study using adapted questions from the Schedule for the Evaluation of Individual Quality of Life (SEIQoL) (O'Boyle, 1994) and the Lancashire Quality of Life Profile (Oliver, 1991). The benefits of adopting both approaches were the inclusion of both objective and subjective forms of measurement thereby integrating philosophical reflection of mental health issues with the psychometric measurement of quality of life (Rosenberg, 1995).

PART TWO - METHODOLOGY

CHAPTER 3 PILOT WORK

This chapter describes the pilot work that contributed to the development of the protocol and questionnaires for the main study. The work may be divided into two stages:

- Stage one (Section 3.1) concentrates on selected findings of a needs assessment exercise of psychiatric in-patients (see Bowling and Parkman, 1993 for full research report). The researcher (SAF) interviewed an in-patient sample for this study and these results are discussed.
- Stage two (Section 3.2) explores medication issues and definitions of quality of life with attenders of four community psychiatric nurse 'depot' clinics.

3.1 Pilot work: a study of psychiatric in-patients

- **Introduction**

In December 1991, the Purchasing Unit of City and Hackney Health Authority commissioned a needs assessment exercise on psychiatric services. The study involved a one-week census of all psychiatric in-patients and out-patients of St. Bartholomew's and Hackney Hospitals. Staff were interviewed about the diagnosis, problems, treatment, needs and costs. Patients and carers were also interviewed about their needs and satisfaction with services. The background, method and results are reported in detail elsewhere (Bowling and Parkman, 1993). A random sample of patients with a diagnosis of schizophrenia was followed-up separately. Specific aspects of these in-patients' interviews (conducted by SAF) concerning experiences with medication, satisfaction with services and unmet needs will be discussed below.

- **Method** (For full details, see Bowling and Parkman, 1993)

Ward staff invited in-patients with a probable diagnosis of schizophrenia to take part in the study. A semi-structured interview questionnaire was used to collect the data three days a week over a period of one month. The questionnaire asked about the care and support the patients were receiving. The same interviewer administered each questionnaire (SAF). The

patient and interviewer went through the questionnaire together and any additional comments were noted. Hospital notes were used to establish diagnosis.

- **Measures**

Items from the RAND needs/outcome of mental illness questionnaire

TAPS Patient Attitude Questionnaire (Leff, 1993)

TAPS Physical Health Index (Leff, 1993)

Global Assessment Schedule (Endicott *et al.* 1976)

- **Results**

Participants

During the study period (one-month), there were few new admissions and therefore, a small sample was studied. Thirty patients agreed to take part (16 males). However, 7 patients (all male) were not included in the analysis because five could not complete the questionnaire due to their delusional state, one patient insisted on keeping the questionnaire and one patient was an out-patient spending the day on the ward. Therefore, 23 questionnaires were analysed (9 male and 14 female).

Diagnoses were recorded for 19 patients from their hospital notes. The diagnoses were schizophrenia (13), paranoid psychoses (1), severe chronic schizoaffective disorder (1), mania (1) and mixed schizoaffective disorder (1). The remaining four diagnoses were not ascertained because either they were not documented in the hospital notes or the hospital notes were unavailable.

Views of medication

The in-patients in Bowling and Parkman's study (1993) were asked about their views of their medication (see Table 3.1).

“Would never have got well again if didn't have it.”

“I feel a bit better than before.”

“Unhelpful in this environment. Drug helps you relax a bit, slows down the pace, it was recommended. I don't want to be in that state, it frightens me. Adverse effects not good.”

“I only take it because I’m tired of protesting.”

“If I don’t want to take my tablets, they demand that I take it. I think it’s wrong. I take them myself all the time in the community.”

“[The Haloperidol is] so painful. [My] eyes go up after the injection.”

“I get dizzy spells. I sleep.”

“Changed recently, still getting used to it.”

“I prefer taking no medication. I want to use homeopathy.”

Table 3.1 In-patients’ views of their medication

	Number of respondents (%)
Very helpful	2 (9)
Helpful	9 (40)
Indifferent	2 (9)
Unhelpful	1 (4)
Very unhelpful	1 (4)
Don’t know	1 (4)
Not taking any medication	1 (4)
Unrateable response	1 (4)
Total number of respondents	23

Satisfaction with services and unmet needs

The interviews also highlighted other interesting findings about satisfaction with services and unmet needs. Six out of 21 patients reported that they had experienced difficulty receiving services from the psychiatrist. Four out of 21 patients did not receive any services from a general practitioner (GP) and of the remaining 19 patients, two had experienced difficulty receiving GP services. When asked about their unmet needs, the following were reported by the patients:

- 14 patients reported needing help to claim benefits
- 13 patients needed personal counselling
- 12 patients needed a companion, someone to be with all the time
- 12 patients needed help to find accommodation

- 10 patients requested help to find employment
- 9 patients requested help to furnish accommodation or to make it habitable
- 9 patients expressed a need for social activities or a structured activities programme
- 6 patients reported having no support from either family, friends or neighbours

Finally, patients were asked to comment on what help they would need if they went home. Their comments mainly included help with their medication and the management of their illness, social support and accommodation.

“[Help with] medication. Make sure to come back to see doctors, nurses not to relapse. See social worker to keep me off drugs.”

“There’s no therapy what so ever. It’s very, very bad. You need therapy. Something to take you mind off your troubles, stops you thinking inward all the time. I don’t want to go back to my flat.”

“I’d like to do something so I’m tired at night so I deserve to sleep. I’d like to live like an ordinary life. I’m going to be lonely. I’d like some friends do some voluntary work with, with the handicapped.”

“[I would need] my own GP. Need someone to set it up for me.”

“To see my husband, the best friend I’ve ever had. If I go to church regularly I stick with him and the children too.”

“General support from my family.”

“In a flat I felt so lonely, you miss the friendship. Then I entered the wrong company. I’d like to be in a family. The council are willing to give me another flat but I don’t want it. I think it’s better to move in with a family... The family would protect me. It’s just, if I get lonely the illness could happen again.”

“Don’t like the flat I’m in at the moment. Don’t mind living in same area as this, near a big park.”

“Maybe a hostel.”

● **Summary and Discussion**

The complete results of this study have been reported and discussed in detail elsewhere (Bowling and Parkman, 1993). Although the study sample was small (n=23), the interviews were of a semi-structured nature intending to stimulate issues of interest concerning the in-patients’ medication and needs. There were three main issues raised by the in-patients concerning their medication. First, they focused on the benefits of medication in reducing

the symptoms of their illness. The second issue related to the concept of autonomy and the ability to make choices about their medication. The third issue patients discussed was the subject of adverse effects or the risks associated with the medication. These three issues raised further questions:

- Are these issues of concern about medication (in terms of the benefits in reducing symptoms, ability to make choices and the adverse effects of medication) typical of in-patients? If so, do the patients' perceptions of their medication change after patients are discharged?
- Do these three issues affect an individual's adherence rate to medication, after discharge, in the community? (All medication taking was supervised in this hospital).
- Is the decision of medication adherence (or non-adherence) after discharge from hospital, a rational assessment of benefits versus adverse effects, or, is it a way of expressing freedom of choice and autonomy, despite the effects?
- Do patients interpret the benefits (or adverse effects) of antipsychotic medication in terms of improving (or inducing) symptoms, or more globally, in terms of 'quality of life'?

Specific areas of importance may be derived from patients' satisfaction with services and unmet needs (see Measures reported earlier). The replies inferred that the areas of life that were significant to the respondents were accommodation, medication, support from health professionals, social and family support, relationships, religion, a daily occupation and income. These responses stimulated further questions:

- Do these areas of life contribute to the 'quality of life' of people with mental health problems being discharged into the community?
- Do these areas of life have any association with the effects of medication (benefits or adverse effects) or medication-taking behaviour?

This study provided the researcher (SAF) with valuable experience interviewing people with severe mental health problems in hospital and revealed a potentially rich source of data about the issues of importance to in-patients about their medication. However, as a study population, in-patients with mental health problems were problematic. They were

unpredictable in their willingness to take part, occasionally bizarre in their responses (depending on their delusional state) and sometimes passive and non-critical with open questions. For future interview surveys that included hospital in-patient respondents a short simple questionnaire would be most appropriate with closed and open questions to attempt to obtain the maximum item response and insight into their medication-use and condition.

3.2 Pilot work: semi-structured interviews with attenders of community psychiatric nurse ‘depot’ clinics

● Introduction

Medication issues relating to adherence need to be explored from the patients’ viewpoints. It is their opinions and views of medication that will affect their medication-taking behaviour. This exercise considered the views of regular attenders of four community psychiatric nurse (CPN) clinics to inform the development of the instruments for the final study. Everyone who attended this clinic received an intramuscular injection of antipsychotic medication (“depot”). This patient group was chosen because they were less likely to be in an acute stage of their illness, they were accessible (due to their attendance at the CPN clinics) and unlike in-patients, they were responsible for taking their own medication or attending the depot clinic. This exercise aimed to encourage a broad discussion on different aspects of medication and its use. The definition of quality of life as described by people with chronic mental health problems was also investigated. Question wording was tested for respondents’ understanding and interpretation and the ability of the outpatient population to complete a successful interview was also noted.

● Method

Four local community psychiatric nurse (CPN) depot clinics were attended on four separate occasions. The CPN invited the out-patients to participate in the research at the end of their consultation. The CPN gave a small invitation letter prepared by the researcher to the patients to help introduce the exercise (see Appendix Three). The study interview was set up in a separate room and if the patient agreed to participate, the CPN would accompany them to the room and introduce the patient to the researcher. The patients were interviewed

using a short semi-structured interview questionnaire. The questionnaire included items concerning feelings about medication and its unwanted effects, other items asked respondents to describe their quality of life, the good and bad things about life and whether medication affected these areas of life (see Appendix Four). The researcher pursued any respondent-led issues of interest with the use of probes and prompts. The interviews were audio taped with each of the patient's permission and transcribed later. After the interview was complete and the patient had left the room, the researcher also made note of any observations of significance. Typed transcripts were made from each of the taped recordings and these were analysed with the notes of observation.

● **Results**

Participants

Twenty-three respondents were interviewed. There were no non-respondents. One respondent refused to allow the interview to be tape recorded but gave their permission for the researcher to take notes. These notes were included with the transcripts for the analysis. The characteristics of the regular attenders are shown in Table 3.2.

Knowledge of medication

Fourteen respondents (61%) claimed that they knew the names of all the medication they were taking. Five respondents (22%) reported that they could name some of the medication they were prescribed, while the remaining four respondents (17%) said that they could not name any of the medication they were taking.

The importance of medication

When asked 'Do you think medication is important?' most respondents reported that medication was important (16, 73%). Two respondents (9%) answered "no", two respondents (9%) answered "sometimes" and two respondents (9%) reported that they did not know. (One answer was missing). Respondents were asked to qualify their answers with reasons; sometimes respondents gave more than one reason. Of the 16 respondents who answered "yes", most (11) reported that the medication offered them benefits, i.e. it kept them well, calm and relaxed. Seven respondents related the importance of medication to negative experiences that had resulted from stopping their medication in the past. This led

to hospital admissions for four respondents, an increased “nervous” feeling for two respondents and one respondent described that without medication, “...it would be very tough on me.” Another respondent agreed that medication was important and added “...but I don't feel I should be on such a high dosage.” Three of the respondents who reported that medication was important gave reasons that described a passive acceptance of their medication. Two reported that it must be important because they had been taking it for 20 years and the other respondent said that because they needed to take it, then it must be important.

Table 3.2 **Characteristics of the regular attenders interviewed at the four community psychiatric nurse depot clinics**

	Number of respondents (%)
Sex:	
Male	10 (44)
Female	13 (56)
Number of years since last admission to hospital:	
< 1 year	0 (0)
≥ 1 year but < 2 years	3 (13)
≥ 2 years but < 5 years	2 (9)
5 years or more	9 (39)
	9 (39)
Marital status:	
Single (never married)	11 (48)
Married/cohabiting	6 (26)
Separated	1 (4)
Divorced	5 (22)
Widowed	0 (0)
Household composition:	
Lived alone	8 (35)
Lived with:	
family only	9 (39)
friends only	2 (9)
family and friends	0 (0)
others	4 (17)
Total number of respondents	23

Two respondents reported that medication was not important. They added:

“I think I got myself well. I went along with the injections. I had it when I had to. I didn't feel I needed it though, in the first place. I was only on four [mg], it wasn't even a spoonful, so I can't see where it helped. It's not as though it was one hundred [mg] or some people are on much more than that. But just a spoonful, I couldn't see where it was helping in anyway, just apart from giving me lumps in my arm or in the buttock.”

“I don't feel I need it. Doesn't make a difference, [I have] put on weight with it.”

A further two respondents reported that medication was only sometimes important because there were negative consequences to the medication such as adverse effects and the medication (in their experience) did not always work. The final two respondents did not know if medication was important but commented on the consequences of taking medication: “...if stop it have to go to madhouse”; “Keeps me out of trouble with the police.”

Non-adherent experiences of medication

Twelve respondents reported that they had wanted to stop their medication in the past. Of these 12 respondents, four reported that when they had stopped their medication their symptoms had returned. They concluded that they “needed” the medication. Two respondents had stopped their medication and reported that it made no difference. Two other respondents explained that they had wanted to stop their medication but they could not because they would become more anxious without it. Another two respondents described the medication as useless and causing side-effects.

“I'm frightened to take it all the time because it gives me side-effects in my hands, stiffness. When I scrub my teeth in the morning, sometimes I take ages.”

Finally, the last two respondents who also did not want to take their medication, stated that it was not their choice to stop taking it. One respondent reported:

“I think I'm made to go. My sister tells me to have them and the doctor. The surgery tells me to have them. So, I come over and have them.”

Eight other respondents reported that they had not wanted to stop their medication. Four of these 8 respondents said that they wanted to take it and that they felt they needed it. However, one respondent replied that they just “...follow the doctor.” (The remaining three answers were missing).

The role of the patient in the prescribing process

The questionnaire went on to consider the prescribing of medication and the role of the patient in the prescribing process. Eight respondents reported that their medication had been reviewed within the last month; 7 respondents reported between one and up to six months; two respondents reported between six months and up to one year; and one respondent reported between one and five years. For five respondents the value was missing. When asked if the patients thought that they could influence the type of medication they received, 12 respondents answered the question (11 missing answers). Eight respondents thought that they could influence the type of medication they received. Three of these respondents recounted how the doctor had reduced the dose of the medication on their request. Of the other five respondents, three could not qualify their opinion, where as the other two added:

“Yes but the doctors say no. I mean the doctor. He make it lower a little bit. They say for one year only and now is over one year now. But I think I need it until I finish completely from my sickness.”

“He thinks [doctor] I should stay on it. I’d be worse without it... It made me too sleepy...[He said] well that’s up to you. If you think you should cut them down, cut them down. But I’m telling you, my advice is to stay on them. So, I don’t want to go against him because I went against him before and I got barred. He’s a doctor after all. He knows best.”

Two respondents did not think they could influence their medication. One commented that “It’s up to the doctor”, where as the other respondents said “I always have wished that I had more control over what the doctors give me.”

Finally, two respondents went on to describe a consultation with their doctor where they had discussed medication:

“I’ve discussed it with the psychiatrist and the GP. I’m on it all my life.”

“The doctor thinks it’s working but I don’t think it is. He doesn’t want to take me off it... He wants me to carry on taking it.”

Desired changes to medication

The questionnaire also explored whether the respondents would like to change anything about their medication. Eighteen respondents answered this question. Of these, 11 did not want to change anything about their medication. Additional comments supported respondents’ opinions:

“I’ve got to take the injection.”

“I’ve been on it so long.”

Five respondents wanted to change an aspect of their medication. Two of these respondents wanted to reduce the dose. One respondent wanted to change their tablets and another respondent wanted to receive tablets rather than the injection (because of the pain involved with receiving the injection). The fifth respondent just wanted to stop the injection.

Experiences of unwanted effects

Twenty respondents discussed their experiences with unwanted effects (three missing answers). Ten respondents described effects such as tiredness, shaking, dry mouth, constipation, eyes rolling, body weakness, stiffness, diarrhoea, impotence, slurred speech, dizziness and lack of motivation.

“I used to work before I took this injection. I used to work seven days a week even. I haven’t worked for seven years now.”

“I feel sad because the medication stops you what you’re wanting to do, like a job. You can’t get up early in the morning because of the drugs. I’d like a job, a tea lady. ... I have no choice. If I don’t take it I end up in the hospital. If you decrease them you end up in hospital. I asked for them to be decreased and that’s what happened. It’s about time I came off it.”

“I don’t want it to make me sleepy. This morning I was tired and I couldn’t take him [her son] to school.”

“The injection slows you down a lot. I wouldn’t be able to work as fast as I could before.”

Eight respondents reported that they did not experience any unwanted effects. The remaining two respondents described unwanted experiences and added that they were unsure whether these were attributable to the medication. One respondent reported that since he had been taking the medication, he had encountered an increased hair loss. The other respondent explained that she thought of words without any meaning and that she could not control this.

Support networks

Respondents were asked whether there was anyone that they could talk to if they did not feel well or if they had any problems with their medication. Twelve of the 20 respondents named different people they could talk to if they had problems (sometimes more than one). Five

named the community psychiatric nurse (CPN), two respondents named the general practitioner (GP), one respondent named the psychiatrist and 7 respondents named significant others. For example, their wife, children, CPRU (Community Psychiatric Rehabilitation Unit), the key worker, clinic, day centre and their friend.

Six respondents reported that there was no-one with whom they were able to discuss any problems. There were additional comments:

“I do come across people in life that I feel I can talk to but they're either social workers may be or doctors. They haven't got the time. They're not always psychiatrists, the people in the position that have the time or sometimes they're friends and I feel that I don't want to inflict my personal life on them.”

“No-one. I just talk to my man and he says I'm mental, loony.”

“I need someone to talk to. I'm very lonely at home. Just by talking to someone, I feel better... I've seen enough psychiatrists, they are no help to me at all. They don't give me advice. They don't talk to me, they just write everything down.”

The remaining two respondents said that they didn't worry about anything.

Lay definitions of quality of life

One objective of this exercise, was to examine the lay definition of quality of life according to people with chronic mental health problems. Twenty-one respondents gave comment to the description of their quality of life (two missing answers). Of these, 11 respondents were indifferent, neither positive nor negative in their description, or mixed:

“...all right, ...could be better, could be worse, ...sometimes it's all right and sometimes I feel very down, ...I get by.”

A further 9 respondents offered positive descriptions:

“...quite happy, ...keeping very well, ...satisfied, ...happy man with my family, ...not too bad, ...good, ...100%, ...very good.”

Five respondents commented negatively on their quality of life:

“...lonely, ...restricted, ...quite terrible, ...not very good, ...miserable.”

When asked to name the good things about life, 12 respondents listed items where as 6 respondents commented that they did not know what the good things were. (There were five missing answers). These were the subjective comments:

“...I’ve got a stamp collection; ...listening to music; ...television; ...reading; I’m able to get out and about; I go every Sunday to church; I like to go to Trafalgar Square, Buckingham Palace; ...going out and having fun; I look after my husband well; I’m going to be a grandma again; ...playing bingo; ...food; I like bad things, smoking, drinking; I’ve got a nice home; I’ve got the use of my limbs and my eyes; I can talk, I can walk; ...eating; ...watching the bird life.”

Two respondents focused their comments around their illness:

“I’ve got used to living, living and doing nothing.”

“I am carrying on.”

When asked about the bad things in life, 11 respondents answered that there were no bad things in life, one respondent did not know and 6 respondents mentioned items. (There were five missing answers). The items named included:

“...the general misunderstanding of people... and they haven’t got time for you; It can’t be good all the time; ...the world is in a terrible state; ...poverty; ...hunger; You walk down the street and get mugged.”

One respondent related the bad things in life to their illness:

“I’ve got a sick feeling and a pain...bad feelings.”

Quality of life and medication

Respondents were asked to consider the effect of medication on the good and bad items named. Twenty respondents were unable to answer the question. The remaining three respondents reported that medication did not affect their quality of life.

Further comments

The interviews highlighted other items of interest. One respondent talked of the future -

“In the future I will have another injection, the same injection but without the side-effects...”

Four respondents described their illness and the role of medication:

“In Africa, we’re coming from Tanzania, ...I was given the same medicines here...because the schizophrenic problem. I did go mad after I don’t take medicines. I got mad so sometimes I beat everyone. Without taking medicines, ...I can’t control my brain.”

“When I was first taken there [hospital] I was taken off all pills, no pills at all for two months. Then a month later, I fell ill again, very ill and they put me back on the pills again.”

“One doctor told me that if you don’t have the injection, you are like a motor car gone out of gear, you’ll go faster and faster and can’t stop. That’s why I need injection to stop me thinking overtime.”

“Now, 30 years I’ve been taking the injection every two weeks, my delusions don’t go. One injection and they used to vanish...When I go and see the doctor, he says you’re suffering from schizophrenia, carry on with your injections. Nothing else, he says.”

One respondent discussed the relationship they had with their family.

“I’ve got a family but they don’t come to see me. I cry sometimes because I’m lonely, but they don’t want to know me. Maybe because I’m married to a black man.”

Another respondent described their accommodation.

“It gives me bad nerves. I’d like to move. I want to get a place with one bedroom. I’ve been here, just in one room, twenty-one years. I’ve got all the windows screwed in. It’s stone cold. Not very nice, a bedsitter... I’d like to move, it’d make my nerves better.”

Question wording

During analysis, the questions were scrutinized for their content and the responses they achieved. It was considered whether the questions were adequate and appropriate in their language, and whether there were any problems of ambiguity or misunderstanding (see Appendix Four for the interview schedule).

The first questions asked the patients to name the medication, including any injections, they were taking. These worked well as introductory questions by focusing the patients’ minds on their medication. However, patients had to be reminded that ‘medication’ also included any injections. It seemed that most patients understood medication simply to mean tablets or mixtures that they were taking on a daily basis. Throughout the interview, when questions used the word ‘medication’ the researcher repeated that this also included any injections.

Question 7 asked patients if they thought that they were able to influence the type of medication they received. The researcher wanted to find out how involved respondents felt in the decisions about changes to their medication. This question was confusing and unclear for almost one-third (8) of the respondents. Four respondents did not answer the question. Two respondents answered “yes” but could not expand on their view. One respondent asked

the researcher to qualify the question and another respondent thought that the question asked whether he could actually influence the way the medication worked on his body.

Question 9 asked about the unwanted effects of medication. For 10 respondents, the word 'unwanted' had to be supported by the word 'side-effects' for respondents to understand the meaning of the question.

The quality of life questions (questions 11-13) did not generate as valuable information as had hoped. One reason may be that the patients found it difficult to respond to the open nature of the questions. The first question was intended to elicit a definition of quality of life. However, poor question wording resulted in subjective ratings of general life satisfaction rather than definitions of quality of life.

The final question asked the patients whether they thought that medication affected the good or bad items of life. Three respondents answered this question. The other 20 respondents were unable to answer it. If a similar question wanted to be explored in the future, directing respondents towards activities of daily living and other personal aspects of life may be more appropriate.

Immediately after completion of the interview and the patient had left the room, the researcher noted any observations made throughout the meeting. It was interesting that comments made by the patient to the nurse during the consultation were not always discussed in the interview with the researcher. For example, the researcher overheard a patient commenting to the CPN during the consultation that the injection was painful, but this was not reported at any stage during the interview with the researcher. Occasionally during the interviews, the researcher noticed that a patient was restless, showing a tremor or spoke with slurred speech but none of the patients reported these problems.

● **Summary and discussion**

Most of the respondents had been living in the community for at least two years. Six respondents had not had an admission to hospital for ten years. They were all regular attenders of the service. A regular attender is defined as one who attends all appointments

as arranged and adheres to the medication regimen prescribed. Many of the respondents described a settled life in the community with some form of support. Six were married or living with a partner and fifteen shared accommodation with family, friends or others.

Most patients were satisfied with their medication although they reported experiencing some adverse effects. The benefits of medication were illustrated by accounts of negative consequences caused by stopping medication in the past. Admissions to hospital, increased anxiety and a decrease in coping ability were all attributed to previous non-adherent behaviour. A few of the respondents described a passive acceptance of their medication and that the health professionals were 'in control'. Some described a 'trading' that occurred between themselves and the doctor during negotiations for revised doses. Ultimately, however, it was the doctor who took precedence. Concerns were expressed about high doses, side-effects and the fact that the medication was not always successful in treating the symptoms. Throughout all the interviews, only one respondent said that they wanted to stop their present medication. For some, it seemed that they were making a rational decision by weighing the benefits against the risks of adhering to the medication. While others described their medication-taking role as lacking autonomy and choice.

The issue of having someone to talk to about medication or any illness problems raised some interesting points. Most of the people named were representatives of the mental health services and only a few were family or friends. Considering that all respondents were in touch with the community mental health services at the time of the interview, six (30%) reported that there was no-one with whom they could discuss their problems.

The respondents answered the general quality of life question using subjective descriptions; the majority of respondents had mixed feelings or were positive about life. The items listed as the good things about life may be grouped as leisure activities, family, accommodation, essential items (e.g. food) and items related to health. The bad things respondents thought about life may be grouped as the lack of social relationships, the environment, personal/neighbourhood safety, essential items (e.g. poverty, hunger) and items related to health. This illustrated that the respondents interpreted the concept of quality of life both positively and negatively. During the interview, aspects of life were briefly commented upon

where medication had an adverse effect: employment; getting up in the morning; role functioning; personal hygiene. A question focusing on the effects of medication and its adverse effects on areas of activities of daily living may be a more appropriate stimulus to explore the issue of the effects of medication on quality of life.

The question wording was mostly appropriate and stimulated an interesting discussion. However, 'medication' did not always include the depot injection for the respondents and this had to be reinforced throughout the interview. An introduction before the quality of life questions to set the scene, may have stimulated a better response to these questions. A valid tool to measure the quality of life in subsequent studies would be a valuable adjunct, since the response to these open questions was extremely variable and could not be used alone.

Some attenders were observed to display a restlessness and tremor that may have been adverse effects of their medication but they did not report them during the interview. Including an observer-rated measure of adverse effects in subsequent interviews may be appropriate. The interview was mainly patient-led which encouraged a relaxed and informal atmosphere. However, there were disadvantages to this approach. Some issues initiated by the patients were not always appropriate to the theme of the interview and conversely, not all the patients covered all the relevant items. This may be partly attributed to the inexperience of the researcher. Also, some patients may have found some of the questionnaire items irrelevant which is known to lead to poor response rates.

Sampling from community psychiatric nurse (CPN) clinics gave a better response rate than recruiting from hospitals. The out-patients were more involved in the exercise, answering the questions and there was less variation in the severity of illness and functional ability compared with hospital in-patients. However, this exercise did not offer access to people who stopped their medication after discharge from hospital. The out-patients interviewed were all established in the community and adhered to the medication regimen prescribed. To investigate patients who may default from the medication regime prescribed, one would have to sample before discharge from hospital and then follow-up the respondents in the community.

If a true measure of adherence to prescribed medication was needed for subsequent interviews, then the inclusion criterion could be the prescription of depot (intramuscular injection) medication. The advantage of this method of administration is that it would have to be provided by a health care specialist and therefore, a record of doses received would be available. Doses received as a proportion of doses prescribed may be calculated as a measure of adherence. It would also give other qualitative information such as whether the patient received the dose on the appropriate day as prescribed, whether the patient was active in seeking treatment by attending a clinic or whether an outreach service was required for the community psychiatric nurse to visit the respondent at home to administer the depot medication.

CHAPTER 4 THE MAIN STUDY PROPOSAL - MEDICATION AND QUALITY OF LIFE: A STUDY OF PEOPLE WITH A DIAGNOSIS OF SCHIZOPHRENIA

4.1 Introduction

The pilot work of stages one and two were used to inform the aims, objectives, research protocol and questionnaires of the main study. This provided three issues worthy of exploration:

- patients' views and experiences of antipsychotic medication both in hospital and in the community after discharge
- definitions of 'quality of life' by people with chronic mental health problems
- the associations between antipsychotic medication and quality of life (if any) for people with chronic mental health problems.

The broader model of quality of life was explored in this study because of the wider impact of mental illness on all aspects of an individual's life. Health-related quality of life was considered too narrow a concept for this study population.

4.2 The aim of the study

The overall aim of the study was to explore associations between the effects of antipsychotic medication, medication adherence and the quality of life of people with a clinical diagnosis of schizophrenia. The conceptual model of quality of life adopted in this study was based on the needs satisfaction and life satisfaction models. These models are based on the level of QoL achieved by an individual based on a common set of values defining one's needs, wants and desires. However, individuals can vary and therefore, including an assessment of the importance of areas of life to the individual is also important (see Section 4.5 for the measures used in this study that operationalised these concepts).

Only those persons prescribed an antipsychotic depot injection, at the time of discharge from

the hospital, were included in the study. Administration of depot medication is by deep intramuscular injection at intervals of one to four weeks. Adherence was defined by the degree of attendance to receive the depot medication during the time from discharge to the follow-up interview in the community. It was expected that this period would be three months.

The patients' attendance records for their injections were used to compute two measures of medication adherence:

- (i) The number of doses received by the patient were divided by the total number of doses possible, according to the medication regime during the follow-up period (**% depot attendance**).
- (ii) The number of doses received by the patient on the day of appointment were divided by the total number of doses possible, according to the medication regime during the follow-up period (**% depot day attendance**).

The medication regime defines the frequency of dosing (e.g. once a month, once every two weeks). It was taken into account if prior arrangements had been made with staff members for those patients who did not receive their injection on the day of appointment.

This study wanted the opportunity to interview people who demonstrated varying degrees of adherence (or non-adherence). It was decided that respondents would be identified in the hospital as in-patients and then followed-up three months after their discharge date, to assess adherence and quality of life in the community. The three-month follow-up period was decided for two reasons.

- Bowling and Parkman's census (1993) reported on patients of psychiatric services aged 18<65 years old. They considered the 'length of stay of current admission'. One third of the patients (33, 34%) had been in hospital for less than four weeks; one third (31, 32%) had been in hospital between four weeks and six months; one third (33, 34%) had been in hospital for more than six months. Twenty-five per cent (22) of these respondents had also experienced one or more previous admissions for a mental health problem in the last twelve months. The period from discharge to the follow-up community interview therefore, needed to be short to avoid losing cases

due to re-admissions. Secondly, if the patient experienced a long length of stay, then the follow-up interview in the community had to be soon after discharge due to the restricted time available within the study for data collection.

- A depot antipsychotic medication regime may be as infrequent as once a month. Consequently, the community interview could not be too soon after discharge. The researcher wanted to allow the respondent sufficient time to experience their medication and to display varying degrees of medication adherence (or non-adherence).

The medication adherence measure was focused in the community setting since it was here that patients were in charge of their own medication-taking behaviour. The overall aim of this study was to assess the associations between quality of life and medication adherence. The quality of life measure therefore, also needed to be administered in the community. It is known that quality of life measures do not transfer adequately between settings because different areas of importance will define 'quality of life'. For example, the Lancashire Quality of Life Profile includes items on travelling on public transport, the safety of the neighbourhood, improving living conditions which are obviously inappropriate for hospital in-patients. Quality of life therefore, was not measured in the hospital setting. There was no opportunity to compare quality of life in the hospital and the community settings in this study.

Different domains of the community quality of life measure were correlated with medication adherence. It is acknowledged, however, that differences in quality of life may be due to personality factors or factors related to the illness *per se*.

4.3 The objectives of the study

The seven objectives were:

- i. to investigate the views and experiences of antipsychotic medication of people with a diagnosis of schizophrenia, at baseline in the hospital and again, three months post discharge in the community;
- ii. to detect any changes in the views or experiences of antipsychotic medication of people with schizophrenia after discharge from hospital;

- iii. to observe any associations between particular views and experiences of medication and medication-taking behaviour (i.e. whether people adhered to their medication or not);
- iv. to describe the respondent-led important areas of life that contributed to the quality of life of people with a diagnosis of schizophrenia;
- v. to analyse whether the Lancashire Quality of Life Profile measures all those areas of life important to people with a diagnosis of schizophrenia (content validity) (see Appendix One for a description and the psychometric properties of the Lancashire Quality of Life Profile);
- vi. to determine if there were any associations between the domains of quality of life and the degree of medication adherence (or non-adherence) in the first three months after discharge from hospital;
- vii. to make recommendations about the future measurement of quality of life for people with a diagnosis of schizophrenia.

4.4 The study method

The study method was a survey design, using face-to-face interview methods combining structured and open-ended questions. Recruitment baseline interviews took place with hospital in-patients, alongside an audit of hospital medical notes. Community follow-up interviews with respondents took place three months post-discharge; and a postal questionnaire was sent to a significant other, i.e. a person nominated by the patient as someone who knew them well (where patients gave permission). The study took place in the former districts of City and Hackney and Tower Hamlets (currently part of the East London and the City Health Authority). The methods are described in more detail below.

1. All in-patient acute psychiatric admission wards, where consultants had given permission, were visited once every 7-10 days throughout a one year period. Care was taken to ensure that the same ward was not visited on the same day each week to avoid a systematic selection bias.
2. In all individual cases, the permission of the patient's consultant was obtained. After

receiving consultant, junior medical staff and nursing staff approval that a person may be interviewed, clinical staff asked the patient on the behalf of the researcher, whether they were willing to participate in the study. Local ethics committees requested that written consent was obtained from each patient who wished to be involved (see Appendix Five). The researcher retained one copy and one copy was placed in the patient's notes. A summary of the consent form was given to the patient at the end of the interview in a patient information leaflet (see Appendix Six) with a contact name, address and telephone number. Patients who were eligible for inclusion but were either missed or refused were noted. Only information on gender was gathered for these patients since medical records could not be studied without the patients' written consents.

3. The recruitment interview questionnaire (see Appendix Seven) was administered to the patients to determine their views and experiences of medication, insight into their illness/problems and socio-demographic data (e.g. age, marital status, ethnicity, social class). The latter information was also recorded from the medical notes, where possible. Close liaison with the ward managers was required to attempt to minimise the loss of the sample through unexpected discharge. For example, people who had weekend leave and returned to find their bed no longer available due to an acute admission at the weekend, could be discharged at short notice.
5. The recruited patients were followed-up in the community three months after their discharge date. The questionnaire (see Appendix Eight) was administered to the patients to determine their views and experiences of medication, insight into their illness/problems, stigma, service network and to measure their quality of life. These interviews took place in general practitioner surgeries, community psychiatric nurse clinics, day centres and at hostels where staff assessed clients as non-aggressive. The researcher only attended patients' own homes when accompanied. Close liaison with the staff both at the hospital and in the community was used to identify potentially dangerous persons not suitable for interview.
6. Where possible, 'a significant other' (nominated by the patient) was sent a postal

questionnaire (see Appendix Nine) as a second source of information about the patient's objective quality of life indicators. For non-responders two weeks after sending the questionnaire, two 2-weekly reminder letters were sent and then a reminder phone call was made two weeks later again to enhance the response rate.

4.5 The sample

4.5.1 Description of the sample

All patients eligible for inclusion in the study were aged 18-64 years, diagnosed with a clinical diagnosis of schizophrenia and prescribed depot (intramuscular) antipsychotic medication at the time of discharge from the hospital. Clinical diagnoses of schizophrenia were determined by the psychiatrists and verified by the researcher (SAF) using DSM-III-R criteria (American Psychiatric Association, 1987) (see Appendix Ten).

Patients were excluded from the study if they had difficulty completing the recruitment interview because of English language difficulties, self-discharged against medical advice or were discharged outside the study districts (City and East London and Tower Hamlets).

4.5.2 Determination of the sample size

The sample size of a study could be calculated using the method of statistical power. This considers the probability of rejecting the null hypothesis when it is false, or the likelihood of detecting any existing differences. It will depend on the difference being looked for and the number of members in each of the different sub-groups to be analysed (Freeman and Tyrer, 1992). This method could not be applied to this study because the existing literature could not provide us with a hypothesis nor an estimate of the expected differences between the groups. The study design was exploratory and combined inductive and deductive approaches. The sample size for this study was decided using three pieces of information:

1. The discharge rate of patients with a diagnosis of schizophrenia from all district hospitals with in-patient psychiatric facilities (St. Bartholomew's and Hackney

Hospitals in the former City and Hackney district) in 1992, was analysed. One hundred and twenty-three people were discharged throughout the year with a diagnosis of schizophrenia (as recorded in their medical records). Forty-four of these were multiple admissions therefore leaving a possible sample of 79 patients. The reliability of the diagnostic information recorded on the hospital database from the medical records was not analysed. There was no record of the medication prescribed at discharge. It would be impossible to determine how many of the 79 patients in 1992 would have been eligible for inclusion in this study. To maximise the potential for a larger sample, the study was extended to include all hospitals with in-patient psychiatric facilities of an adjacent district (The Royal London and St. Clement's Hospitals in the former Tower Hamlets district). Inclusion of the district of Newham (the remaining district in the new East London and the City Health Authority) was not pursued. It was judged that this would make the sample size unmanageable. Further, practical considerations were concerned with travelling between the different hospitals and community settings.

2. It was decided that one hundred people would be a practical size for the researcher to deal with and allow for sample attrition. This was because there would be a period of approximately 9 months where there would be recruitment interviews and audits of medical notes at four different hospital sites. Simultaneously, community interviews with respondents and a postal questionnaire survey with 'significant others' would also be taking place. The literature warns that there can be up to a 50 per cent decrease in response rate for follow-up studies (Freeman and Tyrer, 1992). Interviewing one hundred people was expected to leave a minimum of at least 50 patients as a final sample.

Practical considerations also influenced which hospital wards would be used for sampling. Long-stay rehabilitation wards and those for forensic psychiatry were not included. These patients were more likely to have long in-patient episodes, most of whom would not be discharged within the study period. Further, many of those patients who would require secure beds would be in private hospitals out of the study district. There were only twelve secure beds in Hackney Hospital but there were forty or more mostly in Kneesworth House

Hospital, Yorkshire and St. Andrews, Northampton available for use by patients from the Hackney district (personal communication, Dr Jeremy Coid, Consultant Forensic Psychiatrist, Hackney Hospital).

It was decided, therefore, that the sample should comprise one hundred consecutively discharged in-patients aged 18-64 years with a clinical diagnosis of schizophrenia and prescribed depot antipsychotic medication on discharge. The sample was recruited from St. Bartholomew's, Hackney, The Royal London and St. Clement's Hospitals throughout a one year period. The focus of sampling was from the acute psychiatric in-patient wards.

4.6 Measurements used in the study

The information collected in the study and the measurements used are summarised below. (For further information, see Appendices Seven to Ten).

- **Diagnosis**

All participants had a clinical diagnosis of schizophrenia according to medical or nursing staff. The diagnosis was confirmed by the researcher (SAF) with DSM-III-R diagnostic criteria (American Psychiatric Association, 1987) using medical notes retrospectively. The DSM-III-R criteria provided detailed description to operationalise the definition of schizophrenia. Diagnosis comprises a 5-digit code identifying the disorder and its subclassification. The diagnosis of schizophrenia is 295.XX, where XX represents the subtypes of schizophrenia at a more detailed diagnostic level. There were no specific resources to validate this. However, where possible, the presence of a DSM-III-R diagnosis of schizophrenia was confirmed by junior medical staff.

- **Recruitment interviews**

The hospital-based recruitment questionnaire asked respondents for the following information:

Views and experiences of medication

Insight (taken from the Present State Examination (PSE 9) (Wing *et al.* 1974)

Admission/current symptoms and problems (taken from Bowling and Parkman, 1993)

Age and date of birth

Marital Status

Ethnicity (taken from Bowling and Parkman, 1993)

Home circumstances (taken from Bowling and Parkman, 1993)

Support from relatives

Employment (taken from the General Household Survey (Office of Population Censuses and Surveys, 1987))

Education (taken from the General Household Survey (Office of Population Censuses and Surveys, 1987))

Permission to contact others

Severity of illness was assessed by the researcher using the Global Assessment of Functioning Scale (American Psychiatric Association, 1987) and where possible, patients were also assessed by hospital ward/community staff.

The researcher recorded the length of the interview (in minutes), place of the interview, sex of patient and any other observations.

● **Information from medical notes**

Hospital medical notes were used to collect objective information, previously reported by the respondents in the recruitment questionnaire, as a process of triangulation. It is acknowledged, however, that there was no way of checking the validity of the information recorded in the medical records. Information was collected on:

Discharge address

Date of birth

Date of admission and discharge

Name and address of general practitioner (where respondents gave permission)

Diagnosis

Marital status

Circumstances of admission

History of presenting complaint

Past psychiatric history

Date first diagnosed with schizophrenia

Insight (recorded as part of the Mental State Examination)

Treatment and progress on ward

Outcomes/plans from discharge meeting

- **Community interview data**

The community-based follow-up questionnaire included questions and scales to measure the following:

Views and experiences of medication

Service and social networks

Insight (taken from the Present State Examination (PSE 9) (Wing *et al.* 1974)

Informed (taken from the 'Index of Health Related Quality of Life' (Rosser *et al.* 1992))

Stigma (taken from the 'Index of Health Related Quality of Life' (Rosser *et al.* 1992))

Current symptoms and problems (taken from Bowling and Parkman, 1993)

The conceptual model of quality of life adopted in this study (see Section 4.2) was operationalised using the following measures:

Open-ended quality of life questions (adapted from the 'Schedule for the Evaluation of Quality of Life (SEIQoL)' (O'Boyle, 1994)). The 'Delight-Terrible Faces' Scale' (Andrews and Withey, 1976) was adapted for rating current quality of life according to each of the respondent-led areas of life and overall quality of life.

Lancashire Quality of Life Profile (Oliver 1991) (also see Appendix One). Using objective and subjective indicators, the Lancashire Quality of Life Profile collects information in nine life areas:

- Work/Education (7 items)

- Leisure/Participation (8 items)

- Religion (4 items)

- Finances (7 items)

- Living situation (12 items)

- Legal and safety (5 items)

- Family relations (7 items)

- Social relations (6 items)

- Health (10 items)

The Lancashire Quality of Life Profile also includes items on global well-being,

positive and negative affect and self-esteem. Perceived quality of life is operationalised as a series of respondents' satisfaction ratings about objective life in each of these domains. The ratings are made using the life-satisfaction scale developed from the Delighted-Terrible response scale (Andrews and Withey, 1976). The final section of the profile measure asks the respondents to name anything that would improve their quality of life which the authors claim as an internal measure of content validity. The interviewer is also expected to rate the quality of life of the respondents using the Quality of Life Uniscale (Spitzer *et al.* 1981).

Other questions:

Community care (questions based on the 'Care Programme Approach')

Permission to contact others

Severity of illness was assessed by the researcher using the Global Assessment of Functioning Scale (American Psychiatric Association, 1987) and where possible, patients were also assessed by community staff.

Record of attendance for antipsychotic depot medication was collected from community psychiatric nurse, general practitioner, or out-patient services.

The researcher recorded the length of the interview (in minutes), places of the interview and any other observations.

● **Information from significant others**

After completion of the community interview, respondents were asked to name a 'significant other' whom the researcher could contact to validate the objective information reported. Each of the 'significant others' named was sent a postal questionnaire. Information was collected on:

Knowledge and views of respondent's medication

Evidence of non-adherence to medication by the respondent

Service network

Respondent's on-going symptoms/problems

Occupational/employment status

Educational status

Objective items from Lancashire Quality of Life Profile (Oliver, 1991) in the nine life areas:

Work / Education (4 items)
Leisure/Participation (4 items)
Religion (2 items)
Finances (3 items)
Living situation (4 items)
Legal and safety (3 items)
Family relations (3 items)
Social relations (4 items)
Health (6 items)

Severity of illness was included using the Global Assessment of Functioning Scale (American Psychiatric Association, 1987).

4.7 The limitations of the study

The questions in this thesis were exploratory and therefore, qualitative semi-structured interview approaches were appropriate for investigating if there was an association between medication adherence and quality of life. If a relationship was identified between medication adherence and quality of life then a longitudinal survey design would be the most appropriate method for future studies. Although achieving an appropriate sample size could be difficult if one wanted to sample before the initial prescription of antipsychotic medication. (During the year of 1992, there were only thirty-two people discharged from Hackney Hospital, who, for the first time, were diagnosed with schizophrenia). The nature of this research question would preclude a randomised controlled trial because ethically patients could not be randomised to enter a medication adherent or non-adherent group.

If there had been sufficient resources, this study would also have included an evaluation of population norms with the quality of life measures in the local communities. This study, therefore, is limited to an exploratory survey to determine if there are any associations between adherence to depot antipsychotic medication post-discharge and quality of life in the community. The direction of any association would be unknown but results would generate hypotheses for future research.

4.8 Analysis of the results

A main objective of the study was to collect qualitative information, in a semi-structured format, to explore the views and experiences of respondents about their antipsychotic medication, to investigate an individual approach to quality of life measurement (using adapted questions from the Schedule for the Evaluation of Individual Quality of Life) and to test the content validity of the Lancashire Quality of Life Profile. The qualitative data was annotated with descriptive labels and analysis proceeded by grouping the descriptive labels according to common issues. The qualitative analysis was intended to complement the quantitative information by focusing on conceptual ideas and developing hypotheses for future research in this field. A detailed qualitative analysis was thought to be inappropriate due to the semi-structured nature of the interview.

The quantitative information from the questionnaires was coded and analysed using the Statistical Package for Social Sciences (SPSS for Windows) (7th version). The package provides a range of simple and complex statistical procedures for both parametric and non-parametric distributions of data. Strictly, the scales and questions should be analysed using non-parametric statistics, as they involve mainly dichotomous and rank ordered (scaled) response choices. However, it is common practice, although technically wrong, to convert the (non-metric) data to interval levels (assuming equal levels between ranks) and then use parametric statistics on the assumption that the tests are robust enough to cope. Therefore, statistical analysis was limited mainly to frequency distributions, Spearman's rank correlations and Chi-squared (χ^2) tests for univariate and bivariate analyses, and multiple regression for the multifactorial analyses. Attention was drawn to significant differences at the $p \leq 0.05$ level. However, given the small sample size, attention was drawn also to the size of the differences between groups since statistics are sensitive to sample size and small samples are less likely to achieve statistical significance (Pocock, 1983).

CHAPTER 5 PILOTING OF STUDY QUESTIONNAIRES AND ETHICAL REVIEW

5.1 Pilot of community questionnaire at community psychiatric nurse ‘depot’ clinics

- **Introduction**

The recruitment interview questionnaire was mainly composed of questions about socio-demographic and questions exploring the respondents’ experiences of medication. The latter were repeated in the community follow-up questionnaire. The aim of the pilot exercise was to test the community follow-up questionnaire with patients attending three different community psychiatric nurse (CPN) clinics for depot antipsychotic medication. This was carried out in the borough of Hackney, London. The specific objective was to test the content validity, question wording and appropriateness and make any final adjustments to the questionnaires.

- **Method**

Three local CPNs agreed to the researcher attending their clinics for the purpose of piloting the questionnaire with those clients who consented to participate. After the patient's consultation with the CPN had finished, each patient was invited by the CPN to take part in the exercise. If the patient agreed to take part, the CPN would introduce them to the researcher (in an adjacent room to the CPN) and leave. The interview questionnaire took approximately forty-five minutes to complete and was divided into nineteen sections: medication views and opinions; service contact and frequency; insight; stigma; symptoms and problems; Quality of Life (QoL) open questions and ratings using faces scales; Lancashire QoL Profile - general well being, work/education, leisure/participation, religion, finances, living situation, legal and safety, family relations, social relations, health, self-concept, general well-being; QoL open questions.

It was explained to the patients that different issues would be covered throughout the interview. The title of the section was read out before the questions were asked. Patients

were told that they could answer as many or as few questions as they wished. Given that this was an out-patient clinic, respondents were expected to only spend a short time (about 10 minutes) with the researcher.

● **Results**

Six clinic sessions were attended. Seventeen patients were interviewed. One patient refused and two patients were not asked to participate because the CPN felt that they were too ill to cope with the questionnaire.

Community care

As a result of the pilot, the final changes made were to the questions on supervised discharge. Often, the patients did not understand what the words 'supervised discharge' meant. The question wording read:

“Are you part of a supervised discharge plan?”

This was changed to:

“Before you were discharged, do you know if there were any special plans made for your care in the community?”

The final question asked:

“Do you have a treatment plan?”

Again, the patients found this ambiguous and had to be given further explanation. This was changed to :

“Do you know if there are any special plans concerning your treatment, medication or injection?”

On the whole, the questionnaire stimulated an interesting interview with the patients and acceptability among respondents was high. This exercise marked the end of the development and pilot work.

5.2 Decisions advised by the district research ethics committees

● Introduction

Dr Trevor Turner (consultant psychiatrist, Department of Psychological Medicine, St. Bartholomew's Hospital) and Dr Simon Fleminger (consultant psychiatrist, The Royal London Hospital) were the named supporting psychiatrists for the City and Hackney District Research Ethics Committee and the Tower Hamlets District Research Ethics Committee applications respectively. These were submitted in June 1993 and approved in September 1993. The concerns and reservations expressed by the ethics committees were used to refine the protocol and questionnaires.

● Safety of the researcher

The protocol submitted to the ethics committees specified that the patients would be followed-up during a three-month period post-discharge in the community. It was anticipated that these interviews would take place at general practitioner surgeries, community psychiatric nurse clinics, day centres and only at homes where staff had assessed patients as non-aggressive. The committees expressed reservation at the researcher's intention to visit patients in their own homes. It was decided that these visits could only take place when the researcher was accompanied.

● Recruitment of the sample

The Tower Hamlets ethics committee stipulated a procedure that had to be followed for recruiting patients to the study:

- i. Consultant, junior medical staff and nursing approval must be sought to confirm that the patient could be interviewed.
- ii. Clinical staff must ask the patient on the behalf of the researcher, whether they (the patient) would be willing to see the researcher so to discuss their taking part in the study.
- iii. The researcher must be introduced to the patient by a member of the clinical team.
- iv. The researcher must explain the study and the requirements that will be expected of the patient. The patient must sign a consent form and then the recruitment interview could take place and the hospital medical notes viewed.

● **Sectioned patients**

The two committees disagreed over whether patients detained under the Mental Health Act 1983 should be included in the study. The response from the Tower Hamlets Committee read:

“Exclusions. This must surely include patients who are "sectioned", because they are detained against their will. However, there is the difficult question of those who are 'sectioned' under Sections 37 or 41 while they are in hospital, but of course are not so when they go back home. Unfortunately, the proposed study straddles right across periods of forcible detention and the reverse.”

Conversely, the response from the City and Hackney committee read:

“The Committee wished to know whether Sectioned patients would be permitted to take part in the research.”

It was clarified that the City and Hackney committee believed that ‘sectioned’ patients should be involved.

After taking advice from clinicians, the researcher decided that “sectioned” patients would be included in the study for three reasons:

1. It was felt that the study would be severely compromised if the researcher was unable to study those people who were least likely to adhere to their medication, given that adherence was a fundamental interest of the study.
2. A 1992 census of psychiatric in-patients of St. Bartholomew's and Hackney Hospitals (Bowling and Parkman, 1993) revealed that 52% (55) of in-patients were currently being detained in hospital using a section of the Mental Health Act 1983. Recruitment to the study, therefore, would be severely compromised if these patients were excluded.
3. The researcher concluded that since patients had the right to refuse inclusion to the study, then it was unfair and bias not to offer this group an equal chance of being included in the study.

These reasons were explained to the Tower Hamlets ethics committee and a compromise was made. They suggested, where possible, that consent should be obtained from the next-of-kin, in addition to that of the ‘sectioned’ patients.

Coid (1993) reflected that the emphasis of QoL work in psychiatry has been in response to the de-institutionalisation programme and the resettlement of people in the community. Consequently, the inclusion of these patients is further justified on the basis that few studies have attempted to include patients who have experienced a compulsory detention in hospital. It is assumed that negative attitudes towards detention could affect subjective perceptions of QoL (Coid, 1993). However, little work has considered this sub-group of the population and the relevance of administering standardised instruments. This study is an opportunity to inform the literature on the quality of life of people who have experienced a compulsory admission to hospital.

● The Recruitment Questionnaire

Ethnicity

The City and Hackney ethics committee wanted the question about ethnicity to fit the 1991 Census categories. It was decided that the detailed categories (which had been developed in a previous survey for the same districts - Bowling and Parkman, 1993) would still be used in the questionnaire as these codes were compatible with the census codes and may be re-grouped in the analysis. Either categories could then be used to describe the sample in any published material.

The detailed groups are:

White	Jewish
	Irish
	English
	Turkish
	Kurdish
	Scottish
	Welsh
	Other European
Black	African
	Afro-Caribbean
	U.K./British
Asian	Chinese
	Vietnamese
	Pakistani
	Bangladeshi
	Indian
Other,	please specify

The 1991 Census categories are:

White
Black Caribbean
Black African
Black Other
Indian
Pakistani
Bangladeshi
Chinese
Other - Asian
- Other

- **The Community Questionnaire**

Finance questions

The City and Hackney ethics committee decided that the questions on finance from the Lancashire Quality of Life Profile should be preceded by:

‘I would like to ask you some questions about your finances, for example, questions about the benefits you receive and whether, IN YOUR OPINION, you receive enough money to live on. Some people may find these types of questions embarrassing and you don't have to answer them if you don't want to.’

Although it is not normally acceptable to alter questions and scales which have been tested, published and copyrighted, this condition had to be accepted by the researcher in order that the research could proceed. This was the final stage of preparatory work before the main study commenced.

PART THREE - RESULTS

CHAPTER 6 RECRUITMENT INTERVIEW AND MEDICATION ISSUES IN HOSPITAL

6.1 Introduction

All consultants of the acute psychiatric admission wards of the four study hospitals were asked for their permission to involve the patients under their care in the study. One consultant refused because the patients under his care were involved in his own research work. Another consultant was working as a *locum tenens* and therefore, permission was sought of the newly appointed consultant as soon as he was in position (May 1994). A total of ten consultants from six acute psychiatric admission wards gave permission for the patients under their care to be included in the study. Table 6.1 shows the recruitment phases by ward and consultant.

Table 6.1 Recruitment phases and the number of patients recruited to the study by ward and consultant

Hospital	Ward	Consultant	Dates of first interview	Dates of last interview	Number of patients recruited No. (%)
St. Bartholomew's	Strauss	TD/PW	25.10.93	30.08.94	16 (18%)
Hackney	Brett	MD/MS	26.10.93	15.12.94	20 (22%)
Hackney	Connolly	TT/MS	27.10.93	09.12.94	30 (34%)
Royal London	Rachel	JP/TR	20.01.94	13.10.94	7 (8%)
St. Clement's	Lansbury	SF/JF [†]	25.01.94	08.12.94	9 (10%)
St. Clement's	Green	EP	25.01.94	08.12.94	7 (8%)
Total number of patients recruited					89

[†] JF gave permission for his patients to be included in the study from 17.05.94.

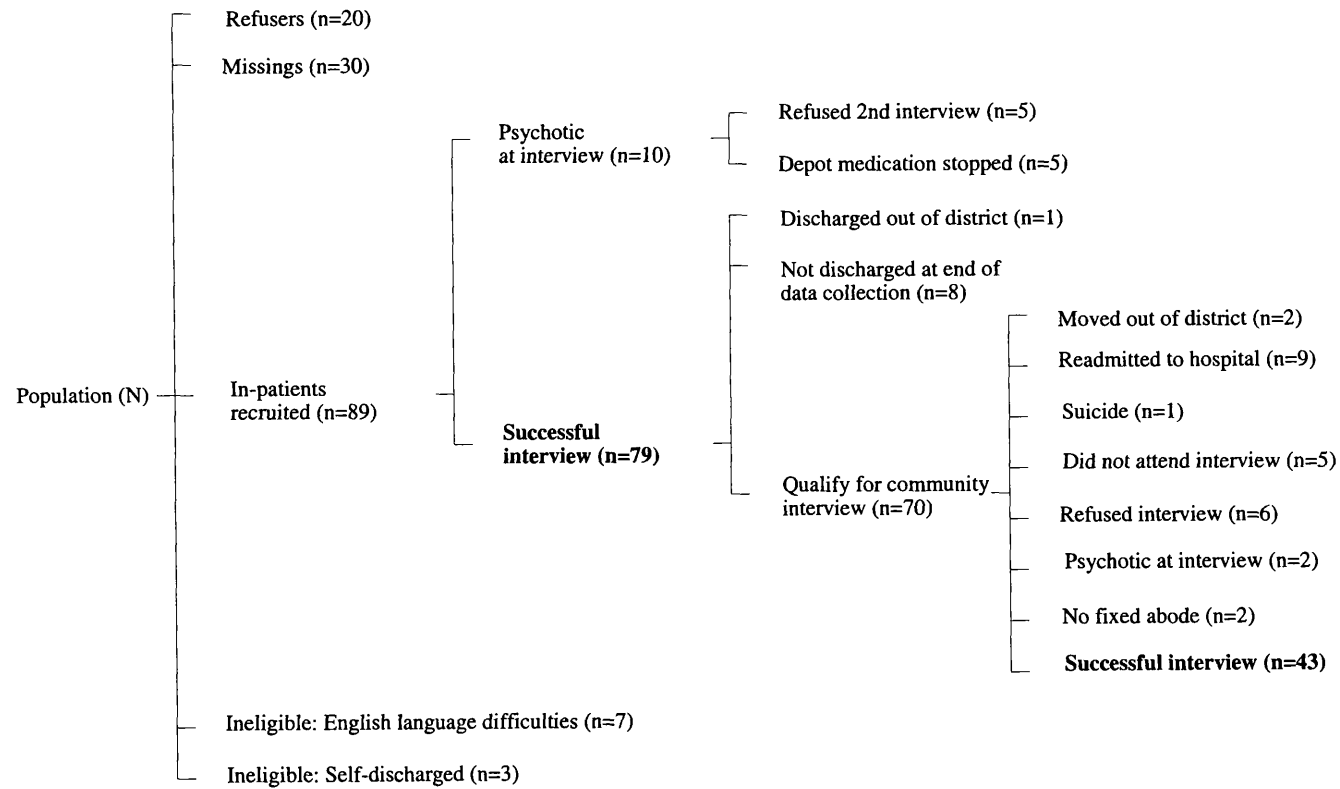
All patients eligible for inclusion in the study were aged 18-64 years, diagnosed with a clinical diagnosis of schizophrenia and prescribed depot (intramuscular) antipsychotic medication at the time of discharge from the hospital. Patients excluded from recruitment to the study were unable to complete the questionnaire due to English language difficulties

(n=7) or self-discharged against medical advice (n=3).

Figure 6.1 is a schematic representation of the respondents in this study. Eighty-nine in-patients were recruited to the study from six wards in four different hospitals of the City and East London district. Twenty in-patients refused to take part (13, 65% were male) and 30 potential respondents were 'missed' (22, 73% were male). Of the 89 in-patients who were recruited, 10 gave delusional responses at the recruitment interview. Of the 79 patients who successfully completed the recruitment questionnaire, 70 were eligible for a community interview. Forty-three patients were successfully followed-up in the community and will be called the 'community sample'. However, 2 of the 43 respondents did not fully complete the community questionnaire and refused to arrange another appointment.

Finding out the exact size of the total population eligible for the study was impossible (N) from routine statistics because prescribed medication at discharge from the hospital was not recorded. However, attempts were made to find an estimate of the number of people eligible for inclusion in the study. Hospital trust managers were asked to provide a list of names that included people aged 18-64 years, who were admitted under one of the participating consultants and discharged during the recruitment phases with a diagnosis of schizophrenia. It was the intention that the researcher (SAF) would eliminate those respondents already accounted for in the study (Figure 6.1) from the list and then select a random sample of the remaining names and retrieve their discharge medication from consultant discharge letters. This would give an estimate of the proportion of clients who were discharged on depot antipsychotic medication. A subsequent estimate could then be calculated for the population size of the study (N). All consultants gave written permission for this exercise to occur. One of the trust managers, responsible for two of the hospital sites agreed to obtain the information. However, after numerous phone calls, he has yet to provide the information. The remaining trust manager, responsible for the other two hospital sites, has not replied to the researcher's letters or phone calls.

Figure 6.1 Schematic representation of the outcome of the study population



Without a population estimate, a response rate for participating in the study cannot be calculated. For the community phase, if the total number available for the community phase interview (n=58) is used as the denominator, then the response rate was 74%. Availability for the community interview excludes those patients who were readmitted to hospital (n=9), moved out of the study district (n=2) and deceased (n=1).

While acknowledging that this is a small sample, quantitative and qualitative data were collected. Quantitative analysis was used to provide descriptive data while qualitative data was used for more in-depth analysis. First, qualitative data provided a detailed insight into respondents' complex views of medication and their perceived roles in managing their medication. Secondly, qualitative information was collected to inform the development and appropriateness of Quality of Life measurement scales for people with schizophrenia. Given the time-consuming nature of the collection and analysis of qualitative data, only a small sample was practicable.

Chapters 6 and 7 will report on the results for the recruited sample as a whole (n=79), and highlight the characteristics of the two sub-samples: the recruitment-only sample, n=36 (those respondents who completed recruitment interviews but were not interviewed in the community) and the community sample, n=43 (those that were successfully interviewed in the community). Case numbers will identify individuals to reserve anonymity and for ease of reference throughout the text. The results will be presented as follows:

- Socio-demographic and descriptive information (e.g. symptoms, problems, insight into illness) collected during the recruitment phase of the study is presented in Section 6.2 and Section 6.3 (n=79). Information reported by the respondents was checked for concordance with hospital medical notes. Data is compared between the recruitment-only sample (n=36) and the community sample (n=43).
- Medication issues are considered at the recruitment phase of the study when all respondents were in-patients (n=79) (Section 6.4). This information is compared between the recruitment-only sample (n=36) and the community sample (n=43).
- Descriptive information collected during the community phase of the study is presented in Section 7.2. Information reported by the respondents was checked for concordance with out-patient medical notes. For the community sample (n=43)

descriptive information reported when in-patients is compared with the responses gained at the community interview.

- Section 7.3 considers medication issues reported at the community phase of the study when the respondents were discharged and living in the community. For the community sample (n=43) responses to the medication questions as in-patients is compared with the responses gained at the community interview.

6.2 Characteristics of the respondents (n=79)

This section describes the socio-demographic characteristics and admission details of the respondents (n=79). Simultaneously, the data is divided to compare the recruitment only sample (n=36) and the community sample (n=43) to reflect the differences and similarities between the sub-groups.

6.2.1 Socio-demographic characteristics

Table 6.2 shows the socio-demographic characteristics of the total sample. Forty-eight respondents were male (61%) and most of the respondents was aged less than 40 years old (50, 63%). The age of the total sample (n=79) ranged from 19-63 years with a mean of 38 years (s.d.=11.7). The mean ages of the recruitment (n=36) and community (n=43) sub-samples were 37 years (s.d.=10.6) and 43 years (s.d.=12.5) respectively. Sex and age variations were compared between the sub-samples using the χ^2 test and the Mann-Whitney test respectively. There were no significant differences ($p \leq 0.05$). When the respondents were asked to report their age, three said that they did not know (Case 15 - recruitment sub-sample and Cases 36 and 79 - community sub-sample) and two respondents reported ages greater than +/- 2 years compared with the age in their medical records (Cases 12 and 73 - recruitment sub-sample). For purposes of validity, the age of each respondent was calculated using the date of birth as stated their medical notes.

Ninety-one per cent of the sample (72) were either single, separated, divorced or widowed. Medical notes were checked for concordance with the reporting of marital status (n=78). Discrepancies were found in 8 cases (10%). In these cases, the respondents' categories were

used for analysis. Due to the small numbers in individual categories, 'single (never married)' was compared, using the χ^2 test, with all other categories for the recruitment-only and community sub-samples; there were no significant differences ($p \leq 0.05$).

Table 6.2 Socio-demographic characteristics of the respondents

Characteristics of the respondents	Recruitment only sample (n=36)	Community sample (n=43)	Total Sample (n=79)
	No. (%)	No. (%)	No. (%)
Sex			
Male	22 (61)	26 (60)	48 (61)
Female	14 (39)	17 (40)	31 (39)
Age[†] (years)			
19-29	13 (36)	13 (30)	26 (33)
30-39	11 (31)	13 (30)	24 (30)
40-49	7 (19)	5 (12)	12 (15)
50+	5 (14)	12 (28)	17 (22)
Marital status			
Single (never married)	26 (72)	36 (83)	62 (78)
Married/cohabiting	4 (11)	2 (5)	6 (8)
Separated	1 (3)	2 (5)	3 (4)
Divorced	4 (11)	2 (5)	6 (8)
Widowed	1 (3)	0 (---)	1 (1)
Not answered	0 (---)	1 (2)	1 (1)
Ethnicity			
Asian Bangladeshi	1 (3)	0 (---)	1 (1)
Asian Indian	2 (6)	0 (---)	2 (3)
Asian Vietnamese	1 (3)	0 (---)	1 (1)
Black African	2 (6)	4 (9)	6 (8)
Black Caribbean	5 (13)	4 (9)	9 (12)
Black U.K./British	4 (11)	11 (26)	15 (19)
Black other [‡]	4 (11)	3 (7)	7 (9)
White English	4 (11)	8 (20)	12 (15)
White Irish	0 (---)	4 (9)	4 (5)
White Jewish	0 (---)	1 (2)	1 (1)
White Scottish	1 (3)	0 (---)	1 (1)
White Welsh	1 (3)	0 (---)	1 (1)
Other European	4 (11)	1 (2)	5 (6)
Other, e.g. 'Mixed race'	3 (8)	3 (7)	6 (8)
Unrateable response	4 (11)	4 (9)	8 (10)
Total number of respondents	36	43	79

[†] Age was calculated using the date of birth as recorded in the medical notes and the date of recruitment interview.

[‡] E.g. Case 14: "Black Caribbean cos I was born in Jamaica and Black U.K./British cos I live in Britain."

The most common single ethnic group was Black U.K./British (15, 19%), while Black African, Black Caribbean, Black U.K./British and Black other together comprised 47% (37) of the sample. Eight respondents (10%) gave 'unrateable responses' either because they refused or they felt unable to assign themselves to an ethnic category (Cases: 36, 54, 64, 68, 55, 43, 88, 69). Four 'Asian' respondents (5%) were recruited to the study, however not one person belonging to this category was successfully interviewed in the community. Similarly, for those respondents who nominated themselves as 'other European' (5, 6%); only one person was successfully interviewed in the community. When all 'white' people (19, 24%) were compared with all 'black' people (37, 47%) between the sub-sample groups, there were no statistically significant differences ($p \leq 0.05$). 'White' people were no more, or less, likely to answer the community questionnaire than 'black' people.

Twenty-seven respondents were born outside the U.K. (34%) and of these, over half (17, 63%) had been resident in the U.K. for more than 20 years. Two respondents did not know where they had been born (Cases 15, 73) and another two respondents gave unrateable responses (Cases 36, 74). There was no significant difference in the respondents' places of birth between sub-samples. Respondents born outside the U.K. were dichotomised by the year they arrived in the U.K.. Twelve respondents (44%) arrived in the U.K. more than 30 years ago (i.e. 1965 or earlier) while a further fourteen (52%) arrived in the U.K. within the last thirty years (i.e. later than 1965). Respondent recruitment and community groups were compared for arriving in the U.K. 1965 or earlier and later than 1965; there was no difference using the χ^2 test for significance ($p \leq 0.05$).

Forty-nine (62%) of all respondents' mothers and 54 (68%) of fathers were born outside the U.K.. Country of birth of mothers and fathers were compared between the recruitment-only and community groups using the χ^2 test for significance ($p \leq 0.05$); there was no difference between the groups.

About half the sample (44, 56%) had attended either full or part-time education classes (not leisure classes) after leaving school (see Table 6.3). Sixteen of these people (36%), specifically named skills training courses such as car maintenance or brick laying. When asked about the highest qualification they had achieved, 39 (49%) reported that they did not

have any educational or technical written qualifications.

The recruitment-only and community sub-samples were compared using the χ^2 test for significance at the $p \leq 0.05$ level. There was no difference between the groups for attending further education classes after leaving school nor between those who had written qualifications compared with those without written qualifications. Respondents were asked at what age they left further education classes. However, this question was not analysed since it does not necessarily reflect continuous education. Some people returned to education classes after working or being unemployed for a period. For this question to be useful, it should ask the respondent to stipulate whether attendance at education classes was continuous or intermittent.

Respondents were asked to describe their most recent employment and social class was indicated using the Registrar General's Classification of Occupations (Office of Population Censuses and Surveys, 1980). However, all women ($n=31$) were classified according to their own most recent occupation. Four women were married women, three of whom had never worked. The remaining 'married' woman (Case 43) was not reported as married in her medical notes. She was living in a hostel before the current admission and was classified in Social Class V based on her most recent occupation. Most of the sample (50, 64%) belonged to social classes III-manual, IV and V. Thirteen respondents (16%) could not be attributed to a social class grouping, 12 of whom had never worked. The other respondent without a social class grouping (Case 09) claimed to be a psychotherapist. There is no code for this occupation. Furthermore, neither hospital ward staff nor medical notes could verify this information. The recruitment-only and community sub-samples were compared using the χ^2 test for significance at the $p \leq 0.05$ level. The sub-samples who had worked were compared by grouping social classes I, II and III non-manual together and testing the frequency against each of social class III-manual, social class IV and social class V. There were no significant differences between sub-samples. The test was repeated including a fifth group ('never worked') and again there was no statistical difference between sub-samples.

Table 6.3 Personal histories of the respondents

	Recruitment only sample (n=36)	Community sample (n=43)	Total Sample (n=79)
	No. (%)	No. (%)	No. (%)
Further education after leaving school:			
Yes	22 (61)	22 (51)	44 (56)
No	13 (36)	20 (47)	33 (42)
Don't know	1 (3)	1 (2)	2 (2)
Highest qualification obtained:			
Degree level qualification	1 (3)	1 (2)	2 (2)
Teaching qualification	1 (3)	0 (---)	1 (1)
GCE 'A' levels/City & Guilds Advanced/Final level	1 (3)	2 (5)	3 (4)
GCE 'O' levels grades A-C/GCSE grades A- C/ CSE grade 1/School Certificate/City & Guilds Craft/Ordinary	7 (19)	5 (12)	12 (15)
CSE Grades 2-5/GCE 'O' levels grades D&E/ GCSE grades D-G/Clerical qualifications/ Apprenticeship	6 (17)	7 (16)	13 (17)
CSE ungraded/Other qualifications (e.g. Irish exams - grades unknown)	1 (3)	2 (5)	3 (4)
No qualifications	16 (44)	23 (53)	39 (49)
Don't know	3 (8)	3 (7)	6 (8)
Social class by most recent occupation[†]:			
Social class I	1 (3)	0 (---)	1 (1)
Social class II	1 (3)	1 (2)	2 (2)
Social class III non-manual	5 (13)	8 (19)	13 (17)
Social class III manual	6 (17)	6 (14)	12 (15)
Social class IV	6 (17)	17 (40)	23 (30)
Social class V	8 (22)	7 (16)	15 (19)
Never worked	9 (25)	3 (7)	12 (15)
Unrateable response	0 (---)	1 (2)	1 (1)
Total number of respondents	36	43	79

[†] Coded using the Registrar General's Classification of Occupations (1980). All women were coded based on their own occupations.

Table 6.4 reports some aspects of the respondents' psychiatric histories as detailed in the medical notes. Almost half the sample (35, 44%) had been diagnosed with schizophrenia for at least ten years. In the twelve months before the current admission, almost half of all respondents (38, 48%) had experienced at least one other in-patient admission for a mental health problem. Twenty-five people (32%) had each experienced at least six previous in-patient admissions for a mental health problem. Of these, 12 people had experienced ten or

more admissions with one person having a psychiatric history consisting of 30 previous admissions. The recruitment-only and community subgroups were compared for differences in their psychiatric histories.

Table 6.4 Psychiatric histories of the respondents taken from medical notes

	Recruitment only sample (n=36)	Community sample (n=43)	Total Sample (n=79)
	No. (%)	No. (%)	No. (%)
Number of years since first diagnosed with schizophrenia:			
Present admission	3 (8)	5 (12)	8 (10)
Less than 1 year	2 (6)	5 (12)	7 (9)
1 year < 5 years	8 (22)	0 (---)	8 (10)
5 years < 10 years	8 (22)	10 (23)	18 (23)
10 years or more	14 (39)	21 (49)	35 (44)
Information unavailable	1 (3)	2 (4)	3 (4)
Total number of previous admissions for a mental health problem			
a) in the least twelve months:			
0	16 (44)	23 (54)	39 (49)
1	14 (39)	17 (40)	31 (39)
2	5 (14)	1 (2)	6 (8)
3	0 (---)	0 (---)	0 (---)
4	0 (---)	1 (2)	1 (1)
information unavailable	1 (3)	1 (2)	2 (3)
b) ever:			
0	1 (3)	5 (12)	6 (8)
1-5	18 (50)	25 (58)	43 (54)
6 or more	16 (44)	9 (21)	25 (32)
information unavailable	1 (3)	4 (9)	5 (6)
Total number of respondents	36	43	79

6.2.2 Admission details of the respondents

The medical notes were used to inform the admission details of the respondents' current admissions (Table 6.5). The most common pathway to hospital for any individual was following a domiciliary visit by health professionals (18, 23%). The police brought a further 16 people (20%) to hospital. Twenty-one people (26%) were admitted via the Accident & Emergency department of the hospital (not including the specialist psychiatric emergency

services). The pathway of admission to hospital did not differ significantly between sub-samples using a χ^2 test of significance ($p \leq 0.05$).

Medical notes were examined for recorded evidence of non-adherence to antipsychotic medication immediately before the current admission. Almost three-quarters of the total sample (56, 71%) were reported as stopping their antipsychotic medication. The recruitment-only and community sub-samples were compared using the χ^2 test for significance at the $p \leq 0.05$ level. There was no significant difference between sub-samples for those respondents who had stopped their antipsychotic medication (non-adherent) before their current admission and those who had not (adherent).

Over half the sample (41, 52%) had been admitted formally to hospital using the Mental Health Act, 1983. The most common section used to detain a patient was Section 3 (14, 34%). The purpose of this section is ‘...the compulsory admission of a patient for the treatment of his mental disorder.’ (Bluglass, 1984). The initial period of detention is six months. The Responsible Medical Officer may renew this for a further six months and then at annual intervals (for more details see Bluglass, 1984). Section 4, the second most common MHA status on admission (10, 25%) is an emergency application for admission to assess the patient. The duration of this Section is 72 hours from the time of admission. Seven people, admitted informally, were subsequently detained under a Section of the Mental Health Act (1983) during their admission. The sub-sample who completed the community interview did not differ significantly by Mental Health Act (1983) status during their admission compared with the recruitment only sub-sample (χ^2 test, $p \leq 0.05$).

Table 6.5 Admission details of the respondents taken from medical notes

	Recruitment only sample (n=36)	Community sample (n=43)	Total Sample (n=79)
	No. (%)	No. (%)	No. (%)
Sources of referral for current admission:			
Following domiciliary visit by health professionals	7 (19)	11 (25)	18 (23)
Brought by police to hospital	8 (22)	8 (19)	16 (20)
Brought by nonprofessionals	10 (28)	3 (7)	13 (16)
Self-referral	4 (11)	4 (9)	8 (10)
Brought by member of community mental health team	2 (6)	5 (12)	7 (9)
GP referral	3 (8)	3 (7)	6 (8)
Following arrest by police or via courts	1 (3)	3 (7)	4 (5)
Other [†]	1 (3)	4 (9)	5 (6)
Information unobtainable	0 (---)	2 (5)	2 (3)
Admission via Accident & Emergency:			
Yes	9 (25)	12 (28)	21 (26)
No	27 (75)	28 (65)	55 (70)
Information unobtainable	0 (---)	3 (7)	3 (4)
History of stopping antipsychotic medication before current admission:			
Yes	25 (69)	31 (72)	56 (71)
No	10 (28)	8 (19)	18 (23)
No previous admissions	1 (3)	4 (9)	5 (6)
Legal status on admission:			
Informal	15 (42)	23 (53)	38 (48)
Formal (detained under a section of the Mental Health Act, 1983)	21 (58)	20 (47)	41 (52)
Mental Health Act status on admission:	n=21	n=20	n=41
Section 2	5 (24)	4 (20)	9 (22)
Section 3	6 (29)	8 (40)	14 (34)
Section 4	6 (29)	4 (20)	10 (25)
Section 37 + 41	2 (9)	1 (5)	3 (7)
Section 136	2 (9)	1 (5)	3 (7)
Other section	0 (---)	2 (10)	2 (5)
Legal status during admission:			
Informal for whole of admission	13 (36)	17 (40)	30 (38)
Formal at some point during the admission	22 (61)	26 (60)	48 (61)
Information unobtainable	1 (3)	0 (---)	1 (1)
Total number of respondents	36	43	79

[†] Other source of referral: n=36 Case 13: Admitted from a medium secure unit. n=43 Case 01: Transferred from a medical ward; Case 02: Admitted from a medium secure unit; Case 64: Found wandering in the hospital grounds; Case 67: Admitted following a mental health assessment on the streets by a team of health professionals.

6.2.3 Diagnosis

All patients recruited to the study had a clinical diagnosis of schizophrenia. Diagnoses were obtained by asking the psychiatric medical staff on the wards. After receiving patients' permissions, diagnoses of the study sample were confirmed using the medical notes and classified according to the DSM-III-R criteria (American Psychiatric Association, 1987) (see Appendix Ten). A Registrar Psychiatrist carried out an independent validation exercise (Dr Vincent Kirchner) to check the researcher's use of the DSM-III-R criteria. This exercise required the Registrar (who routinely used DSM-III-R criteria) to confirm the diagnosis of schizophrenia for each patient involved in the study with whom he had been in contact. Fifty-four in-patients had been recruited to the study at that time, of whom the Registrar was familiar with 17 (31%). The Registrar confirmed that all 17 had a DSM-III-R diagnosis of schizophrenia (295.XX). Secondly, as a further process of validation, both the researcher and the Registrar studied all the medical notes of the patients of one ward (n=35). Each in-patient was classified with a 'diagnosis of schizophrenia' or with a 'diagnosis other than schizophrenia'. Full agreement (100%) was achieved between both sets of diagnoses.

6.3 Recruitment interview at hospital

Seventy-nine recruitment interviews each took between 10 and 67 minutes to complete. The mean completion time was 22 minutes (s.d.=8.8) with a median value of 20 minutes. The mean completion times for the recruitment-only (n=36) and the community (n=43) samples were 20 minutes (range=10-36 minutes; s.d.=6.5) and 23 minutes (range=10-67 minutes; s.d.=10.2) respectively. The completion times of the subgroups were compared using a Mann-Whitney test ($p \leq 0.05$) and there was no significant difference.

Almost three-quarters of the 79 recruitment interviews (58, 73%) took place either at St. Bartholomew's or Hackney Hospitals (of the former City and Hackney district). The remaining interviews (21, 27%) took place at The Royal London or St. Clement's Hospitals (of the former Tower Hamlets district). The recruitment-only and community sub-samples were compared using the χ^2 test of significance at the $p \leq 0.05$ level for the place of recruitment interviews. There was no significant difference between the sub-samples.

6.3.1 Home circumstances

Table 6.6 shows that almost two-thirds of the respondents (52, 66%) were renting local authority accommodation before their current admission to the hospital. Six respondents (7%) were of no fixed abode and one respondent (Case 02) was in prison. Social Trends 25 (Central Statistical Office 1995:182) reported that in the U.K. in 1993, more than three-quarters of the heads of households were professionals, employers and managers buying their homes with a mortgage. Households that an unskilled manual worker headed were the group most likely to rent their home (58%).

For those respondents who were living in accommodation before this admission (n=72), most (42, 58%) reported living alone. Twenty-one respondents (29%) reported living with family. Of these, the majority (15, 71%) lived with parent(s) and/or sibling(s). The remaining 6 (29%) lived with their spouse and/or children. Respondents were asked whether their previous accommodation would be available to them after discharge. Forty-seven respondents (60%) reported that they could return to their previous accommodation. Comments suggested that this was not favourable for all respondents.

“...but I don’t want to go back. I’ll be ill again. *[What type of accommodation would you like?]* Hostel. I want to be with people but I worry about my cat. I don’t want him destroyed.”

(Case 50)

Over a quarter of respondents (21, 27%) were unsure as to the type of accommodation to which they would be discharged.

“The social worker want me to give it [council flat] up for another. I’ve got to mix with friends and other people.”

(Case 26)

The recruitment-only and community sub-samples were compared using the χ^2 test at the $p \leq 0.05$ level for the accommodation variables. There was no significant difference between the sub-samples whether they had lived alone before admission or whether they had lived with others (including family and friends). When comparing whether respondents knew what type of accommodation they expected after discharge, there was no significant difference between the two sub-samples.

Table 6.6 Accommodation details of the respondents

	Recruitment only sample (n=36)	Community sample (n=43)	Total Sample (n=79)
	No. (%)	No. (%)	No. (%)
Accommodation before admission:			
Rented from local authority	23 (64)	29 (67)	52 (66)
No fixed abode	3 (8)	3 (7)	6 (8)
Hostel	3 (8)	3 (7)	6 (8)
Privately rented	2 (6)	2 (5)	4 (5)
Housing association	3 (8)	2 (5)	5 (6)
Owner/occupier or living in same household as owner occupier	1 (3)	3 (7)	4 (5)
Bed & Breakfast	0 (---)	1 (2)	1 (1)
Prison	1 (3)	0 (---)	1 (1)
For those with accommodation before admission:	n=33	n=39	n=72
Was it shared?			
Lived alone	19 (58)	23 (59)	42 (58)
Lived with family	10 (30)	11 (28)	21 (29)
Lived with friends	2 (6)	2 (5)	4 (6)
Lived with others (e.g. sharing a hostel)	2 (6)	3 (8)	5 (7)
Type of accommodation after discharge:			
Same as before admission	23 (64)	24 (56)	47 (60)
Rented from local authority	3 (8)	2 (5)	5 (6)
Bed & Breakfast	1 (3)	0 (---)	1 (1)
Owner/occupier or living in same household as owner occupier	0 (---)	1 (2)	1 (1)
Hostel	2 (5)	2 (5)	4 (5)
Don't know	7 (20)	14 (32)	21 (27)
Total number of respondents	36	43	79

6.3.2 Relative Support

Forty-two respondents (53%) expected support from relatives after discharge (Table 6.7). This was either by sharing a household or by regular visiting. Most of the respondents (35, 83%) were happy with the support they received; for others the support they received was not always a positive experience.

“My brother. He’s mad as well. One minute he wants to be with me and one minute not.”

(Case 15)

“My sister will help me but my brother will just get me into trouble.”

(Case 62)

Six respondents (14%) were unhappy or unsure (1, 3%) about the support they received from their relatives.

“Not sure. Brother called here one week ago. I have his address. At times it can be a nuisance. It can cause a stress having to be in a certain time. I prefer to have them available when I want them.”

(Case 34)

“They don’t visit enough. One lives up the road five minutes away.”

(Case 60)

“I’d rather them not come. I feel happier without them.”

(Case 68)

Thirty-seven respondents (43%) reported that there were either no relatives to support them or they were unsure of the support available to them after discharge. Of these respondents, the most sought after support was regular visiting (22, 60%). Two-thirds of these respondents (25, 67%) did not want to live with anyone else after discharge.

“I like to be lonely.”

(Case 03)

“...because I’d like to do private study at home, therefore, I’d like to be on my own. Also to marry, if I live with other people it would hinder me from marrying.”

(Case 40)

Relative support was compared for the sub-sample groups using the χ^2 test at the $p \leq 0.05$ level. There was no significant difference between the amount of relative support expected after discharge.

Table 6.7 Relative support expected after discharge from hospital

	Recruitment only sample (n=36)	Community sample (n=43)	Total Sample (n=79)
	No. (%)	No. (%)	No. (%)
Relative support available after discharge?			
Yes, living with me	8 (22)	8 (18)	16 (20)
Yes, visiting regularly	14 (39)	12 (28)	26 (33)
No	13 (36)	21 (49)	34 (43)
Unsure	1 (3)	2 (5)	3 (4)
If no or unsure, would you want someone to:	n=14	n=23	n=37
a) visit you regularly after discharge?			
Yes	9 (64)	13 (57)	22 (60)
No	3 (22)	9 (39)	12 (32)
Don't know	2 (14)	1 (4)	3 (8)
b) live with you after discharge?			
Yes	4 (29)	4 (18)	8 (22)
No	7 (50)	18 (78)	25 (67)
Don't know	3 (21)	0 (---)	3 (8)
Missing information	0 (---)	1 (4)	1 (3)
If yes, are you happy with this arrangement?	n=22	n=20	n=42
Yes	19 (86)	16 (80)	35 (83)
No	3 (14)	3 (15)	6 (14)
Missing information	0 (---)	1 (5)	1 (3)
Total number of respondents	36	43	79

6.3.3 Employment history

Table 6.8 shows that most of the respondents (70, 89%) were unemployed before their current admission to hospital. Of these, two-thirds (47, 67%) reported that they were not looking for work. The main reason was that the respondents classified themselves as 'long term sick or disabled' (21, 45%).

"Because I've been labelled as schizophrenic, not normal to look for work. It's hard being in a mental institute, hard to explain the government has spent money on you. I've been victimised."

(Case 34)

"I was going in and out of hospital and with the medication, I couldn't do a job. If I was to tell them I was getting an injection, they would ask what is the matter with me and sack me. The tablet made me sleepy. I couldn't work like that, sleepy all the time."

(Case 20)

Table 6.8 Employment histories of the respondents

	Recruitment only sample (n=36)	Community sample (n=43)	Total Sample (n=79)
	No. (%)	No. (%)	No. (%)
In paid employment before admission?			
Yes	5 (14)	4 (9)	9 (11)
No	31 (86)	39 (91)	70 (89)
If no, were you:	n=31	n=39	n=70
unemployed looking for work	8 (26)	15 (38)	23 (33)
unemployed but not looking for work	23 (74)	24 (62)	47 (67)
Main reason for not looking for work	n=23	n=24	n=47
Long term sick or disabled	12 (53)	9 (37)	21 (45)
Doesn't want/need employment	3 (13)	3 (13)	6 (13)
Believes no jobs available	1 (4)	4 (17)	5 (10)
Looking after family/home	3 (13)	1 (4)	4 (9)
Too old/retired	1 (4)	3 (13)	4 (9)
Student	2 (9)	0 (---)	2 (4)
Not yet started looking	0 (---)	2 (8)	2 (4)
Other reason [†]	1 (4)	2 (8)	3 (6)
When was your last full-time employment?			
Less than 3 months before admission	5 (14)	4 (9)	9 (11)
3 months < 1 year before admission	1 (3)	0 (---)	1 (1)
1 year < 3 years before admission	1 (3)	6 (14)	7 (9)
3 years < 5 years before admission	4 (11)	5 (12)	9 (11)
5 years < 10 years before admission	7 (19)	6 (14)	13 (17)
10 years or more before admission	9 (25)	19 (44)	28 (36)
Never worked	9 (25)	3 (7)	12 (15)
Will you look for work after leaving hospital?			
Yes	18 (50)	20 (46)	38 (48)
No	16 (44)	20 (46)	36 (46)
Unsure	2 (6)	3 (8)	5 (6)
If not, why not?	n=16	n=20	n=36
Long term sick/disabled	9 (55)	7 (35)	16 (44)
Too stressful	2 (13)	4 (20)	6 (17)
Does not want to work	2 (13)	2 (10)	4 (11)
Too old/retired	1 (6)	2 (10)	3 (8)
Physical health problems	0 (---)	2 (10)	2 (6)
Other reason [‡]	2 (13)	1 (5)	3 (8)
Not answered	0 (---)	2 (10)	2 (6)
Total number of respondents	36	43	79

[†]Other reason: n=36 Case 43: "Don't know how to go about it." n=43 Case 02: prison; Case 33: voluntary work.

[‡]Other reason: n=36 Case 74: look after family/home; Case 65: "Going back to the training centre." n=43 Case 33: voluntary work.

Over half the respondents (41, 53%) had not worked full-time for at least 5 years.

“Brick layer’s mate. Forgotten how to do it now. I’d have to be taught all over again. I went to a Brick Layer’s College and was taught how to do it but I wasn’t all that good.”

(Case 28)

“Owner mini cab driver. Because of the medication I had to pack it in. My license was suspended.”

(Case 29)

“Hospital porter. Moorfields Eye Hospital. I had a medical certificate but she wrote psychotic on it and when I went back I couldn’t have it [the job] back.”

(Case 50)

Almost half the respondents (38, 48%) reported that they intended to look for work after discharge. ‘Long term sick or disabled’ was the main reason reported by those who did not intend to look for work after discharge (15, 42%). Employment variables were compared for the two sub-sample groups using the χ^2 test at the $p \leq 0.05$ level. There were no significant differences between the two groups on any of the variables.

6.3.4 Insight

The difficulty of defining and measuring the concept of insight has already been discussed (see section 1.5.3). During the recruitment interview, open responses to the Present State Examination (Wing *et al.* 1974) question of insight were recorded verbatim and later coded into one of the four predefined categories as shown in Table 6.9.

More than one quarter of respondents (22, 28%) had some insight into their illness.

“Sometimes I feel people are looking at me, taking the mickey. I know there’s no cure. I understand my illness. My medication is just to stable me...It struck me when I was 15. Diagnosed when I was 17. I’ve been in St. Clement’s, Longrove, Hackney [hospitals]. Nineteen ECTs. I’ve been on Nardil, Tofranil, Stelazine, that made me restless. I’m completely addicted to the benzhexol. I’ve been taking them for 20 years. [Why did you need to come to hospital?] I was cracking up with my paranoid thoughts.”

(Case 50)

“A madness feeling in my brain. The Doctor put it down to a nervous disorder, but the other doctor said I was schizo. [Why did you need to come to hospital?] Because I was confused. Thinking mad thoughts, wanting to kill myself. It’s part of the confusion in my brain.”

(Case 14)

Table 6.9 Insight of the respondents[†]

	Recruitment only sample (n=36)	Community sample (n=43)	Total Sample (n=79)
	No. (%)	No. (%)	No. (%)
Full insight in intelligent subject	0 (---)	1 (2)	1 (1)
Insight dependent on social background / intelligence	8 (22)	13 (30)	21 (27)
Agrees to a nervous condition with delusional explanations	10 (28)	11 (26)	21 (27)
Denies nervous condition entirely	18 (50)	18 (42)	36 (45)
Total number of respondents	36	43	79

[†] taken from the Present State Examination (Wing *et al.* 1974)

Almost a half of all respondents (36, 45%) denied experiencing a nervous condition.

“There’s nothing wrong with me at all, just short of breath. [*Why did you need to come to hospital?*] Don’t know. Because I was truant from work, a warehouse.”

(Case 48)

“I have no illness. I have never had illness. My eldest brother brought me to hospital but the brother I follow wouldn’t have brought me. He says I should leave my eldest brother alone. We have a misunderstanding.”

(Case 77)

Insight categories were compared for the two sub-sample groups using the χ^2 test at the $p \leq 0.05$ level. The first two categories in the table were collapsed together. There were no significant differences between the two groups.

Attempts were made to compare the respondents’ insights of their illnesses at admission (as recorded in medical notes) with the researcher’s assessment of in-patient insight at the time of the recruitment interview. The record of insight in the medical notes at time of admission was inadequately described. Phrases such as ‘...some insight’ or ‘..little insight’ were not useful in the comparison with the researcher’s insight categories.

6.3.5 Symptoms and problems on admission and at time of recruitment interview

Table 6.10 illustrates the reasons for admission as reported by the respondents. The

responses given were not always reasons for admission but a statement of who was involved with their admission, such as health professionals or the police (15, 19%). Most of the respondents (45, 57%) reported being ill or needing help. Twelve respondents (15%) did not know why they had been admitted. The frequencies were too small for statistical comparison.

Table 6.10 Reasons for admission as reported by the respondents

	Recruitment only sample (n=36)	Community sample (n=43)	Total Sample (n=79)
	No. (%)	No. (%)	No. (%)
Needed help / were sick / danger to self	22 (61)	23 (53)	45 (57)
Due to health professional involvement	6 (17)	2 (5)	8 (10)
Accommodation problems	2 (5)	5 (12)	7 (9)
Due to police involvement	3 (8)	4 (9)	7 (9)
Danger to others	2 (5)	3 (7)	5 (6)
Physical health problem	1 (3)	2 (5)	3 (4)
Not taking medication	1 (3)	1 (2)	2 (5)
Other reason [†]	1 (3)	3 (7)	4 (5)
Don't know why admitted	3 (8)	8 (19)	11 (14)
Unrateable response	1 (3)	3 (7)	4 (5)
Refused to answer	1 (3)	0 (---)	1 (1)
Total number of respondents	36	43	79

Note: Percentages do not equal 100 since respondents could give more than one answer.

[†] Other reason: n=36 Case 77: "Because I was brought into an environment of mentally ill people, I have become mentally ill." n=43 Case 28: "Because my Mum had a fall and couldn't stand to put up with me or my incontinence I was having."; Case 53: "Because of the hands." [The hands showed a tremor]; Case 59: "I think it's because I have arguments with my Mum. She's alright. I've got nothing against her."

Most frequently respondents reported that they were not experiencing any symptoms on admission (33, 42%) and similarly, at the time of the recruitment interview (43, 54%) (Tables 6.11 and 6.12). Some of the 'symptoms' reported could be attributed to the adverse effects of antipsychotic medication (e.g. loss of libido, shaking, drowsiness) and as such, have been collectively termed 'potential drug-related problems'. Reporting at least one symptom was compared with reporting no symptoms for both sub-sample groups. The χ^2 test of

significance at the $p \leq 0.05$ level showed no significant differences between the two groups.

Table 6.11 Symptoms on admission as reported by the respondents

	Recruitment only sample (n=36)	Community sample (n=43)	Total Sample (n=79)
	No. (%)	No. (%)	No. (%)
Hallucinations	9 (25)	9 (21)	18 (23)
Delusions	1 (3)	7 (16)	8 (10)
Depressed mood	4 (11)	1 (2)	5 (6)
Ideas of self-harm	4 (11)	1 (2)	5 (6)
Somatic complaints	2 (6)	3 (7)	5 (6)
Aggressive / Hostile behaviour	3 (8)	2 (5)	5 (6)
Anxiety	1 (3)	2 (5)	3 (4)
Thought disorder	3 (8)	0 (---)	3 (4)
Mental illness / mental exhaustion	2 (6)	1 (2)	3 (4)
Confusional states	0 (---)	2 (5)	2 (3)
Appetite / weight loss	1 (3)	1 (2)	2 (3)
Potential drug-related problems (n=36: drowsiness, dizziness; n=43: drowsiness)	2 (6)	1 (2)	3 (4)
Loss of control	0 (---)	2 (5)	2 (3)
Not coping / unable to look after oneself	2 (6)	1 (2)	3 (4)
Other symptoms [†]	2 (6)	3 (7)	5 (6)
No symptoms on admission	14 (39)	19 (44)	33 (42)
Not answered	1 (3)	1 (2)	2 (3)
Total number of respondents	36	43	79

Note: Percentages do not equal 100 since respondents could give more than one answer. Symptoms were office-coded according to the respondents' descriptions.

[†]Other symptoms: n=36 Case 63: Memory problems; Case 81: Panic attacks. n=43 Case 62: Sleep disturbance; Case 72: "Talking to myself."; Case 56: "Asking for things, cigarettes."

Table 6.12 Current symptoms at the time of the recruitment interview as reported by the respondents

	Recruitment only sample (n=36)	Community sample (n=43)	Total Sample (n=79)
	No. (%)	No. (%)	No. (%)
Somatic complaints	6 (17)	4 (9)	10 (13)
Delusions	1 (3)	7 (16)	8 (10)
Potential drug related problems (n=43: drowsiness/lethargy (3); tremor (2); increased appetite (1); loss of libido (1))	0 (---)	7 (16)	7 (9)
Hallucinations	2 (6)	5 (12)	7 (9)
Ideas of self-harm	1 (3)	2 (5)	3 (4)
Confusional states	2 (6)	0 (---)	2 (3)
Other symptoms [†]	3 (8)	2 (5)	5 (6)
No symptoms at time of recruitment interview	22 (61)	21 (49)	43 (54)
Not answered	1 (3)	0 (---)	1 (1)
Total number of respondents	36	43	79

Note: Percentages do not equal 100 since respondents could give more than one answer. Symptoms were office-coded according to the respondents' descriptions.

[†] Other symptoms: n=36 Case 71: "The way I feel is not the way I was feeling."; Case 69: Depressed mood; Case 55: Thought disorder. n=43 Case 01: Anxiety; Case 24: Aggressive/hostile behaviour;

Medical notes were used as a comparison with the symptoms reported on admission for each respondent (Table 6.13). The two most frequently cited symptoms (hallucinations and delusions) were the same as those described by the respondents in Table 6.11. However, there was under reporting by the respondents compared with the medical notes, in particular for the presence of aggressive or hostile behaviour at the time of admission.

Table 6.13 Symptoms on admission taken from medical notes

	Recruitment only sample (n=36)	Community sample (n=43)	Total Sample (n=79)
	No. (%)	No. (%)	No. (%)
Hallucinations	16 (44)	14 (33)	30 (38)
Delusions	13 (36)	16 (37)	29 (37)
Aggressive / Hostile behaviour	14 (39)	12 (28)	26 (33)
Ideas of self-harm	8 (22)	3 (7)	11 (14)
Thought disorder	0 (---)	11 (26)	11 (14)
Sleep disturbance	3 (8)	8 (19)	11 (14)
Depressed Mood	5 (14)	4 (9)	9 (11)
Odd behaviour	3 (8)	6 (14)	9 (11)
Appetite / weight loss	2 (6)	7 (16)	9 (11)
Anxiety	6 (17)	1 (2)	7 (9)
Somatic complaints	2 (6)	1 (2)	3 (4)
Confusional states	1 (3)	1 (2)	2 (3)
Poor self-care	1 (3)	1 (2)	2 (3)
Other symptoms [†]	1 (3)	6 (14)	9 (11)
Information unobtainable	0 (---)	2 (5)	2 (3)
Total number of respondents	36	43	79

Note: Percentages do not equal 100 since respondents could give more than one answer.

[†]Other symptoms: n=36 Case 13: Flat affect. n=43 Case 27: Memory problems; Case 45: incoherence; Case 59: Sexually disinhibited; talking irrationally; Case 70: mute; Case 79: unwell.

The most frequently reported problems reported by respondents on admission (23, 29%) and at the time of the recruitment interview (14, 18%) were accommodation problems (Tables 6.14 and 6.15). Reporting at least one problem was compared with reporting no problems for both sub-sample groups. The χ^2 test of significance at the $p \leq 0.05$ level showed no significant differences between the two groups.

Table 6.14 Problems on admission as reported by the respondents

	Recruitment only sample (n=36)	Community sample (n=43)	Total Sample (n=79)
	No. (%)	No. (%)	No. (%)
Accommodation problems	10 (28)	13 (30)	23 (29)
Discord with family	5 (14)	6 (14)	11 (14)
Financial problems	7 (19)	1 (2)	8 (10)
Stress	0 (---)	5 (12)	5 (6)
Relationship difficulties	2 (6)	2 (5)	4 (5)
Bereavement	2 (6)	2 (5)	4 (5)
Coping at home / looking after oneself	1 (3)	3 (7)	4 (5)
Problems with unemployment	1 (3)	1 (2)	2 (3)
Social isolation	0 (---)	2 (5)	2 (3)
Other reason [†]	1 (3)	3 (7)	4 (5)
No problems on admission	12 (33)	14 (33)	26 (33)
Missing information	2 (6)	0 (---)	2 (3)
Total number of respondents	36	43	79

Note: Percentages do not equal 100 since respondents could give more than one answer.

[†] Other reasons: n=36 Case 18: Security. n=43 Case 09: Physical health; Case 29: Violent/dangerous behaviour; Case 53: Unspecified problems.

Table 6.15 Current problems at the time of the recruitment interview as reported by the respondents

	Recruitment only sample (n=36)	Community sample (n=43)	Total Sample (n=79)
	No. (%)	No. (%)	No. (%)
Accommodation problems	5 (14)	9 (21)	14 (18)
Discord with family	3 (8)	4 (9)	7 (9)
Financial problems	4 (11)	3 (7)	7 (9)
Problems with unemployment	1 (3)	2 (5)	3 (4)
Relationship difficulties	1 (3)	2 (5)	3 (4)
Misplaced belongings	0 (---)	3 (7)	3 (4)
Security / Safety	2 (6)	0 (---)	2 (3)
Physical health	1 (3)	1 (3)	2 (3)
Being in hospital (e.g. other patients)	1 (3)	1 (3)	2 (3)
Social isolation	1 (3)	1 (3)	2 (3)
Other reasons [†]	2 (6)	3 (7)	5 (6)
No problems at time of recruitment interview	15 (42)	19 (44)	34 (43)
Not answered	3 (8)	1 (2)	4 (5)
Total number of respondents	36	43	79

Note: Percentages do not equal 100 since respondents could give more than one answer.

[†] Other reasons: n=36 Case 65: Sexual difficulties; Case 71: No general practitioner. n=43 Case 01: Religion; Case 23: Potential drug-related problem - shaking; Case 53: Unspecified problems.

Thirty-one respondents (39%) reported that they were also experiencing physical or other health problems (Table 6.16). Physical or other health problems were office-coded according to the system of the body affected and as potential drug-related problems (see page 150). Reporting a physical or other health problem was compared with reporting no physical or other health problems for both sub-sample groups. The χ^2 test of significance at the $p \leq 0.05$ level showed no significant differences between the two groups.

Table 6.16 Physical or other health problems reported by the respondents

	Recruitment only sample (n=36)	Community sample (n=43)	Total Sample (n=79)
	No. (%)	No. (%)	No. (%)
Yes	11 (30)	20 (47)	31 (39)
None	24 (67)	20 (47)	44 (56)
Not answered	1 (3)	3 (6)	4 (5)
If yes, system affected:	n=11	n=20	n=31
Chest problems including atopy (e.g. asthma, eczema, hay fever)	3 (27)	7 (35)	10 (32)
Orthopaedic/Rheumatology (e.g. joint problems, bunions)	4 (36)	1 (5)	5 (16)
Endocrine (e.g. diabetes, thyroid problems)	0 (---)	3 (15)	3 (10)
Cardiovascular	0 (---)	3 (15)	3 (10)
Ocular (e.g. short-sighted)	1 (9)	1 (5)	2 (6)
Others [†]	3 (27)	4 (20)	7 (23)
Potential drug-related problems:			
Hormonal (e.g. weight gain, amenorrhoea)	2 (18)	3 (15)	5 (16)
Anticholinergic (e.g. constipation, urinary retention, dry throat)	2 (18)	2 (10)	4 (13)
Parkinsonism (e.g. stiffness)	0 (---)	1 (5)	1 (3)
Total number of respondents	36	43	79

Note: Percentages do not equal 100 since respondents could give more than one answer.

[†] Other health problems: n=36 Case 18: Punctured kidney; Case 88: Teeth; Case 61: Varicose ulcer. n=43 Case 23: One testicle; Case 30: Deaf; Case 49: Depression; Case 79: Incontinence.

6.3.6 Severity of illness

The researcher (SAF) rated severity of illness using the Global Assessment of Functioning Scale (American Psychiatric Association, 1987) at the end of the recruitment interview (Table 6.17). The scale considers the ‘...psychological, social and occupational functioning on a hypothetical continuum of mental health-illness’ (American Psychiatric Association, 1987). Physical limitations are not considered in the rating. Where possible, staff were also asked to rate the respondent (63 (80%) of total cases) as a process of validation. The ratings of 11 individuals (17%) differed between the researcher and the validator. On these occasions, the validator rating was used because they had greater contact with the individual. Six cases were adjusted down the scale and five cases were moved up the scale. Seven people (9%) had mild, slight or minimal symptoms; 15 (19%) had moderate symptoms; and

the remainder (57, 72%) had varying types of major impairment or symptoms. Illness severity was compared for both sub-sample groups. The χ^2 test for significance at the $p \leq 0.05$ level showed no significant difference between the two groups.

6.3.7 Permission to contact general practitioners and significant others

At the end of the recruitment interview, respondents were asked for their General Practitioner's (GP) name, in case the researcher (SAF) would need to contact them during the follow-up period. Most of the respondents (62, 79%) gave their permission (Table 6.18). Of those people who did not give permission, three respondents reported that they were not registered with a GP and one reported: "I don't get on with my GP."

Respondents were also asked for their permission for the researcher to speak to someone who knew them well ('significant other') during the follow-up period. Most of the respondents (59, 75%) named a 'significant other' and gave permission for them to be contacted (Table 6.18). On most occasions (36, 61%), this was a member of the health care team.

Table 6.17 Global Assessment of Functioning Scale (GAF Scale) rating[†] (severity of illness) of the respondents

	Recruitment only sample (n=36)	Community sample (n=43)	Total Sample (n=79)
	No. (%)	No. (%)	No. (%)
Absent or minimal symptoms, good functioning in all areas, interested and involved socially	0 (---)	0 (---)	0 (---)
Symptoms present, but transient/expectable and no more than slight social impairment	0 (---)	0 (---)	0 (---)
Some mild symptoms but generally functioning well, has interpersonal relationships	3 (8)	4 (9)	7 (9)
Moderate symptoms or moderate difficulty with social/occupational functioning	5 (14)	10 (23)	15 (19)
Serious symptoms (e.g. suicidal, obsessional, frequent shoplifting) <u>or</u> any serious impairment in social/occupational functioning	5 (14)	11 (26)	16 (20)
Some impairment in reality testing or communication <u>or</u> major impairment in several areas	13 (36)	10 (23)	23 (29)
Behaviour is considerably influenced by delusions or hallucinations <u>or</u> serious impairment in communication or judgement <u>or</u> inability to function in most areas	10 (28)	7 (16)	17 (22)
Some danger of hurting self or others <u>or</u> occasionally fails to maintain personal hygiene (e.g. smears faeces) <u>or</u> gross communication (e.g. largely mute)	0 (---)	1 (3)	1 (1)
Persistent danger of severely hurting self or others <u>or</u> persistent inability to maintain personal hygiene <u>or</u> serious suicidal act	0 (---)	0 (---)	0 (---)
Total number of respondents	36	43	79

[†] Validator rating used if different to the rating determined by the researcher.

Table 6.18 Respondents willing to name general practitioners and significant others for interview

	Recruitment only sample (n=36)	Community sample (n=43)	Total Sample (n=79)
	No. (%)	No. (%)	No. (%)
Willing to name general practitioner (GP)			
Yes	27 (75)	35 (82)	62 (79)
No	6 (17)	7 (16)	13 (16)
Not answered	3 (8)	1 (2)	4 (5)
Willing to name 'significant other'			
Yes	28 (78)	31 (72)	59 (75)
No	6 (17)	11 (26)	17 (21)
Not answered	2 (5)	1 (2)	3 (4)
If answered 'yes', who?	n=28	n=31	n=59
Health Team Workers (e.g. ward staff, social workers, hostel workers)	14 (50)	22 (71)	36 (61)
Family	12 (42)	6 (19)	18 (31)
Friends	1 (4)	2 (7)	3 (5)
Not specified	1 (4)	1 (3)	2 (3)
Total number of respondents	36	43	79

6.4 Medication issues in hospital

6.4.1 Knowledge of medication

Most respondents (62, 78%) claimed to know the medication that they were taking (Table 6.19). However, less than half (33, 42%) could actually name all the medication they were taking. Medication knowledge did not differ significantly between the recruitment-only and community sub-samples.

Sixty respondents (76%) reported the total number of medication they were taking (see Table 6.20). Most commonly people (24, 39%) were taking a total of three different drugs. The total number of drugs prescribed was in accordance with the medical notes in 37 cases (61%).

Table 6.19 Self-reported ability to name prescribed medication

	Recruitment only sample (n=36)	Community sample (n=43)	Total Sample (n=79)
	No. (%)	No. (%)	No. (%)
Do you know what medication you are taking including any injections?			
Yes	29 (81)	33 (77)	62 (78)
No	7 (19)	10 (23)	17 (22)
How many known by name?			
All	18 (50)	15 (35)	33 (42)
Some	10 (28)	15 (35)	25 (32)
None	8 (22)	13 (30)	21 (26)
Total number of respondents	36	43	79

Over half of all respondents (35, 56%) named both oral and depot (intramuscular) antipsychotic medication. In 44 cases (86%) this information was in accordance with the medical notes. The route of administration for the antipsychotic medication did not differ significantly between the recruitment-only and community sub-samples.

Of those respondents who reported knowing their medication (n=62), 38 (53%) respondents named medication other than antipsychotic drugs in their total drug regime. Accordance with medical notes was gained in 37 cases (77%). Half of all respondents (31, 50%) reported taking a medication with anticholinergic action (prescribed to suppress the extra-pyramidal parkinsonian adverse effects that antipsychotic medication may cause - see Section 1.3). Accordance with medical notes was achieved in 43 cases (81%). The number of respondents who reported taking an anticholinergic medication did not differ significantly between the recruitment-only and community sub-samples.

Forty-two respondents (53%) named their depot antipsychotic medication. The most commonly named depot was flupenthixol decanoate (16, 26%). The named depot preparations were in accordance with medical notes in 41 cases (98%). Sub-samples were compared for receiving either flupenthixol decanoate, fluphenazine decanoate or 'other' depot (intramuscular) medication. Depot medication did not differ significantly between groups.

Table 6.20 Details of prescribed medication as reported by sample

	Recruitment only sample (n=36)	Community sample (n=43)	Total Sample (n=79)
	No. (%)	No. (%)	No. (%)
Reported knowing medication (Table 6.19)	n=29	n=33	n=62
Total number of medicines being taking			
1	2 (7)	4 (12)	6 (10)
2	11 (38)	9 (27)	20 (32)
3	11 (38)	13 (40)	24 (39)
4	4 (14)	2 (6)	6 (10)
5	1 (3)	3 (9)	4 (6)
Does not know number of medicines taking	0 (---)	2 (6)	2 (3)
In accordance with medical notes?	n=29	n=31	n=60
Yes	19 (66)	18 (58)	37 (61)
No	10 (34)	12 (39)	22 (37)
Information missing	0 (---)	1 (3)	1 (2)
Routes of antipsychotic medication named			
Depot (intramuscular) and oral	22 (76)	13 (40)	35 (56)
Depot (intramuscular) only	6 (21)	10 (30)	16 (26)
Does not know name of medication taking	1 (3)	10 (30)	11 (18)
In accordance with medical notes?	n=28	n=23	n=51
Yes	25 (89)	19 (83)	44 (86)
No	3 (11)	4 (17)	7 (14)
Total number of 'other' medication named[†]			
0	7 (24)	8 (24)	15 (24)
1	16 (55)	9 (27)	25 (40)
2	3 (10)	2 (6)	5 (8)
3	1 (4)	2 (6)	3 (5)
Does not know name of medication(s) taking	2 (7)	12 (37)	14 (23)
In accordance with medical notes?	n=27	n=21	n=48
Yes	20 (74)	17 (81)	37 (77)
No	7 (26)	4 (19)	11 (23)
Patient names 'other' medication with anticholinergic action[‡]			
Yes	15 (52)	16 (49)	31 (50)
No	12 (41)	10 (30)	22 (35)
Does not know name of medication taking	2 (7)	7 (21)	9 (15)
In accordance with medical notes?	n=27	n=26	n=53
Yes	23 (85)	20 (77)	43 (81)
No	4 (15)	5 (19)	9 (17)
Missing information	0 (---)	1 (4)	2 (2)
Total number of respondents	36	43	79

[†] Any medication without antipsychotic action. [‡] Medication with anticholinergic action may be prescribed to suppress the extra-pyramidal parkinsonian adverse effects that antipsychotic medication may cause.

Table 6.20 (ctd.) Details of prescribed medication as reported by sample

	Recruitment only sample (n=36)	Community sample (n=43)	Total Sample (n=79)
	No. (%)	No. (%)	No. (%)
Reported knowing medication (Table 6.19)	n=29	n=33	n=62
Name of depot (intramuscular) antipsychotic medication taking			
Flupenthixol decanoate	9 (31)	7 (21)	16 (26)
Fluphenazine decanoate	3 (11)	8 (24)	11 (18)
Zuclopenthixol decanoate	6 (21)	2 (6)	8 (13)
Pipothiazine palmitate	1 (3)	4 (3)	5 (8)
Haloperidol decanoate	1 (3)	1 (12)	2 (3)
Does not know name of medication taking	9 (31)	11 (34)	20 (32)
In accordance with medical notes?	n=20	n=22	n=42
Yes	19 (95)	22 (100)	41 (98)
No	1 (5)	0 (----)	1 (2)
Total number of respondents	36	43	79

6.4.2 Effect of medication on symptoms

Table 6.21 summarises the respondents' replies to the following open question:

'In your opinion, what difference has the medication, including your injection, made to the symptoms of your illness?'

About half of all respondents (41, 52%) described positive or beneficial effects of medication on their symptoms. A further 10 respondents (13%) reported both positive and negative effects. The χ^2 test of significance at the $p \leq 0.05$ level showed no significant differences between the two subgroups.

Later in the questionnaire, respondents were asked a more leading closed question:

'In your opinion, do you feel that medication helps the symptoms of your illness?'

Thirty-seven respondents (47%) reported that their medication helped the symptoms of their illness. (A similar number of positive responses was achieved with the open question above). Recruitment-only and community sub-samples were compared for their views on whether medication helped symptoms; there was no significant difference. Respondents were asked to describe in what ways their medication helped the symptoms of their illness (n=37) (Table 6.21). The most common reason was that the medication helped by decreasing the

symptoms.

Table 6.21 Respondents' perceived effects of medication on symptoms

Perceived effects of medication on symptoms reported by respondents	Recruitment only sample (n=36)	Community sample (n=43)	Total Sample (n=79)
	No. (%)	No. (%)	No. (%)
What difference has the medication, including your injection, made to the symptoms of your illness?			
Positive / beneficial effects of medication	18 (50)	23 (53)	41 (52)
Negative / detrimental effects of medication	10 (28)	7 (16)	17 (21)
Both positive and negative effects reported	5 (14)	5 (12)	10 (13)
No effect of medication on symptoms	3 (8)	8 (19)	11 (14)
Does medication help symptoms?			
Yes	18 (50)	19 (44)	37 (47)
No	11 (31)	14 (33)	25 (32)
Don't know	3 (8)	3 (7)	6 (7)
Missing information	4 (11)	7 (16)	1 (14)
Reasons how medication helps:	n=18	n=19	n=37
Decreases symptoms eg 'voices'	4 (22)	7 (37)	11 (30)
Feel better	5 (28)	3 (16)	8 (22)
Calms my nerves	5 (28)	3 (16)	8 (22)
Keeps me normal	1 (6)	3 (16)	4 (11)
Other reason [†]	3 (17)	3 (16)	6 (16)
Unable to give a reason	1 (6)	3 (16)	4 (11)
Total number of respondents	36	43	79

Note: Percentages of reasons do not equal 100 since respondents could give more than one answer.

[†] Other reasons: n=36 Case 69: "In a general way."; Case 85: "The medication just cleans my system from all the smoke and drink."; Case 15: "It helps to out me in the frame of mind that I can cope with it better. It doesn't get so intense." n=43 Case 31: "I get a good night's sleep."; Case 56: "Helped with the digestion problem."; Case 68: "The medicines help my tummy to settle.".

Respondents' answers were compared for the open and closed questions. Those respondents who reported the positive effects of medication during the open question were more likely to report 'yes' that medication helped their symptoms (closed question) (χ^2 test using Yates' continuity correction=4.466, $p=0.035$). Cohen's kappa was also calculated as a test of concordance between the two response sets (kappa=0.331; $p=0.016$). These tests illustrate consistency of reporting.

Testing the above responses with the measure of insight (Section 6.3.4) checked the validity

of their responses. Respondents who reported that medication had positive/beneficial effects on the symptoms of their illness (open question) were significantly more likely to have some insight into their illness (χ^2 test using Yates' continuity correction=6.008, $p=0.014$). Similarly, respondents who reported that medication helped their symptoms (closed question) were significantly more likely to have some insight into their illness also (χ^2 test using Yates' continuity correction=6.745, $p=0.009$).

6.4.2.1 Role of medication in managing symptoms

From a qualitative perspective, the respondents' comments illustrated a complex and inconsistent picture on the role of medication in managing their symptoms. This may be due to the confusion respondents had in defining their symptoms and illness and differentiating these from the adverse effects of medication.

1) Positive effects of medication on symptoms

Some respondents talked about the benefits of their medication on alleviating specific symptoms. This depended on the individual's ability to acknowledge and understand their illness, i.e. to have a degree of insight into their illness.

"Great difference [with medication]. It's kept me out as outpatient for years and years...Medication keep my mind and feet on the earth. When I don't take medication, voices come back. When take medication, don't have illness."

(Case 01)

"Better. All the fluidity has gone in my brain and in my thoughts. I am having no cerebral pain...this has helped me so much. On medication, all hallucinations, delusions gone."

(Case 09)

"It's made me more milder, not so tempestuous. Sometimes when I'm freaking out, it helps in life. It gives you a break and it gives me a break. It helped my brain to function right. It's kept myself from hurt."

(Case 33)

Other respondents described their medication in more general terms, as having a calming effect or enabling them to cope better.

"Help me to calm down. Help me mentally and physically, my mood, day by day."

(Case 43)

“It’s helping me...Calm me down a little bit...It’s helped me get over the nervous breakdown.”

(Case 82)

“It makes me calmer, not so hyperactive...If I’m angry, I would shout and swear. I would even howl like a dog. But on medication, I feel so calm, it’s hard to get angry.”

(Case 83)

2) Medication provides limited benefit on symptoms of illness

Some respondents commented on the positive effects of medication on symptoms, but added that some symptoms of their ‘illness’ remained.

“It means that my illness has improved slightly but not fully.”

(Case 04)

“Improve on your self, not in a 100% foolproof but in a small way.”

(Case 77)

“[Medication] suppresses them [symptoms] rather than cures them.”

(Case 34)

“It just pushes the illness down. Underneath, the illness is still there.”

(Case 86)

“This is the first time I’ve had the injection, still have the voices but they are quieter.”

(Case 12)

Sometimes, these residual ‘symptoms’ could be classed as adverse effects of medication.

“It’s made me better and worse. Better because my head is stronger. It helps the brain...Worse, it’s made my body worse. It affects me in a menial way.”

(Case 36)

“The injection helps a bit, but if I take it too often, I feel sweaty, sleepy, tired...”

(Case 49)

“I feel better, I’m getting better but there is some nervous energy.”

(Case 60)

Others talked of the transient positive effects of medication.

“Medication takes away the voices, for a little while anyway.”

(Case 31)

Some respondents distinguished between the effects of medication for treating their symptoms and those medicines prescribed to suppress the unwanted extra-pyramidal parkinsonian adverse effects induced by the antipsychotic medication (e.g. procyclidine,

orphenadrine, benzhexol).

“When they give me procyclidine or orphenadrine, it lifts my mood instead of me bending my head between my legs. I don’t see the injection helps. If I only take the injection, I’m still low. If I take orphenadrine, it gives me a lift and I feel much better.”

(Case 38)

“The Stelazine makes me worry. The injection makes me stagnant. Benzhexol stops me worrying, pecks me up...just the benzhexol. Since the benzhexol I feel a bit relaxed now.”

(Case 55)

3) No perceived effect of medication on symptoms of illness

Some respondents reported ‘blanket’ responses to questions about medication. The medication was of no help to their symptoms and medication either made no difference to the way they were feeling or made them feel worse. The measure of insight into their illnesses was considered for these cases: Cases 24 and 64 agreed to a nervous condition but gave delusional explanations and Case 71 denied having a nervous condition entirely.

“Don’t make any difference. Hasn’t cured me. Don’t get me right.”

(Case 24)

“It’s made no difference whatsoever. It hasn’t helped me one iota.”

(Case 64)

“I haven’t found any difference yet. Instead of feeling better, I feel worse.”

(Case 71)

Other respondents were more descriptive and differentiated between the effectiveness of medication for their mental health problems and the medication they were taking for physical illness. By comparison, Case 68 had some insight into her illness.

“...the chlorpromazine isn’t helping the voices...I don’t think the chlorpromazine is very good, not together with the Depixol...I think I’d be better off drugs except the thyroxine. I need something for low thyroid.”

(Case 68)

6.4.3 Unwanted effects of medication

Respondents were asked to report any problems with their medication, such as side-effects. Respondents’ descriptions were office-coded using known adverse effects of antipsychotic medication as a coding frame. However, it is acknowledged that there can be difficulty in differentiating between the adverse effects of medication and symptoms of schizophrenic

illness.

Table 6.22 shows that two-thirds of all respondents (52, 66%) reported experiencing unwanted effects from taking medication. The number of respondents experiencing unwanted effects did not differ significantly between sub-samples. Drowsiness/lethargy (17, 33%) and parkinsonian side-effects such as stiffness and tremor (17, 33%) were the most common unwanted effects reported.

Over half (27, 54%) of these respondents (n=52) subsequently reported that the unwanted effects affected activities they did or wanted to do (Table 6.23). When sub-samples were compared, those who reported that unwanted effects of medication went on to affect activities were significantly less likely to complete the community interview (χ^2 test using Yates' continuity correction=4.38; p=0.036).

Most commonly (17, 61%) the unwanted effects of medication affected physical/leisure activities. Later in the questionnaire, respondents were asked whether they felt that their medication or the symptoms they experienced affected the way they spent their days. Thirty-nine respondents (49%) reported that their days were affected; mostly affected in a negative way (36, 92%). On this occasion, there was no significant difference between the sub-samples for reporting that their medication or the symptoms they were experiencing affected their days.

The total sample (n=79) was analysed comparing those who reported unwanted effects of medication and those who reported, later in the questionnaire, that their medication or symptoms of illness affected their day. Analysis showed no relationship between those respondents who reported unwanted effects and those who reported that their medication or symptoms of illness affected their day (χ^2 test using Yates' continuity correction=3.21; p=0.073).

Table 6.22 Problems with medication as reported by the respondents

Do you have any problems with your medication or your injection, for example, side-effects?	Recruitment only sample (n=36)	Community sample (n=43)	Total Sample (n=79)
	No. (%)	No. (%)	No. (%)
Yes	24 (67)	28 (65)	52 (66)
No	12 (33)	15 (35)	27 (34)
Types of problems reported:	n=24	n=28	n=52
Drowsiness, lethargy	7 (29)	10 (36)	17 (33)
Extra-pyramidal effects: Parkinsonism	9 (37)	8 (29)	17 (33)
Extra-pyramidal effects: Akathisia	4 (17)	6 (21)	10 (19)
Ocular effects	4 (17)	1 (4)	5 (10)
Pain due to injection	1 (4)	3 (11)	4 (8)
Loss of concentration	3 (13)	1 (4)	4 (8)
Cardiovascular	2 (8)	2 (7)	4 (8)
Mucosal dryness	2 (8)	1 (4)	3 (6)
Gastro-intestinal	0 (---)	3 (11)	3 (6)
Temperature control	2 (8)	1 (4)	3 (6)
Extra-pyramidal effects: dyskinesia	0 (---)	3 (11)	3 (6)
Endocrine effects	2 (8)	1 (4)	3 (6)
Skin	1 (4)	1 (4)	2 (4)
Sexual functioning	0 (---)	1 (4)	1 (2)
Nasal congestion	0 (---)	1 (4)	1 (2)
Other effects [†]	5 (21)	5 (18)	10 (19)
Total number of respondents	36	43	79

Note: Percentages do not equal 100 since respondents could give more than one answer. Problems were office-coded according to the known adverse effects of antipsychotic medication. However, it is recognised that there can be difficulty differentiating between some adverse effects of medication and symptoms of schizophrenia.

[†]Other effects: n=36 Case 86: "Depressed."; Case 81: "Headaches."; Case 25: "I cannot sleep."; Case 71: "I couldn't talk well and I lost appetite as well."; Case 73: "Mixture, can't swallow it, makes me vomit. It's too strong." n=43 Cases: 04: "I was walking along one time and my legs collapsed underneath me."; Case 34: "Unbalanced sometimes, not in control...Feel totally bombed out, overstressed in an aggressive way..."; Case 35: "...I think they create dependence."; Case 64: "My head feels as if it's been stamped on."; Case 79: "Tablets make me feel bad. Just don't feel well after them."

Table 6.23 The consequences of taking medication and the symptoms of illness as reported by respondents

	Recruitment only sample (n=36)	Community sample (n=43)	Total Sample (n=79)
	No. (%)	No. (%)	No. (%)
Do the medication problems reported affect areas of living?	n=24	n=28	n=52
Yes	18 (75)	10 (36)	28 (54)
No	4 (17)	10 (36)	14 (27)
Unsure	0 (---)	2 (7)	2 (4)
Information missing [†]	2 (8)	6 (21)	8 (15)
Areas of living affected	n=18	n=10	n=28
Physical/leisure activities	13 (72)	4 (40)	17 (61)
Looking for work/working	3 (17)	5 (50)	8 (29)
Decreased motivation	3 (17)	2 (20)	5 (18)
Self-confidence	1 (6)	2 (20)	3 (11)
Relationships	2 (11)	1 (10)	3 (11)
Other effects [‡]	3 (17)	6 (60)	9 (32)
Does the medication or symptoms of illness affect your day?			
Yes	18 (50)	21 (49)	39 (49)
No	14 (39)	14 (32)	28 (36)
Missing information [†]	4 (11)	8 (19)	12 (15)
How is your day affected?	n=18	n=21	n=39
Positive ways	0 (----)	0 (---)	0 (---)
Negative ways	18 (100)	18 (86)	36 (92)
Positive and negative ways	0 (----)	1 (5)	1 (3)
Missing information	0 (----)	2 (9)	2 (5)
Total number of respondents	36	43	79

Note: Percentages do not equal 100 since respondents could give more than one answer.

[†]This question was a late addition to the questionnaire, therefore, not all respondents had the opportunity to respond.

[‡] Other effects: n=36 Case 16: "It's hard to put on my clothes when I've got a temperature."; Case 61: "Because all I do is sleep all day and night, or day instead of night."; Case 71: "I cannot eat." n=43 Cases: 23: "It affects the way I talk."; Case 49: "Feel sleepy."; Case 49: "Stops you washing my clothes and myself."; Case 58: It just makes me feel uncomfortable. It just makes you want to sleep than do anything else." Case 59: "I have to drink lager but I tried to give it up."; Case 64: "You can't think. Your emotions are stunted."

6.4.3.1 Consequences of adhering to medication

The quantitative analysis showed that respondents could describe specific unwanted effects of their medication. Respondents were also able to report the negative consequences of these

unwanted effects in terms of their everyday lives. Some respondents commented on their experiences of adhering to medication; others discussed the long term consequences of taking medication. These accounts provided an insight into the consequences of adhering to antipsychotic medication from the respondents' perspectives.

"Sometimes the medication makes me feel drugged up and makes me sleep. The medication is just a tranquilliser to help me sleep and that. Sometimes the pill makes me high. I can't read when I'm high. I can only read when I'm relaxed."

(Case 14)

"Sometimes it give me side-effects but I take a little sleep and it wears off. I used to take it when I was working. I asked to take the injection and go back into work and the woman had to send me home straight away for a rest. Other times I have to sit down and not do anything until it wears off because I'm drowsy and because of the pain..."

(Case 33)

"I used to feel a bit drowsy at home with the Depixol and like sweating and it makes you scratch...Feel sleepy. Stops you washing my clothes and myself. You need rest too, you need a lot of rest because of the illness and the treatment I'm getting causes that."

(Case 49)

"Feeling inside terrible. Stiff. Tight feeling in the head, more terrible than the body...restless. I can't work, do jobs because of side-effects. I want to go home all the time. I can't relax in any one place. Slowly losing enjoyment. The feeling happy in the body, slowly going away. The normal lack of healthiness."

(Case 78)

"I like to be active, sport, dance etc. and other studies. I can't concentrate any more...The injection making me too tired to do the things that cheer me up. They affect the way I conduct myself. They slow me down, slow my speech down and make me feel like I'm going to black out all the time. I'm very clumsy. I drop things. I fall over...I haven't got any confidence or any hope."

(Case 86)

"It made me feel stiff...My eyes get blurred and tired. It gave me a skin deformance some years ago, darkened and dry. It give me a temperature. It affects me doing sports. I can't run properly when I play badminton. It affects me doing the housework because I feel tired and a bit weak. I kind of can't see to do the work in my house and it's hard to put my clothes on when I've got a temperature."

(Case 16)

"It keeps knocking me out. I keep sleeping all the time and having horrible and hideous nightmares and feelings that I can't breathe and all those ...all I do is sleep all day and night or day instead of night...I don't do anything except sleep. I rarely get dressed. I can't do my washing. I have to have help to make my bed...I'm sleeping all the time. I only get dressed once in a blue moon. I can't function under this medication."

(Case 61)

“I can’t sleep the same night as the Depixol. I feel dog tired but not bed tired. Chlorpromazine, I find, makes my hay fever worse. I get stuffed up nose. I want to sneeze. I hear the voices but I don’t think it’s the side-effects. I’ve heard voices all my life. I’d like to get back to secretarial work... [They] stop me concentrating on the television...I just lay about most of the day in the hostel, all the time. It’s not very good for the piles or the arthritis.”

(Case 68)

“I can not write and I am stiff. I am stiff in my walking. I have to train myself to walk. The medication [procyclidine] makes the disabilities better. I find it difficult to sleep...I like walking. I feel I have to rely on public transport now or a car. I used to be able to cope without public transport as if it never existed, but I can’t now.”

(Case 77)

6.4.3.2 Other/physical health problems that are potential medication-related effects

When the respondents were asked if they had any other health problems or any physical health problems, some problems reported could have been attributed to the adverse effects of antipsychotic medication. When the same respondents were asked about their symptoms or the unwanted effects of medication, such as side-effects, these issues were not reported. These comments illustrated the misconceptions that respondents had in understanding their illness and their medication.

“Sometimes my legs are too stiff. I’m afraid to sit in the bath tub.”

(Case 01)

“I’ve got a blockage in my bowels. I have to take a liquid to help me go to the toilet properly.”

(Case 28)

“Sometimes passing water and [faeces] a problem. The things I passing not normal.”

(Case 78)

“My belly’s got bigger and I keep going to the toilet.”

(Case 43)

“Sometimes I feel very lazy. The inside feels blocked up sometimes.”

(Case 85)

6.4.3.3 Mistrust of medication, hospital and its staff

When talking about specific unwanted effects of medication, respondents also expressed their mistrust in medication. The mistrust of medication was often extended to mistrust and

negative feelings concerning the hospital environment and its staff. Sometimes, these feelings of mistrust were inextricably linked with the paranoid aspect of their illness. These comments highlighted the difficulties associated with treating such an illness and nurturing a partnership of trust between staff and their patients.

“[I think I have an illness] because they give me an injection. I feel all right if they stop this injection.”

(Case 03)

“[What do you think is the cause of your illness?] Don’t know. Could be side-effects.”

(Case 14)

“The injection gives me boils in my bottom...”

(Case 20)

“Unbalanced sometimes. Not in control, but not due to myself but sometimes due to medication. Feel totally bombed out, over stressed in an aggressive way. Not normal for me, therefore, due to medication...After 13 years, no education, no job, no use to society or the state...Normally [the symptoms] have happened when I’ve been taking the injection.”

(Case 34)

“I think they create dependence...It may be because I became dependent on the injections and when I stopped taking them I developed symptoms of mental illness...I can’t figure out the doctors’ opinions.”

(Case 35)

“I’m addicted to the diazepam because I’ve been on it for so long...I’m completely addicted to the benzhexol. I’ve been taking them for 20 years. I ran out of Artane. I smashed up the flat. I can’t stand it without the Artane. Diazepam is pretty bad, very bad if I run out of that as well.”

(Case 50)

“I don’t think the chlorpromazine is very good. Not together with the Depixol. I think that’s what got me here, mixing the two...I just feel as though I should be just on the thyroxine. I’ve got a sister-in-law who’s on thyroxine. She’s got high cholesterol and I do, but hers came down. You don’t know what the chlorpromazine and Depixol do. I mean they go into the blood. They may affect the cholesterol.”

(Case 68)

“I don’t believe those medicines can help me, they only make me depressed. [Medication] brings me into hospital every time. It gets me into trouble. I’m always changing my views, generally. I’ve changed from what I was before to something else. This has been happening to me since I’ve been on this medication. Before this medication it wasn’t happening...the injection gives me boils in my bottom. I’ve told the doctor and he says they’ve modified it, but they haven’t, I still get pain...It makes me depressed and sometimes wild, wondering what is going on. It makes me not be able to think properly... sometimes I can’t concentrate, may be, if I’m typing, I make a mistake...They only make me depressed...with the medication I couldn’t

do a job. If I was to tell them I was getting an injection, they would ask what is the matter with me and sack me...The tablet made me sleepy. I couldn't work like that, sleepy all the time. Sometimes they give me a different one, apart from the boils, I act very strangely."

(Case 20)

"I'm very ill under the medication...My physical appearance has been demolished as far as I'm concerned due to the medication and because of this and other effects, I haven't got any confidence or concentration or any hope. I haven't got an illness. They're saying I've got it...I believe talking therapy would cure it but I can't trust the doctors to be confidential or believe what I say. They've given me a cocktail of drugs which hasn't agreed with me. They've just taken my freedom away... An animal gets treated better."

(Case 86)

"[The medication has] altered the madness into another type of madness. Instead of having one type of madness. I've got a different type of madness now. Different but equally as bad. Coming off [the medication] straight away, I had withdrawal symptoms...I shall come off [the medication]. It doesn't suit me and on top of that, they give me too much."

(Case 61)

"The medicine has made me a disabled person...all my energy has been sucked out by the two injections they have given me. I am being treated against my will...They think they are very superior intellectual. I am totally nothing in their eyes."

(Case 77)

"If the injection overdose, if they put more that they should, if they don't measure it properly, I feel anxious and I can't go anywhere."

(Case 60)

6.4.4 Experience of non-adherence to medication

Table 6.24 illustrates that over three-quarters of the respondents (60, 76%) reported experiencing feelings of previously wanting to stop their medication. Feelings of previously wanting to stop medication were not related to respondents' insights into their illnesses.

The experience or fear of side-effects (19, 32%) was the most common reason for wanting to stop medication, followed by the view that medication was either unnecessary or unhelpful (15, 25%). The number of respondents wanting to stop their medication did not differ significantly between the sub-samples. Twenty-three respondents (38%) who claimed that they had wanted to stop their medication in the past, reported that they had never actually stopped it. Of those who reported that they had stopped their medication, the most commonly perceived outcome was that nothing had happened (13, 21%).

Table 6.24 Experience of non-adherence to medication as reported by the respondents

	Recruitment only sample (n=36)	Community sample (n=43)	Total Sample (n=79)
	No. (%)	No. (%)	No. (%)
Experienced feelings of wanting to stop medication in the past			
Yes	27 (75)	33 (77)	60 (76)
No	8 (22)	10 (23)	18 (23)
First time prescribed this medication	1 (3)	0 (---)	1 (1)
Reasons why wanted to stop medication	n=27	n=33	n=60
Potential/experienced unwanted effects	10 (37)	9 (27)	19 (32)
Not helping/unnecessary/makes no difference	8 (30)	10 (30)	18 (30)
Medication unsuitable eg injection painful, too much medication	5 (14)	2 (6)	7 (12)
Fed-up/can't be bothered/don't feel like having it	1 (4)	5 (15)	6 (10)
Wanted to try without medication/trying to prove sickness	2 (7)	1 (3)	3 (5)
Forgot to take it	0 (---)	2 (6)	2 (3)
Other reason [†]	0 (---)	2 (6)	2 (3)
Not answered	2 (7)	5 (15)	7 (12)
Consequence of non-adherence to medication	n=27	n=33	n=60
Nothing	5 (19)	8 (24)	13 (21)
Became ill / symptoms worsened	6 (22)	5 (15)	11 (18)
Felt better	4 (15)	0 (---)	4 (7)
Felt better initially and then became ill	2 (7)	2 (6)	4 (7)
Started taking it again (own decision)	2 (7)	1 (3)	3 (5)
Started taking it again (health professional follow-up)	0 (---)	1 (3)	1 (2)
Never actually stopped taking medication	8 (30)	15 (46)	23 (38)
Not answered	0 (---)	1 (3)	1 (2)
Total number of respondents	36	43	79

Note: Percentages do not equal 100 since respondents could give more than one answer.

[†] Other reason: n=43 Case 04: "Because the guy I was living with told me, only a friend, he said it was no good for you. He'd stopped taking it."; Case 33: "They [the hospital] told advised me to stop taking my medication."

Medical notes were examined for a record of stopping medication at the time of admission. This was compared with the number of respondents who wanted to stop their medication at the time of the recruitment interview. There was no relationship using the chi-squared test for significance ($p \leq 0.05$). Those respondents who reported wanting to stop their medication in the past were no more or less likely to be recorded as having stopped their medication at

the time of admission in their medical notes.

Respondents added illustrative comments concerning their experiences of non-adherence to medication. From their experiences, some respondents had gained an informed insight into the benefits of medication by relating the outcomes of either adhering to or experimenting without their medication.

“I went without injection and I suffered. I go too high, out of reality.”

(Case 01)

“...the guy I was living with told me,...he said it was no good for you. He’d stopped taking it. I stopped taking it for a short period of time but then I started taking it again because I felt the need to get better.”

(Case 04)

“I thought I could do without it. I felt sick again eventually.”

(Case 30)

“Sometimes I just leave it. I just forget it. When I don’t have the injection, I lose contact with reality.”

(Case 72)

“Worse without the injection. The voices told me I had too many medicines in the body and not enough of the natural things...The first two weeks, it’s all right, not 100%, but later, become more, problem bring back in the head.”

(Case 78)

“If I’m home and discharged I don’t always feel like going for the injection. I skipped one and nothing really happened. I continued with the next one. It takes 2 to 3 months of not taking it before I get really sick.”

(Case 38)

“Because some days I felt I didn’t need them but then in the next few days I shake a lot and hear the voices. It’s horrible and it’s then I take them. You’ve got to take them then.”

(Case 69)

“When I feel like I’m back to myself again. I don’t feel like taking it. I don’t feel I need it. Skipped it three weeks or a month sometimes. I get depressed and ill again. I’ve noticed when I stop the injection but take the two tablets, I don’t get depressed.”

(Case 85)

Other respondents had gained no insight into their illness by experimenting with their medication regime but described the benefits of stopping their medication in terms of improved functioning.

“I just got fed-up. I skipped it and went out to work, four or five years ago.”

(Case 14)

“Been without it for one and a half years. Everything was fine.”

(Case 87)

“When I stopped taking it for good, sometimes I was getting better, feeling better, feeling content. Don’t feel like making any bad mistakes. I tried to get on with people. I couldn’t keep up with the medication or injections because I didn’t feel well to take it. Because I came off part of it, I was feeling hot on my face. I had a temperature. I felt much better when I stopped taking it.”

(Case 16)

“Because I felt it was about time, I stopped it about 4 years ago. *[What happened?]* Nothing. I just felt it was about time I lead a normal life.”

(Case 88)

6.4.4.1 Consequences of illness

By stopping their medication, some respondents had gained some insight into the torment their illness can cause and its effect on everyday living.

“Every pause on the radio, I think I heard a shout from the kids as if they know when there is a pause. Everything really, I can’t watch tv, I know people are going to disturb me when I watch it.”

(Case 50)

“I like to be up and about. My illness cost me my job...I used to be a care assistant for an elderly person with Newham Council.”

(Case 30)

“Working problems. I wasn’t attending work, I was on sick leave. I lost interest in my work. I don’t know why, perhaps because I was developing mental illness.”

(Case 35)

“I like painting. I like horse riding. I like animals. I used to work for the RSPCA. I used to take in the road accidents. I don’t do these any more.”

(Case 47)

“I wouldn’t go out so often and I did feel suicidal quite a few times because of the recurrence of being in the vicinity of people with problems.”

(Case 18)

6.4.5 Behaviour of respondents in managing their medication

Some respondents made additional comments in response to the open questions of the recruitment interview that gave some insight into how they interacted with their medication. Comments were annotated with descriptive labels and analysis proceeded by grouping the descriptive labels according to common issues. This process developed a classification

system for the behaviour of the respondents in managing their medication: passive acceptance, active participation, ignored participation, reluctant acceptance and conditional acceptance. However, other respondents did not make any additional comments and therefore were not included in the qualitative analysis.

The behaviours of the medication-takers had many facets moulded by the respondents' experiences and views of their medication. Their perceptions of the benefits and unwanted effects of their medication and subsequently the consequences of adherent or non-adherent behaviour contributed to their medication management behaviour. Throughout the interviews, the respondents reported how they responded to their experiences and interchanged between different management strategies. The behaviours were not exclusive to individual clients with some respondents describing more than one type within the same interview. In particular, passive acceptance overlapped with ignored participation suggesting that individuals wanted to be involved but sometimes they resigned to being ignored which led to a more passive acceptance of their medication. Also, conditional acceptance of medication overlapped both with ignored participation and reluctant acceptance suggesting that respondents were putting conditions on their acceptance as a means of trying to regain 'control'. The behaviour of the respondents expressed at the time of the recruitment interview must be considered in the knowledge that all respondents were in-patients and had little autonomy in managing their medication.

1) Passive acceptance of medication

A 'doctor knows best' attitude best describes the passive acceptance of medication. These respondents talked about 'drifting along' with their medication without questioning or thinking about them. They did not participate in the management of their medication or suggest any changes to their medication regime. The four cases below had little or no insight into their illness (Section 6.3.4).

"The doctor tell me what I need and suppose it does me good."

(Case 11)

"I'm just drifting along. I've been on Depixol 12 or 13 years. It's been like a dream with pictures."

(Case 34)

“I don’t know what effect the drugs have. I’ve never been off them for any length of time. I’m on them constantly. I’ve never been off them for any length of time since 1976...I don’t know what it’s like to be off medication.”

(Case 35)

“I don’t worry. I just take it as a normal thing.”

(Case 54)

2) Active participation in managing medication

Respondents described as ‘active participants’ demonstrated informed behaviour when managing their medication. Their comments illustrated a risk-benefit approach to assessing their medication, which informed their decisions about the medication. They described consequences of adhering and not adhering to medication that drove their sense of autonomy and personal control. Generally, they had experienced unwanted effects of medication that had either resolved or they had changed medication and experienced greater benefit. Seven of the respondents below had some insight into their illness. The remaining two respondents (Cases 72 and 63) had little or no insight according to the earlier questions (Section 6.3.4).

“I stopped taking it for a short period of time but then I started taking it again because I felt the need to get better.”

(Case 04)

“After a week, it gets rid of all the faces but you’ve got to keep having it, once a week regularly, otherwise the faces come back.”

(Case 28)

“It’s helped me recover from schizophrenia. Generally, it helps me sleep at night. It causes a bit of stiffness, the injection does for the first couple of days.”

(Case 66)

“I feel fine because I know what it does now. It’ll stop me getting ill again.”

(Case 70)

“When I don’t have the injection, I lose contact with reality...[Injection] keeps the illness under control.”

(Case 72)

“I used to stop taking it before and relapse. [It] stops the voices, soothes my nerves and calms me down.”

(Case 63)

“When I don’t take it I get sick. When I take it I’m all right. I can go on for a few years or so.”

(Case 38)

3) Ignored participation in managing medication

While ignored participants wanted to participate in managing their therapy, they perceived that others disregarded their opinions. They felt that they had no involvement in suggesting alterations to their medication regime. Often they thought that the medication did not do them any good but they were formally expected to take the medication. (Forty-eight (61%) respondents were detained at hospital under a section of the Mental Health Act 1983 at some point during their admission). Of the respondents below, all but one (Case 15) had little or no insight into their illness (Section 6.3.4).

“Need Kemadrin for side-effects but they don’t give me it...I want something to make me sleep. After a week I need my injection. I don’t need the 80mg, but now it’s down to 40mg. I might need about 50. I had 40mg last time.”

(Case 01)

“Only had treatment since being here. It’s too frequent. I could do with it every month instead of every two weeks.”

(Case 08)

“I don’t want any of it. I feel better without it.”

(Case 79)

“[The medication has] made me worse because the injection gives me boils in my bottom. I’ve told the doctor and he says they’ve modified it but they haven’t, I still get pain.”

(Case 20)

“I’ve asked to change [the medication] but they don’t take much notice of you in hospital...Stelazine makes me worry a lot. I want to stop that and the injection and only take the benzhexol...I want different medicines so I can enjoy myself. I can’t watch tv. The wireless gets on my nerves. I’m all tensed up.”

(Case 55)

“It used to help before, but I had a great massive dose last year which made me stop because I had a hard lump. I’d rather take oral medication, capsule form or tablets...At times I wanted my injection at greater time intervals...The injection does help but you don’t need such vast quantities so often. I’d like to try the capsules some time.”

(Case 15)

“I don’t think I need it. I don’t think I want to be on it. I’m not sick in the way I need medication. My illness does not require any medication.”

(Case 87)

“Don’t like it. I don’t believe in tablets and injections. I don’t think I need it.”

(Case 75)

“It’s against my principles to inject tranquillisers. I was put on tranquillisers when I was well and I think they create dependence...I’m on too high a dose.”

(Case 35)

“For me, they give me these against my will...There was no option.”

(Case 40)

“It’s not my decision. I have to have it. I do feel like saying what’s the point sometimes.”

(Case 83)

“I was forced to take the injections...I was normal and the normality has been taken away from me. I don’t know if I will recover. The doctors speculate that I will recover and will become normal again and will benefit from all the suffering.”

(Case 77)

4) Reluctant acceptance of medication

The reluctant acceptor is different from the ignored participant since a passive role existed alongside the negative feelings associated with the medication. Respondents expressed a grudging acceptance to take their medication. They may have wanted to stop their medication but were unlikely to have stopped it. There was an underlying acceptance that they needed the medication either in their own eyes or following instructions from staff. Experience of unwanted effects promoted this role however, ‘staff-effects’ dominated. Respondents did not think that they necessarily needed the medication, but they would not go against the doctors’ wishes. All the respondents below had little or no insight into their illness (Section 6.3.4).

“Yes [I feel like stopping my medicines] but I still have it.”

(Case 22)

“*[In your opinion what difference has the medication, including your injection, made to the symptoms of your illness?]* Don’t know. I didn’t feel ill before and now I feel zonked, tired.” *[Have you ever felt like not taking your medication or not having your injection?]* Yes because I thought it may be painful. It is sometimes. [Not stopped].”

(Case 27)

“*[Have you ever felt like not taking your medication or not having your injection?]* Yes frequently but I’ve not managed to skip one yet without being reprimanded.”

(Case 45)

“I think I don’t need it anymore. *[Have you ever skipped an injection?]* I wouldn’t do that...I’ve got no choice but I don’t want it.”

(Case 59)

“Just fed-up with having it.”

(Case 67)

“I’m hoping that medication will become less for me.”

(Case 74)

“It makes a difference but I’ve got misgivings because I get fed up because of the side-effects. I know I’ve got to have it though.”

(Case 57)

“Because some days I felt I didn’t need them but then in the next few days I shake a lot and hear the voices. It’s horrible and it’s then I take them. You’ve got to take them then.”

(Case 69)

5) Conditional acceptance of medication

A couple of respondents were ‘conditional acceptors’ of medication. The only reason for taking the medication was that it was hospital-only treatment. Each of these respondents denied that they had a nervous condition (Section 6.3.4).

“Only had treatment since being here. It’s too frequent. I could do with it every month instead of every two weeks. [It’s made] no difference. I don’t refuse. I’ve only been here two months. I don’t know how long I’ll be on it...It’s only whilst I’m in hospital they said.”

(Case 08)

“[Will you be taking medication or having an injection after you have been discharged?] No. It all ends here [in hospital].”

(Case 67)

6.4.5.1 Behaviour influencers: hospital staff commanders

Respondents linked perceptions of their behaviour in managing medication, in particular the ignored and reluctant participants, to their views of staff. A definite lack of autonomy was expressed. Hospital staff were viewed as ‘in control’, making the decisions about medication and ignoring any information from the respondents. These views may also have been tied in with the distorted perceptions and mistrust of the staff resulting from the acute psychotic episode. All but one (Case 68) of the respondents had little or no insight into their illness (Section 6.3.4).

“Need Kemadrin for the side-effects but they don’t give me it.”

(Case 01)

“For me, they give me these against my will...I should be searching for jobs but not staying here. This is controlled by the discharging...There has to be a period of

reducing the dose. They can't stop it quickly. Since they said that they can't stop it quickly, they will see over time that I won't need it. I am under a no discharge condition."

(Case 40)

"...not managed to skip one yet without being reprimanded."

(Case 45)

"I think it does me good to take [medication] but I'm worried I have to take them for the rest of my life. If doctor thought I could reduce them, that would be okay."

(Case 68)

"I was told I should have it."

(Case 20)

"I've asked to change it but they don't take much notice of you in hospital."

(Case 55)

"I was forced to take the injections...It's a very difficult argument with the doctors. They think they are very superior intellectual."

(Case 77)

6.4.5.2 Behaviour influencers: community staff

Some respondents also perceived that relationships with community health care staff were tenuous. One of these respondents had some insight into her illness (Case 33) but the other respondent did not.

"[General practitioner] He doesn't bother about me. I just go for sleeping tablets."

(Case 01)

"Other times I have to sit down...because of the pain because some of the nurses couldn't give it properly. So then I went to the GP to take the injection then. Then I've been coming to the hospital lately. You can't depend on some of the nurses. The following week you never see the same one so I just cut it out."

(Case 33)

6.4.6 Therapeutic information gaps expressed by respondents

During the interviews, many indirect questions, worries and misconceptions were expressed by the respondents about their illness and its therapy.

"I don't know how long I'll be on it [medication]."

(Case 08)

“[What do you think is the cause of your illness?] Don’t know. Could be side-effects.”

(Case 14)

“But after I leave hospital, say in about three weeks, I probably won’t want it but it’s not because I don’t want it. It’s because why I need it. I’ll wonder why I’ll have to have it done after I leave hospital.”

(Case 62)

“I think it does me good to take them but I’m worried I have to take them for the rest of my life... You don’t know what the chlorpromazine and Depixol do. I mean they go into the blood. They may affect the cholesterol.”

(Case 68)

“Stiffness, toes are closed in, my legs are hurting me. I’m not sure if that’s side-effects of the medication.”

(Case 83)

“I don’t know if I will recover.”

(Case 77)

“Slurred speech, lapse in concentration, tendency towards excessive slumberiness. When will all these side-effects be cleared and when will I return to normal? I don’t know how it’ll affect me when I want to go to work.”

(Case 76)

“I don’t mind taking the tablets but if they say I have to take the injection I aint too sure what to do then. Because I feel like I’m going to be dependent on it. Dependent all the time like.”

(Case 85)

“...with the drowsiness and stiffness, there isn’t much mobility, it makes you slow to things. I find I aint got the will power to do activities. I’m not too sure if that’s the medication or me.”

(Case 42)

6.4.7 Intentions of medication adherence after discharge

Most patients (63, 80%) reported that they intended to take their medication after discharge from hospital (Table 6.25). Almost one quarter of these (15, 24%) felt all right or indifferent about this. Ten respondents (16%) felt they had no choice.

Intentions to take medication after discharge did not differ significantly between the sub-samples. Formal or informal in-patient status did not influence the intention to take medication after discharge.

Table 6.25 Intentions of medication adherence after discharge from hospital

	Recruitment only sample (n=36)	Community sample (n=43)	Total Sample (n=79)
	No. (%)	No. (%)	No. (%)
Intention of taking medication after discharge from hospital			
Yes	28 (78)	35 (81)	63 (80)
No	2 (5)	5 (12)	7 (9)
Don't know	6 (17)	3 (7)	9 (11)
How do you feel about taking medication after discharge from hospital?	n=28	n=35	n=63
All right / indifferent	8 (29)	7 (20)	15 (24)
Obliged / no choice	5 (18)	5 (14)	10 (16)
Conditional response (e.g. "As long as it doesn't make me drowsy.")	4 (14)	3 (9)	7 (11)
Unhappy	2 (7)	4 (11)	6 (9)
Happy	3 (11)	2 (6)	5 (8)
Unsure	1 (3)	1 (3)	2 (3)
Information missing [†]	5 (18)	13 (37)	18 (29)
Total number of respondents	36	43	79

[†]This question was a late addition to the questionnaire, therefore, not all respondents had the opportunity to respond.

When respondents discussed their decisions about whether they intended taking medication after discharge, they addressed a range of issues. Respondents sometimes discussed the implications of taking medication in a global way, in terms of their everyday lives. Others illustrated the role they intended to have in managing their medication and the relationship they wanted with health care professionals. Few had 'partnerships' with their medication prescribers where they felt empowered to make decisions regarding their medication. Most felt that being discharged into the community was an opportunity to express their autonomy and decided either not to take their medication or to conditionally accept it.

1) Passive acceptance of discharge medication

These respondents devolved responsibility to the clinicians and reported that they would be taking their medication. Cases 48 and 56 denied having a nervous illness where as Case 49 had some had insight into her illness (Section 6.3.4).

“I’ll just take it.”

(Case 48)

“*[Will you be taking medication or having an injection after you have been discharged?]* Don’t know. It’s up to the doctor.”

(Case 49)

“*[Medication]* Don’t make no difference. It doesn’t do me any good. Don’t like the needle. *[Will you be taking medication or having an injection after you have been discharged?]* Yes. Just take it as normal.”

(Case 56)

2) Active participation in managing discharge medication

Few respondents presented a risk-benefit analysis with the intention to adhere to their discharge medication. Comments supported agreement to take medication after discharge, but they did not suggest long-term adherence. Case 66 had some insight into his illness but Case 88 gave delusional explanations as an explanation for his illness (Section 6.3.4).

“Feel good about [taking medication after discharge] because I’d get residual symptoms if I stopped immediately.”

(Case 66)

“Yes. At the moment I’ll have to get out there and fight again. It’s helping at the moment.”

(Case 88)

3) Reluctant acceptance of discharge medication

At the time of recruitment interview, some respondents suggested that they would be grudgingly adherent with their medication regimes in the community. Whether this behaviour translates after discharge, in the community, when respondents will be responsible for their own medication-taking behaviour will be presented in Section 7.3.6. All but one (Case 68) had little or no insight into their illness (Section 6.3.4). Most of the ‘reluctant acceptors’ expressed a lack of autonomy.

“Even when I’m not under section I have to have it to stay out of hospital. It’s not my decision like I say. I don’t really want to have the injection but I have to.”

(Case 83)

“Yes, because the doctor says so. I have no option but to take it.”

(Case 77)

“If I stop taking them, there is nothing wrong with me. *[Will you be taking medication or having an injection after you have been discharged?]* Yes. I regret it. I’d rather be free from tranquillisers...I’m on too high a dose. I don’t know what it’s like to be off medication. I think I’d like to go off medication or have it

reduced. I had a lot of problems. How can you decide the cause of your problems?”
(Case 35)

“I’ll just have to take it.”
(Case 60)

“I will do if I have to. If they lower it and take me off it, that’s all well and good.”
(Case 68)

“[Will you be taking medication or having an injection after you have been discharged?] I’ve got no choice but I don’t want it.”
(Case 59)

Other respondents either did not want to take their medication, described the practical problems of presenting for their medication, related their decisions to the side-effects they were experiencing or commented on the chronic nature of their illness. All but one respondent (Case 42) denied experiencing a nervous illness (Section 6.3.4).

“Yes. I don’t like the idea but I’m still taking it.”
(Case 75)

“Yes. It’s usually in the morning. I usually feel a bit rough when I go for it. It’s all a bit of a bind. I know if I don’t have it, I’ll go from bad to worse. Just fed-up with all the medication.”
(Case 57)

“Yes. I feel not happy because the side-effects. I use procyclidine sometimes. It helps a little better.”
(Case 76)

“I don’t normally but I have to this time because I keep relapsing. I aint got no choice. I have to take the medication if I’m going to be well.”
(Case 42)

4) Conditional acceptance of discharge medication

Some respondents were aware of their pending increase in autonomy after discharge and listed caveats to agreeing to taking their medication. These conditions mainly included specific forms of antipsychotic medication or depended on the experience of side-effects. All the respondents had little or no insight into their illness (Section 6.3.4).

“I want to have tablets. I’d take the Stelazine, the procyclidine but I really wouldn’t want to take the injection because it’s making me ill.”
(Case 86)

“Tablets only. I like taking tablets.”
(Case 43)

“Yes. I don’t mind taking the tablets but if they say I have to take the injection I aint too sure what to do then.”

(Case 85)

“So long as it doesn’t make me feel drowsy.”

(Case 58)

“Don’t know, depends what I say to him [the doctor], how I feel.”

(Case 55)

5) Autonomy in managing discharge medication

Other respondents also aware of the greater autonomy afforded to them by living in the community, did not express conditional acceptance of discharge medication but suggested that they would be non-adherent after discharge. Some reported that there was no perceived benefit to taking their medication while others either ignored the potential need for medication and highlighted the negative consequences of adhering to medication. Not surprisingly, all respondents had little or no insight into their illness (Section 6.3.4).

“If I knew it could get me right, I’d take them, but it doesn’t get me right. I’d say what’s it for?”

(Case 24)

“I’m not too sure. There’s a possible chance that I will have injections. Either they’ll send nurses around or they’ll send me to the Hackney Hospital for injections. I can’t really say how I’d feel because at the moment I’m all right. But after I leave hospital, say in about three weeks, I probably won’t want it but it’s not because I don’t want it, it’s because why I need it. I’ll wonder why I have to have it done after I leave hospital.”

(Case 62)

“No. I shall come off it. It doesn’t suit me and on top of that, they give me too much.”

(Case 61)

“They’ll expect me to. I prefer to do more useful things. I don’t like illness. I don’t want to spend all my time nurturing this illness. I want to do something positive...I don’t want to keep using Hackney [hospital] once a month for an injection.”

(Case 34)

“Usually I wait three months and then I stop taking it. I wean myself off it for three months, then I stop taking it.”

(Case 87)

“Occasionally. Practically, I would like to have children when I’m off medication. I am well enough to look after children, a house. It’s very hard for me to say yes, because when I take them I feel dead.”

(Case 16)

CHAPTER 7 COMMUNITY INTERVIEW AND MEDICATION ISSUES IN THE COMMUNITY

7.1 Introduction

Seventy-nine respondents successfully completed the recruitment interview. Seventy-one respondents were discharged from hospital during the data collection period (see Figure 6.1). The length of in-patient admissions ranged from less than 1 week to greater than 1 year (see Table 7.1). Approximately one third of the patients were admitted for less than 2 months (23, 32%), one third for between two and six months (27, 38%) and another third for 6 months or greater (21, 30%).

Table 7.1 Length of stay in hospital

	Discharged but not followed-up sample (n=28)	Discharged and followed-up community sample (n=43)	Total Discharged Sample (n=71)
	No. (%)	No. (%)	No. (%)
Length of in-patient admission:			
less than one week	1 (4)	0 (---)	1 (1)
1 week < 2 weeks	0 (---)	1 (2)	1 (1)
2 weeks < 4 weeks	2 (7)	2 (5)	4 (6)
4 weeks < 2 months	6 (21)	11 (25)	17 (24)
2 months < 3 months	6 (21)	8 (19)	14 (20)
3 months < 6 months	5 (18)	8 (19)	13 (18)
6 months < 1 year	7 (25)	11 (25)	18 (26)
1 year or more	1 (4)	2 (5)	3 (4)
Total number of respondents	28	43	71

Forty-three respondents out of the remaining 71 were successfully followed-up in the community (two of whom only part completed the community questionnaire) (see Figure 6.1). Primarily, this chapter will discuss the characteristics of the discharged sample (n=71), making comparisons where appropriate, between those who completed the community questionnaire (n=43) and those who did not (n=28). The chapter will then focus on the community sample (n=43, or n=41 for those questions after which Cases 23 and 53 withdrew consent for the study).

7.1.1 Medication characteristics of the discharged sample

Table 7.2 illustrates the details of the discharged medications prescribed for the sample. Most commonly (55, 78%), respondents were discharged with 3 or fewer different medications, including the depot (intramuscular) antipsychotic medication. Approximately, half the sample (38, 52%) was prescribed both oral and depot (intramuscular) antipsychotic medication. Characteristics of discharge medication did not differ significantly between those who were followed-up with a community interview and those who were not.

Table 7.2 Details of the medication prescribed at discharge taken from the medical notes

	Discharged but not followed-up sample (n=28)	Discharged and followed-up community sample (n=43)	Total discharged sample (n=71)
	No. (%)	No. (%)	No. (%)
Total number of medication			
1	6 (22)	8 (19)	14 (20)
2	6 (22)	13 (30)	19 (27)
3	10 (35)	12 (28)	22 (31)
4	4 (14)	6 (14)	10 (14)
5	2 (7)	4 (9)	6 (8)
Routes of antipsychotic medication			
Depot (intramuscular) and oral	16 (57)	21 (49)	37 (52)
Depot (intramuscular) only	12 (43)	22 (51)	34 (48)
Name of depot antipsychotic medication			
Flupenthixol decanoate	13 (46)	15 (35)	28 (39)
Fluphenazine decanoate	5 (18)	12 (28)	17 (24)
Zuclopenthixol decanoate	8 (28)	9 (21)	17 (24)
Pipothiazine palmitate	1 (4)	5 (11)	6 (9)
Haloperidol decanoate	1 (4)	2 (5)	3 (4)
Number of 'other' medication[†]			
0	9 (32)	14 (33)	23 (32)
1	12 (43)	17 (39)	29 (41)
2	6 (21)	4 (9)	10 (14)
3	1 (4)	8 (19)	9 (13)
Total number of respondents	28	43	71

[†] Other medications do not have antipsychotic activity.

7.2 Community interview

This chapter will discuss the outcomes of the 43 respondents who were followed-up with a community interview. Chapter 6.2 discussed the characteristics of the community sample (n=43).

7.2.1 Problems associated with the follow-up period

The community interviews took place between March 1994 and May 1995. Figure 7.1 illustrates the timing of the community interviews in relation to the other data collection tasks. Respondents were followed-up between 90 and 342 days after discharge. One hundred and thirty two days after discharge was the median value (just less than 4½ months). Table 7.3 shows the distribution of the follow-up period, from discharge to the community interview.

Table 7.3 Time from discharge to follow-up interviews in the community

	Community sample (n=43)
	No. (%)
3 months	3 (7)
> 3 months < 4 months	11 (26)
≥ 4 months < 5 months	16 (37)
≥ 5 months < 6 months	3 (7)
≥ 6 months	10 (23)
Total number of respondents	43

Notes: (365÷12) days define one month.

If the community questionnaire required more than one visit to complete, the date of the first meeting was taken as the follow-up date.

The research protocol stipulated that the discharged sample would be followed-up three months after the discharge date. In reality, this did not occur due to many reasons often associated with the individual circumstances of the respondent. The greatest stumbling block was the ruling by the ethics committees that the researcher was unable to attend respondents' own homes unaccompanied. For those respondents who attended a clinic for their depot

medication (25, 58%), the researcher would arrange to meet the respondent at the clinic on the date when the next medication dose was due (Table 7.15). On occasions, this could be up to one month later.

A concurrent problem with meeting the respondents at their depot clinic was that the hospital-based clinics had an 'open-clinic' which meant that the respondents could present for their depot medication anytime, between 9.00 am and 5.00 pm. Similarly, this was a problem if the hospital ward expected the respondent to return for their depot medication. Although the researcher stipulated a meeting time in the letters to respondents, the respondents would present according to their own schedule. This resulted in the researcher often waiting many hours to meet a respondent, while some respondents did not attend that day but presented on another day that same week. For the latter respondents, the researcher would have to wait up to another month (the next prescribed dose of depot antipsychotic) for the next opportunity of meeting them (Cases 01, 21, 08, 24, 27, 30, 33, 35, 36, 53, 56).

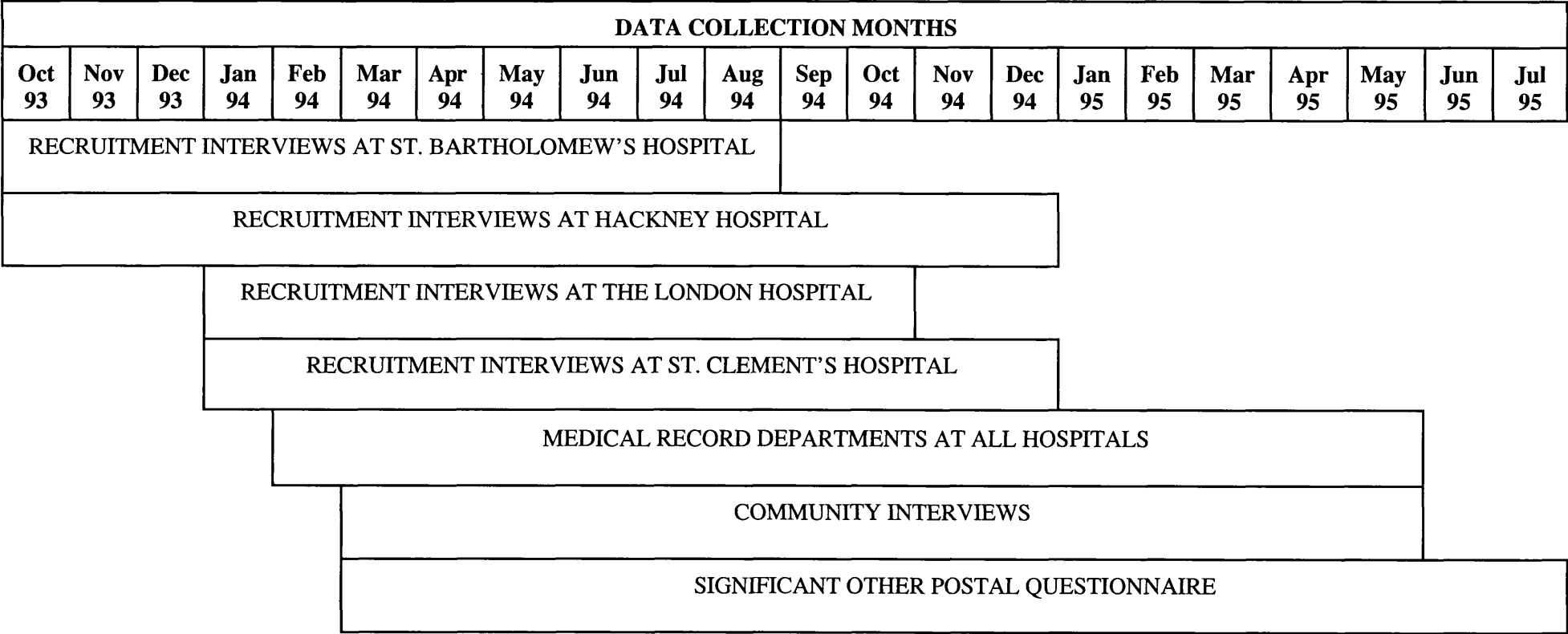
Other reasons for late follow-up included:

- Respondent changed her name after discharge and so there was a delay in identifying her medical notes in the record department (Case 04).
- Respondent was readmitted before the three-month follow-up date. For these individuals, owing to the restricted period available for the community interviews, they were interviewed as soon as they were discharged the second time. Medication adherence was calculated from the primary discharge date. It is acknowledged that this sub-sample has a biased rate of adherence since when in-patients, they were not responsible for their own medication-taking behaviour (Cases 31, 70).
- Discharge date not written in notes nor recorded on the computer (Case 36).
- Not in when called for a home visit (Case 11, 31, 33, 46, 56).
- Change of address not recorded in medical notes (Case 08, 34, 64).
- Change of Consultant after discharge due to setting-up of Locality Mental Health Teams. Permission required from new Consultant (Case 49).
- Over-protective staff. Community Psychiatric Nurse thought that the patient would not want to be bothered. Accessed the patient through another community health care worker (Case 50).

- Stopped medication (Cases 08, 09, 11, 45, 56, 58).

Ten (23%) cases took six months or more to complete a successful community interview (Cases 08, 11, 22, 29, 33, 35, 36, 50, 56, 68. For case reports see Appendix Eleven). The difficulty in establishing community care plans and the time-consuming task of negotiating with community health staff members accounted for the extended follow-up period for these respondents. Figure 7.1 illustrated that often these interviews were taking place simultaneously with recruitment interviews, visits to medical records departments and a postal questionnaire to 'significant others'.

Figure 7.1 Schematic representation of data collection period



One meeting was frequently insufficient for the respondents to complete the community interview (19, 44%) (see Table 7.4). In total, the researcher arranged and attended 99 interviews. This resulted in 41 completed and two part-completed community interviews and 20 occasions where either the respondent refused (Case 05, 38, 73, 76) or the respondent did not attend (Cases 25, 80, 82, 83, 88).

Table 7.4 Total number of meetings required to complete the community interview[†]

Total number of meetings required to complete the community interview	Community sample (n=43)
	No. (%)
1	24 (56)
2	8 (18)
3	7 (16)
4	2 (5)
5	2 (5)
Total number of respondents	43

[†] This includes those occasions where the respondent did not attend a prearranged meeting and times when the interview was only part-completed.

Community interviews were held in various places (see Table 7.5). This depended on whether the respondents were still receiving their depot medication and whether they lived in independent accommodation where the researcher was required to be accompanied to visit the respondent due to ethical committee requirements. The interviews took place at clinics, hospital wards or out-patients on 16 occasions (33%). The remaining two-thirds of interviews took place either at respondents' own homes or at other places in the community.

Forty-one community interviews took between 25 and 107 minutes each to complete. The mean completion time was 57 minutes (s.d.=22.6) with a median value of 50 minutes. On those occasions where the interview took place over two or more meetings, start and finish times were noted and a total interview time was calculated. Two interview schedules were only partly completed before the respondent decided to withdraw from the study (Case 23 and Case 53).

“I don’t want to do this any more. All these questions are making me nervous. I get very nervous now, with this illness. I get scared. I’m scared of people. I’m not scared of you, but I’m scared of people.”

(Case 23)

“I don’t want to do it.”

(Case 53)

Table 7.5 Range of places for the community interviews

	Community sample (n=43)
	No. (%)
Hostel / sheltered accommodation	19 (44)
Respondent’s independent home: visited with CPN (community psychiatric nurse)	6 (14)
Community health centre ‘depot clinic’	6 (14)
Hospital ward	4 (9)
Hospital outpatient department	2 (5)
Hospital ‘depot’ clinic	4 (9)
Respondent’s independent home: visited with chaperone	2 (5)
Other place [†]	5 (11)
Total number of respondents	43

Note: Percentages do not equal 100 because some clients were interviewed more than once in different places.

† Community long stay rehabilitation ward (Case 03); Luncheon club (Case 33); McDonalds restaurant (Case 46); Community Mental Health Team offices (Case 56); Public house (Case 58).

7.2.2 Insight

As for the recruitment interview, open responses to the Present State Examination questions of insight (Wing *et al.* 1974) were recorded verbatim during the community interview and later coded into one of the four predefined categories as shown in Table 7.6.

Table 7.6 Insight of the respondents[†]

	Sample as in-patients (n=42)	Sample in community (n=42)
	No. (%)	No. (%)
Full insight in intelligent subject	1 (2)	0 (---)
Insight dependent on social background / intelligence	13 (30)	12 (29)
Agrees to a nervous condition with delusional explanations	11 (26)	5 (12)
Denies nervous condition entirely	18 (42)	25 (60)
Total number of respondents	42	42

Note: Case 23: Withdrawn from study at this stage

[†] taken from the Present State Examination (Wing *et al.* 1974)

Twelve respondents (29%) had some insight into their illness.

“...I am a potential break down case. I’ve had seven break downs...I’d say I’ve been mentally ill for 30 years, but I’m recovering with therapy and the short term medication in Bart’s hospital. It was only the decanoate that brought me around.”

(Case 09)

“I feel a little bit in the unreal world. I feel a bit spaced out...A certain amount of it is a nervous condition. I think it’s psychiatric...communication problems can cause me to have a breakdown. I find the injection help with that.”

(Case 34)

Almost three-quarters of all respondents (30, 72%) denied experiencing a nervous condition.

“Only pains in my head. [*Why were you admitted to hospital last time?*] Don’t know. Something to do with getting a pint of milk and apparently I might have had shopping in the right hand, my left arm in a sling. Somebody went berserk on the other side of the road and instead of going to them, they came to me. Three police cars. They hand cuffed me. I bit the police woman’s hand because I didn’t know what was going on. I dropped the milk bottle, I didn’t throw it. They took me to Bethnal Green Police Station and left me in a cell. Then, took me to Hackney.”

(Case 08)

“No, there’s nothing wrong with me. I need a new pair of shoes, size 12. I don’t know why I went into hospital. There’s nothing wrong with me. The police drove me there, I think he felt sorry for me. I had no home, no money.”

(Case 24)

Insight categories were compared between the hospital and community settings using the χ^2 test for significance at the $p \leq 0.05$ level. The first two and last two categories were collapsed

together. As expected, a significant relationship existed between the category of insight reported by respondents in the hospital and community settings. Respondents who had 'some insight' in hospital were likely to maintain the same level of insight in the community (Fisher's Exact Test, two-tail test $p=0.00025$).

7.2.3 Informed

Respondents were asked how informed they felt about the state of their health at the time of the community interview. Their responses are shown in Table 7.7.

Table 7.7 Respondents' views of how informed they feel about the state of their health[†]

In your opinion, have you been told as much as you need to know about the state of your health?	Community sample (n=41)	
	No.	(%)
Yes	21	(51)
Partly	4	(10)
No	16	(39)
Total number of respondents	41	

Note: Case 23 and Case 53 had withdrawn from the study at this stage.

[†] taken from the 'Index of Health Related Quality of Life' (Rosser *et al.* 1992)

Almost half of all respondents thought that they were lacking information about the state of their health.

"Doctors don't tell me nothing. They write down everything but they tell me nothing. I want to see a psychotherapist or psychologist, someone to talk to and tell me about my illness."

(Case 01)

"Nobody has told me anything. The last time I saw ... [psychiatrist], I was as mad as a hatter but he thought I was well enough to be released. He didn't want to know what was going on in my mind..."

(Case 09)

"I'm not sure in what direction I should go in. I have not been told how I should cope with suicidal feelings. No advice on how I should go on. I feel I need counselling."

(Case 34)

“Why am I suffering from it? I want to know what I’m suffering from.”

(Case 46)

“If they try and explain to you the range of products you could take... More friendship, with the conversation, with the doctor and they could explain to you and talk to you more, then, you could speak more to them about yourself. A happy doctor makes the patient happy. In my experience, they are just doing their job...the doctor just does his part, he just wants to know his part and you do your part as the client.”

(Case 56)

“They said I’ve been diagnosed as schizophrenic, like to know more about what this means.”

(Case 70)

7.2.4 Stigma

Respondents were asked if they felt stigmatized because of the state of their health (see Table 7.8).

Table 7.8 Respondents’ views of the stigma associated with the state of their health[†]

Do you feel discriminated against because of the state of your health?	Community sample (n=41)
	No. (%)
A lot	8 (19)
Partly	9 (22)
No	24 (59)
Total number of respondents	41

Note: Case 23 and Case 53 had withdrawn from the study at this stage.

[†] taken from the ‘Index of Health Related Quality of Life’ (Rosser *et al.* 1992)

Seventeen respondents (41%) felt they were discriminated against because of their state of health.

“You get a label on you. They call me mad, psychiatric.”

(Case 01)

“Job wise, yes and of course, relationships. People haven’t wanted to have relationships with me because of my ill health.”

(Case 02)

“Yeah, going after a job. If I tell them about my background, they won’t take you on.”

(Case 29)

“A lot of people stare at me and look down on me because of my state of health. I feel cheap.”

(Case 34)

“I walk around and the girl calls me a mad man.”

(Case 46)

“I haven’t had no trouble but if I took sick, they’d probably say something. I find it hard to get a job if I put down mentally ill. You’re better off not putting it down.”

(Case 60)

“A lot of people take the piss out of me. I’ve been in more hospitals than a lot of other people.”

(Case 28)

7.2.5 Symptoms and problems at time of community interview

Current symptoms experienced by the respondents at the time of the community interview were compared with those experienced at the time of the recruitment interview, in hospital (Table 7.9). Most frequently respondents reported that they had not experienced any symptoms in hospital (21, 50%) and this figure had increased at the time of the community interview (27, 64%). Some ‘symptoms’ reported maybe attributed to the adverse effects of antipsychotic medication (e.g. loss of libido, tremor) and as such have been collectively termed ‘potential drug-related problems’. Although it is recognised that differentiating between symptoms of schizophrenia and some of the adverse effects of antipsychotic medication can be difficult. Reporting at least one symptom was compared with reporting no symptoms for both sub-sample groups. The χ^2 test of significance at the $p \leq 0.05$ level showed no significant differences between reports in the hospital and in the community.

Table 7.9 Current symptoms reported when in-patients and at the time of the community interview[†]

	Sample as in-patients (n=42)	Sample in community (n=42)
	No. (%)	No. (%)
Somatic complaints	4 (10)	6 (14)
Delusions	7 (17)	0 (---)
Potential drug related problems [‡]	7 (17)	1 (2)
Hallucinations	4 (10)	3 (7)
Ideas of self-harm	2 (5)	1 (2)
Anxiety	1 (2)	2 (5)
Aggressive/hostile behaviour	1 (2)	0 (---)
Obsessions	0 (---)	1 (2)
Sleep disturbance	0 (---)	1 (2)
Depressed mood	0 (---)	1 (2)
Other symptoms [§]	0 (---)	3 (7)
No symptoms at time of interview	21 (50)	27 (64)
Not answered	0 (---)	1 (2)
Total number of respondents	42	42

Note: Percentages do not equal 100 since respondents could give more than one answer.

[†] Case 23 has withdrawn from study

[‡] Potential drug-related problems: In-patients Cases 03, 36,64: Drowsiness/lethargy; Cases 30, 53: Tremor; Case 22: Increased appetite; Case 89: Loss of libido Community Case 60: Akathisia - "The hands don't know where to put themselves."

[§] Other symptoms: Community Case 49: "My nerves...diarrhoea...incontinence."

Table 7.10 shows the problems reported as in-patients and the problems reported at the time of the community interview. Accommodation problems were the most frequently reported problem, both at the time of the recruitment interview (9, 21%) and the community interview (7, 17%). Almost half the sample on both occasions (19, 45%; 20, 48%) reported not experiencing any problems. Reporting at least one problem was compared with reporting no problems for both sub-sample groups. The χ^2 test of significance at the $p \leq 0.05$ level showed no significant differences between the reports in hospital and in the community.

Table 7.10 Current problems reported when in-patients and at the time of community interview[†]

	Sample as in-patients (n=42)	Sample in community (n=42)
	No. (%)	No. (%)
Accommodation problems	9 (21)	7 (17)
Discord with family	4 (10)	1 (2)
Financial problems	3 (7)	2 (5)
Problem with unemployment	2 (5)	1 (2)
Relationship difficulties	2 (5)	0 (---)
Misplaced belongings	3 (7)	0 (---)
Physical health	1 (2)	0 (---)
Being in hospital (other patients)	1 (2)	0 (---)
Social isolation	1 (2)	2 (5)
Drug abuse	0 (---)	1 (2)
Discord with neighbours	0 (---)	2 (5)
Unsure of self	0 (---)	2 (5)
Other reasons [‡]	2 (5)	6 (14)
No problems at time of interview	19 (45)	20 (48)
Not answered	1 (2)	0 (---)
Total number of respondents	42	42

Note: Percentages do not equal 100 since respondents could give more than one answer.

[†] Case 23 has withdrawn from study

[‡] Other reasons: In-patients Case 01: Religion; Case 53: Unspecified problems Community Case 01: Self-care; Case 09: Inappropriate community services; Case 14: Lack of concentration; Case 21: Waiting for a bus pass; Case 22: The medication; Case 68: A friend in hospital.

Twenty-two respondents (52%) reported that they were also experiencing 'physical or other' health problems in the community (Table 7.11). Physical or other health problems were categorised according to the system of the body they affected and as potential drug-related problems (see Section 6.3.5). Reporting a 'physical or other' health problem was compared with reporting no 'physical or other' health problems between hospital and community settings. The χ^2 test of significance at the $p \leq 0.05$ level showed no significant differences

between the two groups.

Table 7.11 Physical or other health problems reported when in-patients and at the time of the community interview

	Sample as in-patients (n=42)	Sample in community (n=42)
	No. (%)	No. (%)
Yes	19 (45)	22 (52)
None	20 (48)	20 (48)
Not answered	3 (7)	0 (---)
If yes, system affected:	n=19	n=22
Chest problems including atopy (e.g. asthma, eczema, hay fever)	7 (37)	6 (27)
Orthopaedic/Rheumatology (e.g. joint problems, bunions)	1 (5)	3 (14)
Endocrine (e.g. diabetes, thyroid problems)	3 (16)	3 (14)
Cardiovascular	3 (16)	2 (9)
Others [†]	4 (21)	8 (36)
Potential drug-related problems:		
Hormonal (e.g. weight gain, amenorrhoea)	3 (16)	0 (---)
Anticholinergic (e.g. constipation, urinary retention, dry throat)	2 (11)	0 (---)
Parkinsonism (e.g. stiffness)	1 (5)	2 (9)
Allergic (e.g. skin rash)	0 (---)	1 (5)
Total number of respondents	42	42

Note: Percentages do not equal 100 since respondents could give more than one answer.

[†] Other health problems: In-patients Case 30: Deaf; Case 49: Depression; Case 60: Short-sighted; Case 79: Incontinence of urine and faeces. Community Case 01: Lack of motivation; Case 14: Lack of concentration; Case 22: Poor hygiene; Case 28: Incontinence of urine and faeces; Case 30: Deaf; Case 56: Weakness; Case 60: Heavy periods; Case 79: Genitourinary-urinary tract infection.

7.2.6 Severity of illness in the community

The researcher (SAF) rated severity of illness using the Global Assessment of Functioning Scale (American Psychiatric Association, 1987) (see Section 6.3.6). The researcher rated each respondent at the end of the community interview. In 16 cases (37%) a community staff member or 'significant other' was available to rate the respondent as a process of validation. The ratings of 6 individuals (43%) differed between the researcher and the validator. On these occasions, the validator rating was used because they had more contact with the respondents. One case was adjusted down the scale and five cases were moved up the scale.

Table 7.12 shows the illness severity rating of the respondents in the community. Eleven people (26%) had mild, slight or minimal symptoms; 7 (16%) had moderate symptoms; and the remainder (25, 58%) had varying types of major impairment or symptoms. Mild, moderate and major illness severity was compared between the hospital and community settings; there was no significant difference.

Table 7.12 Global Assessment of Functioning Scale (GAF Scale) rating[†] (severity of illness) of the respondents

	Sample as in-patients (n=43)		Sample in community (n=43)	
	No.	(%)	No.	(%)
Absent or minimal symptoms, good functioning in all areas, interested and involved socially	0	(---)	0	(---)
Symptoms present, but transient/expectable and no more than slight social impairment	0	(---)	1	(3)
Some mild symptoms but generally functioning well, has interpersonal relationships	4	(9)	10	(23)
Moderate symptoms or moderate difficulty with social/occupational functioning	10	(23)	7	(16)
Serious symptoms (e.g. suicidal, obsessional, frequent shoplifting) <u>or</u> any serious impairment in social/occupational functioning	11	(26)	16	(37)
Some impairment in reality testing or communication <u>or</u> major impairment in several areas	10	(23)	8	(18)
Behaviour is considerably influenced by delusions or hallucinations <u>or</u> serious impairment in communication or judgement <u>or</u> inability to function in most areas	7	(16)	1	(3)
Some danger of hurting self or others <u>or</u> occasionally fails to maintain personal hygiene (e.g. smears faeces) <u>or</u> gross communication (e.g. largely mute)	1	(3)	0	(---)
Persistent danger of severely hurting self or others <u>or</u> persistent inability to maintain personal hygiene <u>or</u> serious suicidal act	0	(---)	0	(---)
Total number of respondents	43		43	

[†] Validator rating used if different to rating determined by researcher

7.2.7 Contacting general practitioners in the community

Thirty-five of the community respondents (81%) gave their permission at the time of the recruitment interview for their GP to be contacted if required. One GP was contacted for information to help find a respondent (Case 09).

7.2.8 Permission to contact significant others

At the end of the community interview, respondents were asked if the 'significant other' they named at the time of the recruitment interview was still the most appropriate person for contact. (Fourteen people had named hospital ward staff). For those respondents who had not named a significant other, it was a second opportunity to nominate someone. Two respondents (Cases 23 and 53) had refused to continue with the questionnaire and therefore, did not respond to this question.

Table 7.13 Respondents willing to name significant others for interview

	Sample as in-patients (n=43)	Sample in community (n=43)
	No. (%)	No. (%)
Willing to name significant other		
Yes	31 (72)	25 (58)
No	11 (26)	16 (37)
Not answered	1 (2)	2 (5)
If answered 'yes', who?	n=31	n=25
Health Team Workers (e.g. ward staff, social workers, hostel workers, CPN, GP)	22 (71)	20 (80)
Family	6 (19)	4 (16)
Friends	2 (7)	1 (4)
Not specified	1 (3)	0 (---)
Total number of respondents	43	43

Notes: CPN=Community Psychiatric Nurse; GP=General Practitioner

Twenty-seven respondents (66%) had changed their minds since the recruitment questionnaire (either withdrew consent or named a new interviewee). Fifteen significant others (60%) replied to the postal questionnaire. Significant other information was collected

as a second source of information about the respondents' social network and the quality of life objective indicators (see Section 9.4). Respondents in the community were significantly more likely to name a significant other if they had nominated someone in hospital (Fisher's Exact Test, two-tail $p=0.009$).

7.3 Medication issues in the community

At the time of the community interview, 6 people (14%) reported that they no longer received the depot (intramuscular) antipsychotic medication (non-attenders). These respondents will be discussed separately in Section 7.3.10. All other respondents ($n=37$) were adhering to their depot medication to varying degrees. Section 7.3.1 discusses the medication adherence of the community sample ($n=43$). The subsequent medication sections (7.3.2-7.3.9) will concentrate on the information gathered from interviews with the 37 respondents who continued to receive their depot medication.

7.3.1 Medication adherence

The two measures of medication adherence were defined in Section 4.2. The percentage of doses the respondents received during their follow-up periods ranged from 0% to 100% (**% depot attendance**). The mean percentage of doses received was 86%. (The median was 100%). The percentage of doses the respondents received during the follow-up periods on the expected day according to their drug regimen ranged from 0% to 100% (**% depot day attendance**). The mean percentage of doses received on the expected day was 81%. (The median was 100%).

Respondents were classified into three categorical 'adherence status' groups (Table 7.14):

- regular attenders (100% depot day attendance and still attending for the depot at the time of the community interview)
- irregular attenders ($>0\%$ depot day attendance $<100\%$ and still attending for the depot at the time of the community interview)
- non-attenders (respondents who reported that they no longer received the depot medication at the time of the community interview).

Table 7.14 Medication adherence status after discharge from hospital

	No (%)
Regular attender (100% depot day attendance and still attending for the depot at time of community interview)	23 (53)
Irregular attender (>0% depot day attendance <100% and still attending for the depot at time of community interview)	14 (33)
Non-attender (not attending for the depot at time of community interview)	6 (14)
Total number of respondents	43

Table 7.15 shows that the most common type of service that respondents received for the administration of their depot medication was the CPN (community psychiatric nurse) visiting the respondents at their home or hostel (13, 30%).

Table 7.15 The services responsible for the administration of the respondents' depot antipsychotic medication

	No (%)
CPNs visit the respondents' at home	13 (30)
Respondents visit the hospital outpatient depot clinic	10 (23)
Respondents visit the CPNs in local health clinics	8 (19)
Respondents attend hospital inpatient wards	5 (12)
Respondents visit their GPs	2 (5)
Respondents receive their depot from more than one of the above services	5 (12)
Total number of respondents	43

Note: CPN=Community Psychiatric Nurse; GP=General Practitioner

Table 7.16 divides the respondents according to their 'depot status' and illustrates the type of community service required for each respondent to receive their depot (intramuscular) antipsychotic medication. Of the 23 respondents who received 100% of doses of their depot medication on the day intended, almost half required a community outreach service.

Table 7.16 Type of service required for the administration of the depot antipsychotic medication by depot attendance status

Type of service required by the respondent for the administration of the depot (intramuscular) antipsychotic medication	Depot adherence status		
	Regular attender (n=23) No. (%)	Irregular attender (n=14) No. (%)	Non-attender (n=6) No. (%)
Home visits required by respondent	11 (26)	3 (7)	4 (9)
Respondent visits service	12 (27)	11 (26)	2 (5)
Total number of respondents	23 (53)	14 (33)	6 (14)

7.3.2 Knowledge of medication

Thirty-five respondents (95%) claimed to know what medication they were taking (Table 7.17). When asked to name their medication, 22 (66%) could name all the medication they were taking. Respondents were recoded into two groups: those who could name all medication and those who could name some or none. Respondents in the community were significantly more likely to be able to name all their medication if they had named all their medication while in hospital (χ^2 using Yates' continuity correction =3.78;p=0.05).

Table 7.17 Self-reported ability to name prescribed medication

	Sample as in-patients (n=37)	Sample in community (n=37)
	No. (%)	No. (%)
Do you know what medication you are taking including any injections?		
Yes	28 (76)	35 (95)
No	9 (24)	2 (5)
How many known by name?		
All	13 (35)	22 (59)
Some	13 (35)	11 (30)
None	11 (30)	4 (11)
Total number of respondents	37	37

Thirty-four respondents (98%) reported the total number of medication they were taking (Table 7.18). Almost three-quarters of the respondents (26, 74%) were taking a total of two or three different medications. The mean number of different medications was 2.74 in hospital and 2.71 in the community. The mean number of different medications did not differ significantly between hospital and community (Wilcoxon Matched-Pairs Signed-Ranks Test). The total number of drugs prescribed was in accordance with community medical notes in 20 cases (59%).

Over a half of all respondents (19, 54%) named depot (intramuscular) antipsychotic medication as the only antipsychotic medication they were taking. The routes of antipsychotic medication were in accordance with community medical notes in 26 cases (93%). The proportion of people prescribed depot only or depot and oral antipsychotic medication in the community were compared with those in hospital using the Fisher's exact test. There was no statistical difference in the proportion of people taking medication by different routes of administration.

Of those people who reported knowing their medication (n=35), 24 (69%) respondents named other medication as well as antipsychotic medication in their total drug regime. Other medication was in accordance with community medical notes in 20 cases (71%). In 22 cases (63%) one of the 'other medicines' was an anticholinergic drug (often prescribed to suppress

the extra-pyramidal parkinsonian adverse effects that may be caused by antipsychotic medication - see Section 1.3). The reporting of anticholinergic drugs was in accordance with medical notes for 26 cases (87%).

Table 7.18 Details of prescribed medication as reported by the respondents

	Sample as in-patients (n=37)	Sample in community (n=37)
	No. (%)	No. (%)
Reported knowing medication (table 7.16)	n=28	n=35
Total number of different medicines being taken		
1	3 (11)	3 (9)
2	9 (32)	13 (37)
3	10 (36)	13 (37)
4	2 (7)	3 (9)
5	3 (11)	0 (---)
6	0 (---)	2 (6)
Does not know how many medicines taking	1 (3)	1 (2)
In accordance with community medical notes?	n=27	n=34
Yes	15 (55)	20 (59)
No	11 (41)	14 (41)
Information missing	1 (4)	0 (---)
Routes of antipsychotic medication named		
Depot (intramuscular) only	9 (32)	19 (54)
Depot (intramuscular) and oral	10 (36)	9 (26)
Does not know name of medication taking	9 (32)	7 (20)
In accordance with community medical notes?	n=19	n=28
Yes	15 (79)	26 (93)
No	4 (21)	2 (7)
Number of 'other' medication		
0	7 (25)	4 (11)
1	7 (25)	16 (46)
2	2 (7)	4 (11)
3	2 (7)	2 (6)
4	0 (---)	2 (6)
Does not know name of medication taking	10 (36)	7 (20)
In accordance with community medical notes?	n=18	n=28
Yes	15 (83)	20 (71)
No	3 (17)	8 (29)
Total number of respondents	37	37

† Any medication without antipsychotic action.

Table 7.18(ctd.) Details of prescribed medication as reported by the respondents

	Sample as in-patients (n=37)	Sample in community (n=37)
	No. (%)	No. (%)
Reported knowing medication (table 7.16)	n=28	n=35
Patient names 'other' medication with anticholinergic action[†]		
Yes	14 (50)	22 (63)
No	9 (32)	8 (23)
Does not know name of medication taking	5 (18)	5 (14)
In accordance with community medical notes?	n=23	n=30
Yes	18 (78)	26 (87)
No	4 (17)	4 (13)
Missing information	1 (5)	0 (---)
Name of depot (intramuscular) antipsychotic medication taking		
Fluphenazine decanoate	8 (24)	10 (29)
Flupenthixol decanoate	7 (21)	7 (20)
Pipothiazine palmitate	4 (3)	5 (14)
Zuclopenthixol decanoate	1 (6)	4 (11)
Haloperidol decanoate	0 (12)	1 (3)
Does not know name of medication taking	8 (34)	8 (23)
In accordance with community medical notes?	n=20	n=27
Yes	20 (100)	27 (100)
Total number of respondents	37	37

[†] Medication with anticholinergic action may be prescribed to suppress the extra-pyramidal parkinsonian adverse effects that may be caused by antipsychotic medication.

Twenty-seven respondents (77%) named their depot antipsychotic medication. The most commonly prescribed depot medication was Fluphenazine decanoate (10, 29%). The depot medication was in accordance with community medical notes for all cases (27, 100%). Proportions were too small statistically to compare the likelihood of respondents being prescribed the same depot medication in the community as when they were in hospital.

7.3.3 Effect of medication on symptoms

Table 7.19 shows the respondents' replies to the following open question:

'In your opinion, what difference has the medication, including your injection, made to the symptoms of your illness?'

Over half of all respondents (20, 54%) mentioned positive or beneficial effects of medication on their symptoms. One other person named both positive and negative effects. There was no difference between the proportion of respondents who reported positive effects of medication in hospital and whether they reported positive or negative effects in the community.

Later in the questionnaire, respondents were asked a more leading closed question:

'In your opinion, do you feel that medication helps the symptoms of your illness?'

Twenty-five respondents (68%) reported that their medication helped the symptoms of their illness. (A similar number of positive responses was achieved with the open question above). Respondents were asked to describe in what ways their medication helped the symptoms of their illness (n=37) (Table 7.19). The most common reason was that the medication helped by decreasing symptoms (7, 28%).

Respondents' answers were compared for the open and closed questions. Those respondents who reported the positive effects of medication during the open question were more likely to report 'yes' that medication had helped their symptoms (closed question) (Fisher's Exact test with two tail probability; $p=0.004$). Cohen's kappa was also calculated as a test of concordance between the two response sets ($\text{kappa}=0.706$; $p<0.001$). These tests illustrate consistency in reporting for the community interview.

Respondents were compared for their opinions between the recruitment interview and community interview. There was no relationship between those who reported that medication helped their symptoms in hospital and those who reported that medication helped their symptoms in the community.

Table 7.19 Respondents' perceived effects of medication on symptoms

Perceived effects of medicines on symptoms reported by respondents	Sample as in-patients (n=37)	Sample in community (n=37)
	No. (%)	No. (%)
What difference has the medication, including your injection, made to the symptoms of your illness?		
Positive / beneficial effects of medicines	21 (57)	20 (54)
Negative / detrimental effects of medicines	4 (11)	6 (16)
Both positive and negative effects reported	5 (13)	1 (3)
No effect of medicines on symptoms	7 (19)	9 (24)
Missing information	0 (---)	1 (3)
Does medication help symptoms?		
Yes	18 (49)	25 (68)
No	11 (30)	10 (27)
Don't know	3 (8)	0 (---)
Missing information	5 (13)	2 (5)
Reasons how medication helps:	n=18	n=25
Decreases symptoms eg 'voices'	6 (33)	7 (28)
Feel better	4 (22)	6 (24)
Calms my nerves	3 (17)	3 (12)
Keeps me normal	3 (17)	3 (12)
Other reason [†]	3 (17)	3 (12)
Unable to give a reason	3 (17)	4 (16)
Total number of respondents	37	37

Note: Percentages of reasons do not equal 100 since respondents could give more than one answer.

[†] Other reasons: in-patients Case 31: "I get a good night's sleep."; Case 56: "Helped with the digestion problem."; Case 68: "The medicines help my tummy to settle." community sample Case 34: "It keeps me from being totally asocial or withdrawn character that somebody can communicate with."; Case 35: "It helps me to cope with my situation. I can feel content with my situation where as if I was off medication I would become upset with my situation. I think that's what happened the last time. I think I am unable to live up to my own standards."; Case 54: "It makes me feel a happier person. More well person."

An additional item in the community questionnaire (not included in the recruitment questionnaire) asked respondents:

"Since you have been taking your medication, including your injection, how would you say your symptoms have been?"

Respondents were given fixed responses and their answers are presented in Table 7.20. Twenty-one respondents (56%) reported that their medication had improved their symptoms. Again, a similar proportion of respondents as for the earlier questions.

Table 7.20 Respondents' perceived symptom level since taking medication

<i>"Since you have been taking your medication, including your injection, how would you say your symptoms have been?"</i>	Number (%)
Substantially worse	0 (---)
Much worse	0 (---)
Somewhat worse	4 (11)
No change or same	12 (32)
Somewhat better	8 (22)
Much better	11 (30)
All better	2 (5)
Total number of respondents	37

It would have been preferable to have tested the above responses concerning the perceived effect of medication on symptoms with the measure of insight (Section 7.2.2) to check the validity of their responses. However, cells had expected frequencies < 5 and total sample size was > 20. It was inappropriate to test the subgroups statistically.

7.3.3.1 Role of medication in managing symptoms

As for the recruitment interview, the community interviews were examined for quotes relating to the perceived effect of medication on symptoms. These comments were not always made at the time of the 'medication section' of the questionnaire. The researcher noted any additional comments made throughout the interview. The respondents were as varied with their opinions about medication as when in-patients. Some consistency in reporting was evident with a few individuals not changing their opinions since their interview at the hospital.

1) Positive effects of medication on symptoms

Respondents, who were insightful of their illness, could discuss the direct positive effects of medication on the symptoms of their illness.

"Injection keeps me steady...keeps me normal. Sometimes I go out of the world of reality, getting delusions, hallucinations."

(Case 01)

“It’s helped with the illness. I do need the injection to be taken. It’s made me better and me get back on my feet. It does help me along.”

(Case 33)

“It made me feel better in my body. The voices and things have gone away. It’s helped with the voices and seeing things.”

(Case 60)

“It’s got rid of the voices. It’s got rid of the visions, people on the wall. I feel not so depressed. It’s done me good.”

(Case 68)

2) Medication provides limited benefit on symptoms of illness

Other respondents acknowledged the benefits of their medication but added that the effect was not total. Sometimes they described the ‘limited benefit’ in terms of residual symptoms and other times as the length of time they expected to use the medication, i.e. short-term.

“It’s made it a little bit better but not fully. The voices have been quieter and less frequent except for this weekend when they came back again.”

(Case 04)

“I wish I could get rid of it. I can’t control it sometimes. Voices talk to me in my head and tell me what to do...without it [the injection] I attack Mum and I don’t want to attack Mum.”

(Case 28)

“I used to jerk a lot before the injection. It stopped my voices sometimes. It doesn’t stop them completely. They repeat themselves sometimes and they go away some days, I don’t hear them.”

(Case 70)

“They’ve stopped the voices and I feel they are a help that I’m on the road to getting better. They’re not the b-all and end-all and when I get better I won’t be needing them, but I can’t deny they’re keeping me well enough to be in society at the moment.”

(Case 34)

3) No perceived effect on symptoms of illness

Some respondents, such as Case 24, believed that the medication was of no benefit whatsoever, reflecting his lack of insight into his illness. Case 50, however, interpreted the poor effect in terms of a lack of cure and an inability of the drugs to keep his illness stable. This view does suggest a degree of insight into the illness.

“Nothing. Just the same if I have it or if I don’t. Doesn’t do me any harm. Did nothing to me at all. I’m as I am with you now. Medicines don’t make a difference. I’m all right.”

(Case 24)

“Nothing. It doesn’t help me. There’s no cure. All they can try and do is keep me stable on drugs and they can’t even do that now. I’ve never been this bad.”

(Case 50)

7.3.4 Unwanted effects of medication

As for the recruitment interview, respondents were asked to report any problems with their medication, such as side-effects. Respondents’ descriptions were office-coded using known adverse effects of antipsychotic medication as a coding frame. However, it is acknowledged that there can be difficulty in differentiating between the adverse effects of medication and symptoms of schizophrenic illness.

Table 7.21 shows that one half of all respondents (19, 51%) reported experiencing unwanted effects from taking their medication. The people who reported unwanted effects in the hospital were significantly more likely to report unwanted effects in the community (χ^2 using Yates’ Continuity Correction =4.79; $p=0.029$). Parkinsonian side-effects such as stiffness and tremor (13, 68%) were the most common unwanted effects reported.

Nine respondents (47%) subsequently reported that the unwanted effects of medication affected activities they did or wanted to do (Table 7.21). For all cases, (9, 100%) the unwanted effects of medication affected physical/leisure activities. A Fisher’s Exact test did not show any difference between those respondents who reported that their side-effects affected their activities while in hospital and those who reported their activities were affected in the community.

Later in the questionnaire, respondents were asked whether they felt that their medication or the symptoms they experienced affected the way they spent their days. Eighteen people (49%) reported that their days were affected; and in all cases affected in a negative way (18, 100%). There was no relationship between those people who reported unwanted effects of medication and whether they reported that their medication or the symptoms they experienced affected the way they spent their days (Fisher’s Exact Test). There was no relationship between those respondents who reported that their medication or symptoms affected their days in hospital and those who reported so in the community.

Table 7.21 Problems with medication as reported by the respondents

Do you have any problems with your medication or your injection, for example, side-effects?	Sample as in-patients (n=37)	Sample in community (n=37)
	No. (%)	No. (%)
Yes	24 (65)	19 (51)
No	13 (35)	18 (49)
Types of problems reported:	n=24	n=19
Extra-pyramidal effects: Parkinsonism	8 (29)	13 (68)
Extra-pyramidal effects: Akathisia	6 (21)	4 (21)
Cardiovascular	1 (4)	2 (11)
Sexual functioning	1 (4)	2 (11)
Ocular effects	0 (4)	2 (11)
Drowsiness, lethargy	8 (36)	1 (5)
Pain due to injection	3 (11)	1 (5)
Extra-pyramidal effects: Dyskinesia	2 (11)	1 (5)
Gastro-intestinal	3 (11)	0 (---)
Temperature control	1 (7)	0 (---)
Mucosal dryness	1 (4)	0 (---)
Endocrine effects	1 (4)	0 (---)
Skin	1 (4)	0 (---)
Nasal congestion	1 (4)	0 (---)
Other effects [†]	4 (18)	6 (32)
Total number of respondents	37	37

Note: Percentages of problems do not equal 100 since respondents could give more than one answer. Problems were office-coded according to the known adverse effects of antipsychotic medication. However, it is recognised that there can be difficulty differentiating between some adverse effects of medication and symptoms of schizophrenia.

[†] In-patients Cases: 04: "I was walking along one time and my legs collapsed underneath me."; Case 34: "Unbalanced sometimes, not in control...Feel totally bombed out, overstressed in an aggressive way..."; Case 35: "...I think they create dependence."; Case 79: "Tablets make me feel bad. Just don't feel well after them."
Community Case 04, 14: Sleep disturbance; Case 14: "My tongue gets tired."; Case 50: "I'm addicted to the Valium."; Case 54: "I want to have longer time between my injections. Every week is too much for 4 years."; Case 54: "I don't like taking too many tablets."

Table 7.22 The consequences of taking medication and the symptoms of illness as reported by the respondents

	Sample as in-patients (n=37)	Sample in community (n=37)
	No. (%)	No. (%)
Do the medication problems reported affect areas of living?	n=24	n=19
Yes	7 (29)	9 (47)
No	10 (42)	8 (42)
Unsure	2 (8)	0 (----)
Information missing [†]	5 (21)	2 (11)
Areas of living affected	n=7	n=9
Physical / leisure activities	4 (57)	9 (100)
Looking for work / working	4 (57)	0 (----)
Self-confidence	1 (14)	1 (11)
Other effects [‡]	4 (57)	3 (33)
Does the medication or symptoms of illness affect your day?		
Yes	19 (51)	18 (49)
No	13 (35)	16 (43)
Information missing [†]	5 (14)	3 (8)
How is your day affected?	n=19	n=18
Positive ways	0 (---)	0 (----)
Negative ways	16 (84)	18 (100)
Positive and negative ways	1 (5)	0 (----)
Information missing	2 (11)	0 (----)
Total number of respondents	37	37

Note: Percentages do not equal 100 since respondents could give more than one answer.

[†] This question was a late addition to the questionnaire and therefore not all respondents had the opportunity to respond.

[‡] In-patients Case 49: "Feel sleepy... Stops you washing my clothes and myself."; Case 58: It just makes me feel uncomfortable. It just makes you want to sleep than do anything else." Case 59: "I have to drink lager but I tried to give it up." Community Case 46: "Affects my personality." Case 60: "It makes you look like you're handicapped...It's made me put on weight."

7.3.4.1 Consequences of adhering to medication

Respondents were very illustrative with their qualitative comments when discussing the effects of taking medication on their everyday lives in the community, in particular the negative impact on their well-being.

"The injection made me feel stiff and my walking was bad. I feel the injection makes me drowsy. For example, it increases the hardness to write with my hand.

I am having physiotherapy for the hand because it doesn't write due to the stiffness."

(Case 40)

"Blurred vision. Pacing at the bus stop. I got to ask Mum if anyone's watching. Alan [boyfriend] does it as well. When I go for a bus, worried people watching me."

(Case 26)

"It just slows me down. Slowing down. Affects my personality, just slowing down and making me slow. It affects music, playing the piano, my fingers still move though. Chlorpromazine was making me feel a bit sick, making me worse. Makes you feel drowsy and makes you feel lazy. [It affects my] roller-skating."

(Case 46)

"I walk a bit funny you know, it's just funny. It's hard to describe. I'm uncoordinated when I walk. My jaw shakes."

(Case 89)

Some respondents expressed a tolerance to the adverse effects of medication they were experiencing and a certain persistence in their ability to cope and get on with life.

"Sometimes my jaw keeps moving, not all the time and my tongue gets tired and I can't sleep properly but I'm all right, I don't mind them. My hands used to be stiff. Because my nerves are on edge, I get aggressive sometimes when I get irritated. Sometimes I sleep a lot. It affects me in all different ways. I go to the toilet a lot. It sometimes makes me sleep. It stops me from tidying up. Affects me from doing a computer course but I'll do it in time. Sometimes the jaw affects me reading because I can't concentrate."

(Case 14)

Others discussed their experiences of the extreme adverse effects possible with antipsychotic medication.

"The tongue comes out on the Saturday, after the injection on the Thursday. I wasn't that well that week because I had my period as well. It was heavy. It's not good to have the injection when you're on. My hand was going a bit mentally ill, my fingers. I had that symptom too. Funny movements, like they can't help themselves, spastic like. Must be jerks or something. It makes you look like you're handicapped, that's when I forgot to take the procyclidine. My neck goes tense. It's like something stretching my neck. It's painful. It lasts about 20 minutes before it goes normal again. The procyclidine makes me hungry and I keep going in the cupboard all the time. It's making me put on weight. I've got to lie down. You can't eat when the tongue comes out or drink. With the hands, I drop things, glasses, bottles, cups, like your mind forgets you've got it in your hand and you drop it. [The] Pimozide was stopped. I go to a Day Centre in the morning, it makes me yawn too much. I could barely get up in the morning. It makes you drowsy and do clumsy things."

(Case 60)

A few respondents attributed their improved functioning and coping to the positive consequences of adhering to medication.

“It keeps me from being totally asocial or withdrawn character that somebody can communicate with.”

(Case 34)

“It helps me cope with my situation. I can feel content with my situation.”

(Case 35)

7.3.4.2 Other/physical health problems that are potential medication-related effects

During the community interview, some respondents reported potential medication-related adverse effects in place of physical or other health problems. They did not report these adverse effects when asked directly. Indirectly, this illustrates a lack of information about the adverse effects of the antipsychotic medication.

“I feel a bit stiff.”

(Case 03)

“My back when I move about. Stiff when I walk.”

(Case 22)

7.3.4.3 Mistrust of medication and the community health staff

Feelings of mistrust with medication still existed in the community as did expressions of mistrust with mental health care staff. This was sometimes expressed as frustration at lack of information and cure for the illness.

“I have to make an appointment with Dr K [psychiatrist]. They don’t help me at all, they tell me nothing. The cure is in my hands. The doctors cannot cure me.”

(Case 01)

“The nurse just can’t do it [give an injection]. May be they diagnosed me wrong. They weren’t friendly, the doctors.”

(Case 27)

“The doctor insists that I am sick.”

(Case 40)

The confusion between the effects of medication and the symptoms of illness fuelled the respondents’ feelings of mistrust with the medication. Medication provided a convenient

focus on which to blame the illness.

"[Do you think there is anything the matter with you?] Only shaking of the hands. [Could it be a nervous condition?] My nerves are dead. Only started since the injection...I was feeling no pain. Nothing wrong with me."

(Case 07)

"At the moment I feel my nerves in my body, not relaxing. Dr H [psychiatrist] said I've got a nervous disorder. [What do you think the cause is?] Probably the medication."

(Case 14)

Others worried about relying on the medication too much.

"I'd like to get off it and learn how to cope without it."

(Case 34)

"I reckon I'd have got on better without it...I wanted to get off it a little while to get better, then going back on it...I'd like to come off it for good."

(Case 46)

7.3.5 Experience of non-adherence to medication

Table 7.23 illustrates that 25 respondents (68%) reported that they had previously wanted to stop their medication. The lack of perceived therapeutic benefit (11, 44%) was the most common reason in the community, followed by a lack of motivation to adhere to their medication (8, 32%). Feelings of wanting to stop medication reported in the hospital did not influence reporting in the community.

On further exploration with these respondents (n=25), 10 respondents (40%) claimed that they had never stopped their medication in the past. Of those who reported that they had stopped their medication in the past, the most commonly perceived outcome was that nothing had happened (6, 24%). A close second was a recognition of immediate feelings of benefit followed by illness by 4 respondents (16%)

Table 7.23 Non-adherence to medication as reported by the respondents

	Sample as in-patients (n=37)	Sample in community (n=37)
	No. (%)	No. (%)
Experienced feelings of wanting to stop medication in the past		
Yes	30 (81)	25 (68)
No	7 (19)	12 (32)
Reasons why wanted to stop medication	n=30	n=25
Not helping/unnecessary/makes no difference	9 (30)	11 (44)
Fed-up/can't be bothered/don't feel like having it	5 (17)	8 (32)
Medication unsuitable eg injection painful, too much medication	2 (7)	3 (12)
Wanted to try without medication/trying to prove sickness	1 (3)	3 (12)
Potential/experienced unwanted effects	8 (27)	2 (8)
Forgot to take it	2 (7)	0 (---)
Other reason [†]	2 (7)	4 (16)
Not answered	4 (13)	0 (---)
Consequence of non-adherence to medication	n=30	n=25
Nothing	6 (20)	6 (24)
Felt better initially and then became ill	2 (7)	4 (16)
Became ill / symptoms worsened	5 (17)	2 (8)
Felt better	0 (---)	1 (4)
Had to go to hospital	0 (---)	1 (4)
Started taking it again (own decision)	1 (3)	0 (---)
Started taking it again (health professional follow-up)	1 (3)	1 (4)
Never actually stopped taking medication	14 (47)	10 (40)
Not answered	1 (3)	0 (---)
Total number of respondents	37	37

Note: Percentages do not equal 100 since respondents could give more than one answer.

[†] Other reason: In-patients Case 04: "Because the guy I was living with told me, only a friend, he said it was no good for you. He'd stopped taking it."; Case 33: "They [the hospital] told advised me to stop taking my medication." Community Case 14: "I thought a nurse experimented on me."; Case 34: "It may have been a psychotic reason."; Case 49: "I'm suffering with my nerves so I don't feel like having the injection."; Case 60: "I don't know if it's any good for me."

Experience of non-adherence gave some respondents an informed insight into the benefits and risks of adhering or non-adhering to the medication.

"If I stop taking it, I can't stop thinking. Like a motor car, I go faster and faster and can't stop thinking. I get very spiritual without it. I get high trips. I once went without it for 2 months and then I started cracking up after that."

(Case 01)

"I went out to work but I weren't as calm. I was hyper and got up to mischief."

(Case 14)

“I just felt like I was well and I couldn’t notice the difference in me. I thought I was over it. When I missed my injection the other week. I’d had some wild thoughts about a police woman and some bad dreams. I felt a lot better after the injection. I was never as ill before as that day I missed my injection.”

(Case 27)

“If I don’t take it I know I will feel a bit edgy and irritated because I’m living with my wife now and my step-son. The minute I stop taking the medication and injection, I will feel edgy and take out my frustration on them.”

(Case 29)

“Cos sometimes I don’t hear the voices. I don’t think I need it and then I don’t get any stiffness... [When] I wasn’t taking my tablets, I was forgetting to take them, I stopped eating. I was hearing voices and I was losing a lot of weight.”

(Case 70)

“I’ve gone a couple of weeks without the injection. I developed strange thoughts, on a religious theme. I got them out of proportion.”

(Case 72)

“I went a long time without it, a whole year. Nothing happened for a long time. It was a year later before anything happened. I drank some whiskey and started hallucinating.”

(Case 89)

Other clients reported an improvement in their subjective well-being after stopping their medication.

“I feel better without injection.”

(Case 03)

“Nothing never happened at all. I was healthy alright.”

(Case 24)

“Got a lot better.”

(Case 46)

“I don’t need it really. Without the injection, feel alright.”

(Case 53)

“I was forgetting things but I felt quite well, quite normal.”

(Case 56)

7.3.5.1 Consequences of illness

Throughout the community interview, respondents discussed the consequences of living in the community with schizophrenia, in particular the impact on their everyday lives.

“I feel so sad and lonely. I don’t like to keep myself clean. I don’t like to have a bath. I have lots of problems. I feel very lazy. I don’t feel like doing anything. I’m

not motivating myself, this is because of my illness. I used to be quite active and do a lot. I've got to pull myself together."

(Case 01)

"It stops me from leading a normal life, the voices."

(Case 31)

"My head it is not whole, I should be able to do things. I can't handle my money."

(Case 33)

"I'm suffering with my nerves so I don't feel like having the injection. My nerves sometimes prevents me from cooking sometimes."

(Case 49)

"I'm just here, every day is the same. Christmas Day will be the same as every other day. It will be worse thinking of Leslie [a son who died on Christmas Day]. [The illness has] ruined my life. I've got no future. They can't do nothing for me. The CPN [community psychiatric nurse] is going to get in touch with the psychiatrist. I think they're going to increase it [the medication]. It won't do any good. I'm sorry I'm so pessimistic but if you were me you would to. I wake up each morning with nothing to do. Sometimes I lie there for hours. I'm a miserable old sod."

(Case 50)

"The illness affects your whole life. I should be married by now and have children. My father passed away 2 and a half years ago. I was close to my father. I'm all on my own now. I'm lumbered."

(Case 72)

7.3.6 Behaviour of respondents in managing their medication

As for the recruitment interview (Section 6.4.5), the community interview schedules were analysed for evidence of the respondents' perceived behaviour in managing their medicines. In comparison to the recruitment interview, most respondents were now responsible for taking their own medicines. A few respondents remained under section (of the Mental Health Act, 1983) or guardianship orders in the community and were therefore, legally bound to take their medication (Case 02, Case 26, 40).

As for the recruitment data, all behaviours were not mutually exclusive. Individuals showed different combinations of behaviours, highlighting the complex nature of medication management. Some respondents demonstrated both active participation and ignored participation (Cases 2, 14). Others (Cases 68 and 70) illustrated ignored participation and reluctant acceptance. Case 27 showed active participation but also reluctant acceptance with

a different aspect of his regime. Case 49 was a reluctant acceptor of her medication and put conditions on future adherence. Case 34 demonstrated three types of behaviour: active participation, ignored participation and conditional acceptance.

1) Passive acceptance of medication

This role was identified in the recruitment interview (see Section 6.4.5). There were no quotes concerning this role in the community. However, since behaviour-types were identified from additional comments relating to the interview overall, it is likely that passive acceptance was under-represented. Respondents who were likely to demonstrate passive acceptance in the community may not have questioned their therapy and therefore were less likely to make any additional comments.

2) Active participation in managing medication

Respondents gave many comments supporting a more autonomous role in managing their medication. They reported that sometimes they discussed with the doctors dose adjustments to their medication, titrating it according to adverse and subjective effects. According to the insight questions (Section 7.2.2), only two of the respondents below had some insight into their illness (Cases 34 and 60). The remaining respondents had little or no insight into their illness. This suggests that while some may have greater autonomy in managing their medication in the community, their subjective assessment may be based on their delusional beliefs.

“[Medication has been] reduced because it was too powerful. I asked [for it to be changed].”

(Case 02)

“[Medication] used to be every two weeks but now three weeks. I said it was too high so they’re bringing it down.”

(Case 07)

“Had it increased to make it [the faces] go away. I asked it to go from 500 to 750.”

(Case 28)

“Largactil [was] added as a sedative at night. Asked my GP because the Kemadrin was keeping me awake at night.”

(Case 34)

“I was being treated for acute illness when I was in hospital, but now that I am better, they’ve reduced it without the effect being lost. I used to think that the medication used to have detrimental effects but not any more. I don’t think it disables you.”

(Case 35)

“Pimozide was stopped. I go to a Day Centre in the morning, it makes me yawn too much. I could barely get up in the morning. It makes you drowsy and do clumsy things. I stopped it myself. I told [the consultant] and he said it was alright.”

(Case 60)

Respondents often used their anticholinergic medication (sometimes prescribed to suppress the extra-pyramidal parkinsonian adverse effects that may be caused by antipsychotic medication) on an ‘as required’ basis. Case 14 had some insight into his illness (Section 7.2.2).

“Procyclidine, they’re for side-effects and sleeping, so I don’t always take them.”

(Case 14)

Active participation also developed from respondents experimenting with stopping their medication. Of these respondents, Case 27 had little insight and Case 72 had some insight into his illness. This illustrated that respondents’ risk-benefit assessment is according to their own belief systems, which may be delusional.

“Injection helps. I found it out when I missed my injection the other week. I’d had some wild thoughts about a police woman and some bad dreams. I felt a lot better after the injection.”

(Case 27)

“I’ve gone a couple of weeks without the injection. I developed strange thoughts, on a religious theme. I got them out of proportion. [What happened?] I started having them again [the injections].”

(Case 72)

3) Ignored participation in managing medication

Some respondents reluctantly adhered to their medication but were resentful because they perceived their contribution to the management of their medication regime was disregarded. Each of these respondents was rated as having some insight into their illness (Section 7.2.2).

“Just cut it down to once every two weeks, instead of every week.”

(Case 14)

“I don’t like taking too many tablets. I want to have longer time between my injections. Every week is too much for 4 years. I’d like to have them cut down.”

(Case 68)

“I would like it reduced. Eventually stopping.”

(Case 70)

Other respondents, wished for the injection to be stopped completely. Cases 02, 24, 29 and 40 each denied experiencing a nervous condition. Case 46 agreed to a nervous condition but gave delusional explanations. However, Cases 31 and 34 each had some insight into their illness (Section 7.2.2).

“I’d like to stop taking it, all of it, because it’s not doing me any good.”

(Case 02)

“I don’t like having the needle stuck in me, nor would anyone else if they had any sense. Don’t like it. Don’t like it.”

(Case 24)

“I like to try and do without it.”

(Case 29)

“I take it against my will because I have never accepted that I am sick. I just want the doctor to remove the injection and the supply of procyclidine. The stiffness is still there even after reducing the dose, although it is reduced. I want it [the medication] to be removed.”

(Case 40)

“I’d like to come off it for good.”

(Case 46)

“I just don’t feel like taking it.”

(Case 31)

“I’d like to get off it and learn how to cope without it.”

(Case 34)

4) Reluctant acceptance of medication

Reluctant acceptance was a separate behaviour from the ignored participation. Respondents who reluctantly accepted their medication admitted to wanting to stop their medication, but ultimately they continued to take it. This could be because of legal requirements (Case 02) or acknowledgement that while the medication had a negative impact, the positive effects of the medication in controlling the illness had to take priority. Cases 01, 27, 33, 49 and 54 had little or no insight into their illnesses, but Cases 68 and 70 each had some insight into their illness (Section 7.2.2).

“Just got to keep having it.”

(Case 01)

“It can be painful to have the injection, that’s the only thing. I get a bit worried when I have to go. I thought I’d leave hospital having had all the injections but apparently it takes longer than that. I’d like to come off the injections because they’re very painful. I had a tetanus with my GP and it didn’t hurt, that was in my arm. The nurse just can’t do it. Maybe my GP could dish it out. I know they’re keeping me well. I wouldn’t miss it on purpose.”

(Case 27)

“Sometimes you don’t feel like going to hospital for it, but you’ve got to take it. It’s made me better and me get back on to my feet.”

(Case 33)

“I’m suffering with my nerves so I don’t feel like having the injection. The injection could be good in a way but I don’t think it helps my nerves.”

(Case 49)

“I do get fed up of taking the tablets but I do take them all the time.”

(Case 54)

“I’ve been dodging it in the past, a week late and that because it was giving me giddy turns. I’ve stopped it for a month or two in the past but I went back to it. I’ve always felt better with it except when I’ve been having the giddy turns.”

(Case 68)

“Cos sometimes I don’t hear the voices. I don’t think I need it and then I don’t get any stiffness. I’m going to take it until I finish it. Don’t know how long for.”

(Case 70)

5) Conditional acceptance of medication

Some respondents, while currently taking their medication, commented that they intended to stop their medication in the future. This was despite two of the respondents (Cases 34 and 66) having some insight into their illnesses (Section 7.2.2).

“I feel they are a help that I’m on the road to getting better. They’re not the b-all and end-all and when I get better I won’t be needing them, but I can’t deny they’re keeping me well enough to be in society at the moment.”

(Case 34)

“If I had a job after leave college, I’d like to leave my medication and my injection.”

(Case 49)

“It makes me a little bit stiff, that’s all, but I plan to stop it in the future and I’ll see how it goes.”

(Case 66)

7.3.6.1 Behaviour influencers: community staff commanders

The community or hospital out-patient staff who were reported to influence the role of the

respondents in managing their medication, were sometimes reported to do so in a positive way. Case 29 was rated as having little or no insight into his illness, but Cases 70 and 72 each had some insight into their illness (Section 7.2.2).

“I used to shake but the doctor changed the dosage of the medication from 150 to 100 so I don’t shake any more.”

(Case 29)

“It’s been reduced from 200 to 150. I saw [the consultant] in Hackney Hospital and they said they’re going to reduce it.”

(Case 70)

“The Valium is down. I’m on one tablet three times a day. I was on two tablets three times a day. They thought I was taking too many, the doctors.”

(Case 72)

Some respondents reported that staff altered the medication regime without explaining their reasons to the respondents. Respondents frequently mentioned a lack of information from the staff. Each of these respondents were rated as having some insight into their illness (Section 7.2.2).

“Amitriptyline decreased. Don’t know [why], they said they were going to reduce it.”

(Case 31)

“I’m addicted to the Valium. They didn’t tell me that until I’d been taking them 3 months...The CPN is going to get in touch with the psychiatrist. I think they’re going to increase it [the injection].”

(Case 50)

The respondents who were in the community and still under a section of the Mental Health Act (1983) were resentful of the control the staff members had over their medication and its management. Others who were not formally expected to take their medication reported that community mental health care staff made home visits to respondents who had not attended for their medication. Case 40 did not have any insight into his illness. However, Case 68 was rated as having some insight into her illness (Section 7.2.2).

“The injection made me feel stiff and my walking was bad so they decreased the dose. They now give me 250mg. It started at 750mg, then they reduced it to 500mg, but because of the stiffness and my walking they have reduced it to 250mg. I just want the doctor to remove the injection and the supply of Procyclidine. The stiffness is still there even after reducing the dose, although it is reduced. I want to know when I will be discharged from the medication. When the medication will be stopped.”

(Case 40)

“I’ve stopped it for a month or two in the past but I went back to it...They used to come to my house and persuade it. They’ve doubled 40 to 80mg.”

(Case 68)

7.3.7 Therapeutic information gaps expressed by respondents in the community

Many respondents expressed a need for more knowledge about their depot medication and its alternatives during the community interview.

“I wish I could not have the injection. Is there any alternative?”

(Case 01)

“I only get the injection, I know nothing more.”

(Case 07)

“I’d like to know whether the medicines are good, whether the injections are good.”

(Case 21)

On other occasions, the respondents reported misinformation about their therapy.

“[Nurse] says the injection gives me vitamins to give me an appetite but I have an appetite, I like to eat food...Don’t know if they told me why I was on medicines.”

(Case 24)

Long term aims of therapy and the long term nature of the illness were rarely understood.

“I wonder how long I’ll be on the injection. I’ve heard stories from people who’ve been on it a long time. I know someone who’s been on it 5 years. They say I’ll be cured after a course of injections. Don’t know how long the course is. They’ve discussed it with me but Dr L said that I’d only be on the injection in the end, that would be my only medicine. I wished I knew more. They didn’t tell me much. I was never as ill as that day I missed my injection...Still not sure whether the injections are partly to blame for the illness.”

(Case 27)

“I have never known why I should take the medication. I want to know when I will be discharged from the medication, when the medication will be stopped.”

(Case 40)

“I don’t know if its any good for me because sometimes I feel well when I don’t take it. Sometimes I feel it’s not worn out before I take another injection.”

(Case 60)

Other health worries and whether the causes of these were linked to their mental health or their antipsychotic medication confused the patient.

“Sometimes I suffer with diarrhoea and I’m incontinent sometimes. I don’t know what’s causing that.”

(Case 49)

My libido. I don't know if it's the injection or not, or my illness. It's disappeared. I haven't got any libido. This is the one that bothers me the most."

(Case 89)

7.3.8 Medication changes since discharge from hospital

Most patients (21, 57%) reported that their medication had changed since they were discharged from the hospital (Table 7.24). Most frequently, the dose of the intramuscular antipsychotic medication had decreased (8, 38%). The doctor had instigated the change in the majority of cases (11, 52%).

Table 7.24 Medication changes after discharge from hospital as reported by the respondents

	Sample in community (n=37)
	No. (%)
Has your medication changed since you were discharged from hospital?	
Yes	21 (57)
No	15 (40)
Don't know	1 (3)
In what way, has your medication changed?	n=21
Intramuscular antipsychotic medication decreased	8 (38)
Intramuscular antipsychotic medication increased	5 (24)
Antipsychotic medication stopped and new medication started	2 (9)
Antipsychotic tablets stopped	2 (9)
'Other' medication changed	3 (15)
Don't know	1 (5)
Who made the decision to change the medication?	n=21
Doctor instigated change	11 (52)
Patient instigated change with doctor	7 (33)
Patient instigated change without doctor	1 (5)
Not answered	2 (10)
Total number of respondents	37

7.3.9 Intentions of medication adherence after discharge from hospital and resulting medication adherence in the community

Intentions of taking medication after discharge from hospital, expressed at the recruitment interview, were compared with the medication adherence status in the community. Table 7.25 shows that a large proportion of people who reported that they intended to take their medication after discharge from hospital, went on to be regular attenders for their depot (intramuscular) antipsychotic medication. However, the numbers were too small for statistical comparison.

Table 7.25 Intentions of medication adherence after discharge and resulting adherence status

Feelings at time of recruitment interview in hospital	Depot Attendance Status (n=43)			Total community sample (n=43)
	Regular attender for depot medication (n=23)	Irregular attender for depot medication (n=14)	Non-attender for depot medication (n=6)	
	No. (%)	No. (%)	No. (%)	No. (%)
Intention of taking medication after discharge from hospital				
Yes	18 (42)	13 (30)	4 (9)	35 (81)
No	2 (5)	1 (2)	2 (5)	5 (12)
Don't know	3 (7)	0 (---)	0 (---)	3 (7)
How do you feel about taking medicines after discharge from hospital?	n=18	n=13	n=4	n=35
Alright / indifferent	4 (11)	3 (9)	0 (---)	7 (20)
Obliged / no choice	3 (9)	2 (6)	0 (---)	5 (14)
Unhappy	3 (9)	1 (3)	0 (---)	4 (11)
Conditional response (e.g. "As long as it doesn't make me drowsy")	1 (3)	0 (---)	2 (6)	3 (9)
Happy	1 (3)	1 (3)	0 (---)	2 (6)
Unsure	1 (3)	0 (---)	0 (---)	1 (3)
Missing information (question added later)	5 (14)	6 (17)	2 (6)	13 (37)
Total number of respondents	18-23	13-14	4-6	43

7.3.10 Non-attenders for depot medication at time of community interview

The 6 non-attenders are those respondents who, at the time of the community interview, were no longer receiving their depot (intramuscular) antipsychotic medication. Reasons for non-attendance were explored with each respondent. Qualitative information was gathered from the questionnaires to explore their experiences. It must be noted that while these non-attenders had stopped their depot (intramuscular) antipsychotic medication, Cases 08 and 58 were prescribed oral antipsychotic medication. Adherence rates to oral therapy were not explored.

7.3.10.1 Reasons for stopping attendance for depot medication

Only one of these respondents (Case 09) was rated as having some insight into her illness (Section 7.2.2). All of the remaining respondents either denied experiencing a nervous condition (Cases 08, 11, 45, 58) or agreed to a nervous condition with delusional explanations (Case 64).

- **Case 08**

Case 08 reported that the hospital had stopped her medication, but information from her medical notes did not concord with this reason.

“They stopped it, the hospital. The Consultant came and see me and stopped them straight away because they weren’t doing me any good. I was in a coma, they couldn’t wake me up.”

- **Case 09**

Case 09 reported the adverse effects associated with her medication and the negative consequences of adhering to the medication.

“Because I was sluggish, depressed. I was wanting to eat continuously. I couldn’t have conversation. My joints were very painful... I couldn’t find the energy to clear up the flat, read. I felt I may as well be dead if I was going to be on medication for the rest of my life.”

There also seemed to be some confusion between the adverse effects of medication and potential residual symptoms of illness.

“I kept going off into fantasy. I couldn’t focus my mind.”

Case 09 commented on her battle with the ‘community staff commanders’ who were trying to influence her behaviour.

“[Did you discuss this decision with anyone?] My decision. I was the only one who knew what was happening to me. The social worker and Jane [CPN] tried to persuade me but I refused. I managed to hold firm.”

- Case 11

Case 11 reported that the administration of his medication hurt and so he stopped it. He commented that he felt better and suggested that he had moved on from the mental health services.

“It hurts and I feel I’m a bit better now. I’ve stopped going to the day centre. It’s closed down, the one Albion Road. I would like to look for work now, I am still unemployed.”

- Case 45

Case 45 reported that he had stopped his medication because he had lacked the choice in hospital. (Case 45 was formally detained in hospital). His comments suggested that he did not understand the need for medication and by stopping the medication he was expressing autonomy and taking charge. He talked of the ‘staff commanders’ controlling his decisions.

“[Did you discuss this decision with anyone?] No. I just decided to not take any medication. In the first place I wasn’t given any medication in the manner in which I wanted to be given it. I was restricted, I was detained, so I didn’t feel it was appropriate. I didn’t feel I was in distress once I left hospital, so I didn’t feel I needed it. My information I give, about the way I feel, is not taken into consideration but the psychiatrist tells me how I’m feeling, which is out of order I think. They’ve allowed me to do as I please [stopping medication] at present.”

- Case 58

Case 58 had stopped his depot medication and two months later he started taking oral antipsychotic therapy. The researcher questioned both the use of the depot and oral medication. He recognised that there were adverse effects with both types of medication, however, he perceived there were fewer adverse effects with the tablets.

“Too much side-effects. Doctor put me back on the pills. I’ve only just come back on them. [How do you find the pills?] Alright. When I came off the injection there was a gap of about two months and I felt fine, no symptoms. But the pills are better than the injection. [The pills] make me drowsy still but not as much as the injection. I feel the injection was a higher rate, dose. [Did you have any problems with your injection?] Tiredness, drowsiness. When it’s time to get up, you still feel tired, put on weight, couldn’t drink wine or beer, it would taste horrible. It would really affect

you in a bad way. Stiffness, cramps in my body. Speech slurred. *[Do you feel that the side-effects you have just told me about affect anything you do, or anything you would like to do?]* With the pills, find it difficult to ride my bike. *[What about the injection?]* Looking for work, confidence went.”

- Case 64

Case 64 described the negative consequences of adhering to the depot antipsychotic medication.

“Because of the side-effects of the medication. Dizziness, lack of concentration affects your body temperature, there is an imbalance, you’re not sure of your movement, you’re disorientated. Mainly couldn’t go from step one to step two, that is you’d know what to do but couldn’t actually do it.”

7.3.10.2 Consequences of stopping depot medication

The non-attenders described their experiences since stopping their depot antipsychotic medication.

- Case 08

Case 08 reported the benefits of stopping the depot in terms of no longer experiencing the adverse effects.

“They stopped it for good because it was killing me off. It’s making me feel better. The injection was affecting me. I was going giddy and flaking out.”

- Case 09

Case 09 also described the remittance of the adverse effects on stopping the depot medication. She conceded that she benefited from receiving the medication but there was an underlying mistrust of the medication.

“I’m getting better and better. [Above] symptoms have gone and even my joints are more oiled, less stiff. I will say I did need it. I don’t know if I’ll get any better than I am, it’s just a question of time to let the medication come out of my system. When I came off the Stelazine and the amitriptyline, my mind became very rapid and all the memories that the Stelazine had blocked out, came back. I had visions, not hallucinations, like a film of my life. The injection decanoate stopped it completely. I was put on Haloperidol first and that made me worse.”

- Case 11

This gentleman did not mention any benefits from taking the medication. He seemed glad that he was no longer receiving the injection because it hurt and since stopping it, there had been no adverse events.

“I feel alright.”

By the end of the interview, his comments suggested that he preferred to ignore any signs of illness and its treatment and wanted to try to get on with his life.

“I’d find myself in hospital if I brought up all the problems. It would be obvious I would need medical care. I’m hoping for a better day tomorrow.”

- Case 45

Case 45 was keen to stop his medication to increase his autonomy, however, he also acknowledged an increase in anxiety and subsequent negative consequences. He expressed a need for greater information about medication.

“I guess I am a little bit more anxious than usual. No difference than an increase in anxiety. The anxiety affects my outlook and how I deal with things in general. I’m not sure if the pills they give me are for treatment or prevention.”

- Case 58

Case 58 conceded to go back to an oral form of antipsychotic medication, however, preferred to be medication-free.

“I felt alright off the pills and the injection. I felt much more refreshed. I didn’t feel so drugged.”

- Case 64

This gentleman talked of his clarity of thought without medication. He acknowledged that an inpatient stay may have its place when an individual has problems, however, he challenged the use of medication in correcting illness.

“I feel fine. You take stock. You have to look at the past and see where things have gone wrong. Medication is a good way of incarcerating people in their mind instead of in jail. I believe life itself lasts a long time. During the course of your life, you may occur problems which seem insurmountable. Therefore, you may need a period in hospital. I wouldn’t call it illness. It is life negating a path to move on. [Medication] doesn’t actually help but modifies it. It puts it in a stored compartment. The medication envelopes the problems and disguises it. Therefore, on medication, you don’t know if the problem is reality.”

7.4 Summary

This section summarises the data presented in Chapters 6 and 7 in relation to the characteristics of the respondents of the recruitment and follow-up interviews, their drug therapy and the perceived effects and problems of their medication.

Recruited sample in hospital

The sample of in-patients recruited to this study (n=79) were mainly male (61%), aged less than 40 years (63%) and were either single, separated, divorced or widowed (91%). Almost half the sample (47%) reported themselves to be either Black African, Black Caribbean, Black U.K./British or Black other; 24% of the sample reported themselves to be White. National statistics for the districts of Hackney and Tower Hamlets report that 15.7% of all residents are Black Caribbean, Black African or Black other and 68.5% of all residents are White (Office of Population Censuses and Surveys, 1991:101, 110) illustrating a disproportionately high representation of Black respondents in this study sample. This information concurs with other studies that have found that Black Caribbean people are at a higher risk than White people of being admitted to a psychiatric hospital (Moodley and Thornicroft, 1988) or diagnosed with schizophrenia (Harrison *et al.* 1988; King *et al.* 1994). The literature does not provide a clear response to this finding. Although authors suggest that it is evidence that environmental factors have a causative role in psychotic illness among immigrant groups (e.g. Bhugra *et al.* 1996).

In this study, clinical diagnoses were confirmed using the DSM-III-R criteria (American Psychiatric Association, 1987) for schizophrenia and medical notes. Most of the participants in this study were chronically and severely mentally ill with long psychiatric histories and repeated admissions to hospitals. Almost half the sample had been diagnosed with schizophrenia for at least 10 years (44%) and some were 'revolving door' patients, experiencing repeated cycles of being admitted and discharged from hospital. About one-third of the respondents had experienced 6 or more previous admissions. Forty-eight per cent of the sample had experienced at least one other in-patient episode for their mental illness within the previous 12 months. According to medical notes, 71% of respondents had stopped

their antipsychotic medication before their current admission to hospital and 61% of the sample were 'sectioned' during their admission (detained in hospital using the Mental Health Act (1983)). The literature suggests that people from different ethnic groups display different patterns of service use and help-seeking behaviour. Davies *et al.* (1996) reported that Black Caribbeans with psychotic illness seemed to have less voluntary contact with services and were much more likely to be coercively treated, e.g. being detained in hospital under the Mental Health Act. However, in this study, the respondents who reported themselves black were no more or less likely to be detained in hospital using the Mental Health Act (1983) than those respondents who reported themselves as white.

The Global Assessment of Functioning Scale (GAF Scale) (American Psychiatric Association, 1987) is a measure of psychological, social and occupational functioning and illustrated that most respondents (72%) had varying types of major impairment or symptoms in hospital.

Socioeconomic indicators such as level of qualifications, most recent occupation and housing tenure illustrated that the sample mainly belonged to the lower socioeconomic groups. Almost half the sample (49%) reported that they did not have any written qualifications. According to the General Household Survey 1993 (Office of Population Censuses and Surveys, 1995:163) 33% of the general population aged 16-69 years in Great Britain had no qualifications. Social Trends 25 (Central Statistical Office 1995:57) reported the variation in highest qualification attained for people aged 25 to 69 years according to socioeconomic groups in 1992-93. Of 'professionals', 61% had a degree. By comparison, less than 1% of manual skilled workers had a degree and 70% were without any qualifications.

Social class was recorded using the Registrar General's Classification of Occupations (Office of Population Census and Surveys, 1980) according to the respondent's most recent occupation. Occupational functioning was low with most people being unemployed before their current admission (89%) and many had not worked full-time for at least five years (53%). Almost half the sample (49%) belonged to social classes IV and V according to this classification system and a further 15% had never worked. Almost half the respondents (46%) did not intend to look for work after they were discharged from hospital, mainly due

to their state of health. Data from the General Household Survey (Office of Population Census and Surveys, 1995:58-59), showed that 8% of the population aged 18-64 years (n=13,846) were unemployed (looking for work in previous four weeks and available to start work) and 23% were inactive in 1993.

Almost two-thirds of the respondents (52, 66%) were renting local authority accommodation before their current admission to the hospital. Six people (7%) were of no fixed abode and one person (Case 02) was transferred to the hospital from prison. Most respondents were living alone (58%). According to social survey data, most of the adults in Great Britain in 1993 were owner occupiers (67%) and 22% rented from local authorities (Office of Population Census and Surveys, 1995:30).

The potential burden on carers was evident, with 53% of the sample reporting that they expected support from relatives after discharge from the hospital. Fifteen respondents were living with parents and/or siblings before their current admission. Some respondents reported that they were dissatisfied with the amount and type of support received from relatives illustrating sources of conflict that have been shown to compromise rehabilitation, e.g. expressed emotion (Brown *et al.* 1958; Brown, 1959; Leff, 1986). However, 43% of the sample was unsure of, or did not have, any relative support after discharge. Of these respondents, 60% would have liked to receive regular visits from relatives after discharge.

Insight to illness was explored using questions taken from the Present State Examination (PSE) (Wing *et al.* 1974). Thirty-six (45%) denied experiencing a nervous condition, 21 (27%) gave delusional explanations for their nervous condition while the remaining 22 (28%) had some level of insight (see Section 6.3.4). The most common reason respondents gave for admission was for their health or safety (57%). The most common symptoms described were hallucinations (23%). However, almost half the sample (42%) reported that they had not experienced any symptoms of illness at the time of admission. As expected, far more details and a greater number of symptoms were reported in the admission medical notes. At the time of the interview, 54% of the sample reported that they were not experiencing any symptoms. Of those who reported symptoms, most commonly, 13% reported somatic symptoms.

More than half of the in-patient respondents reported experiencing some type of problem that was making their illness worse at the time of admission (64%) and at the time of the recruitment interview (52%). Accommodation problems were the most common type of problem reported on both occasions (29% and 18% respectively). During the recruitment interview, 31 respondents (39%) reported experiencing additional physical or other health problems. On 10 occasions, the health problem reported may have been an adverse effect of their medication.

Follow-up sample in the community

Forty-one respondents completed and two respondents part-completed both the recruitment and follow-up interviews (response rate=74%; n=58) (see Figure 6.1). Socio-demographic characteristics of the community sub-sample did not differ significantly on any variables compared with the non-responders of the community interview (i.e. those who completed the recruitment interview only). Length of in-patient stays of the community sample was less than 2 months for 14 respondents (32%), 2-6 months for 16 respondents (38%) and 6 months or greater for 13 respondents (30%).

According to the measurement of insight, 25 of the 41 people (60%) who completed the follow-up interview denied experiencing a nervous condition at the time of the community interview. Five (12%) gave delusional explanations for their nervous condition while the remaining 12 (29%) had some level of insight (see Section 7.2.2).

Twenty respondents (49%) reported that they wanted more information about the state of their health. Seventeen respondents (41%) reported that they felt discriminated against because of the state of their health. There was no relationship between how informed respondents felt and the stigma reported. The stigma experienced by the respondents compounded their difficulties of adjusting to a meaningful role in the community. Respondents gave examples illustrating the disabling effect of the stigma on gaining employment.

Twenty-seven respondents (64%) reported not experiencing any symptoms that were making

their illness worse in the community. The most common symptoms reported were somatic complaints (6, 14%). Of the 22 respondents (52%) who reported experiencing problems in the community that were making their illness worse, accommodation was the most common type of problem (7, 17%). In the community, 22 respondents (52%) reported experiencing additional physical or other health problems. On three occasions the health problem reported may have been an adverse effect of their medication. Most of the respondents (25, 58%) had varying types of major impairment or symptoms in hospital. Severity of illness (represented by the Global Assessment of Functioning Scale (GAF Scale) (American Psychiatric Association, 1987)) had not significantly improved from the measurement in hospital.

Medication adherence in the follow-up period

Thirty-seven respondents were adhering to their medication (at varying rates) by the time of the community interview (on average five months after discharge from the hospital). However, 6 respondents had stopped their medication. The distributions of medication adherence for depot attendance and depot day attendance were negatively skewed (range: 0-100%; median: 100%). The mean depot attendance was 86% and the mean depot attendance on the expected day according to the prescription was 81%. From a research perspective, it was disappointing that there was not a greater variation in adherence rates. A longer follow-up period may have achieved greater variation in medication attendance rates. However, in this study, 9 of the recruited respondents could not be interviewed in the community because they had been readmitted to hospitals within at least a 3-month follow-up period. Future studies considering a longer follow-up period also would have to consider the potential loss of respondents for follow-up interviews.

The arbitrary classification of regular (23, 53%), irregular (14, 33%) and non-attenders (6, 14%) illustrated a greater split to the group. While, the cut off for irregular attenders may appear severe by < 100% attendance on the expected day as prescribed, it was felt that because medication was 2-weekly or monthly then this cut off demonstrated a reluctance to attend for their medication independently. For those respondents who received their medication on a later date than accorded by their prescription, it was more likely that a community staff member had reminded the respondent to attend for their medication (clinic

nurses would telephone the clients/carers at home) or the community psychiatric nurse (CPN) would make a home visit. Most commonly, respondents received their medication because a CPN had visited them at home (18, 42%; n=43).

The respondents of the community interview were under represented by those, who in hospital, reported that the unwanted effects of their medication affected their activities (χ^2 test using Yates' continuity correction=4.375; p=0.036). It is unknown whether these respondents would have had poorer medication adherence rates. However, for those respondents who were followed-up in the community, there was no relationship between medication adherence rate and the report of unwanted effects of medication affecting activities.

An objective of this study was to investigate the views and experiences of antipsychotic medication of people with a diagnosis of schizophrenia, at baseline in hospital and again, at least three months post discharge in the community. This study also wanted to explore any changes in the respondents' views and experiences of antipsychotic medication between the hospital and the community settings. Analysis of the data showed few relationships between the information reported at baseline in the hospital and the responses to the same questions with the same respondents in the community. This may suggest a lack of reliability in reporting or may be identifying real change in the responses from the clients. However, analysis was difficult in some categories due to the small numbers.

Medication issues in hospital and the community: quantitative and qualitative data

Four medication issues were explored for their relationship with medication adherence: ability to name medication, perceived effects of medication on symptoms, perceived unwanted effects of medication and their subsequent effects on activities, experience of wanting to discontinue medication. Unexpectedly, different medication-taking behaviours, an unmet need for information about the medication and the illness were also identified after further qualitative analysis of the responses to the open questions of the interview. Relationships of these issues with medication adherence will be reported in Chapter 10.

i. Ability to name medication

Sixty-two respondents (78%; n=79) reported that they knew the medication they were taking when in hospital. However, only 33 respondents (42%) could name them all. In the community, 35 respondents (95%; n=37) respondents claimed to know all the medication they were taking; two-thirds of whom (22, 66%) could name all their medication. Community respondents were significantly more likely to name all their medication, if they had known all their medication in hospital (χ^2 using Yates' continuity correction =3.78; p=0.05). However, a greater proportion of respondents could name all their medication in the community compared with hospital (McNemar test; p=0.022).

Over half the respondents in hospital (56%; n=62) reported both oral and intramuscular antipsychotic medication. The literature does not support the routine co-administration of both oral and intramuscular antipsychotic drug therapy because the associated risks have not been quantified (Pathare and Paton, 1997). However, in a hospital setting, using adjunctive oral therapy with intramuscular injections for the additional sedative effects can be appropriate. At the time of discharge from hospital (n=71), 52% of respondents' discharge summaries listed both oral and intramuscular antipsychotic therapy. In the community, about five months after discharge, 37 people were taking medication and of these 26% reported taking oral and intramuscular medication.

Half the patients in hospital who knew the name of their medication (31, 50%; n=62) and 20 patients in the community (57%; n=35) named an anticholinergic medication. It was unknown if they were prescribed as prophylactic therapy or as treatment for extra-pyramidal side-effects. In the literature, incidences of extra-pyramidal side-effects have been reported between 2.3%-40%, depending on the accuracy of assessment and the dose of drugs prescribed (Marder, 1996a). Extra-pyramidal side-effects have been estimated to cause 40-65% of outpatients with schizophrenia to stop oral antipsychotic medication within the first six weeks of therapy (Morrison, 1996). However, it is debated whether routine prophylactic prescribing of anticholinergic therapy should occur (Pathare and Paton, 1997). As a class of drug it also has its own adverse effects such as drowsiness, blurred vision, dry mouth and constipation. Furthermore, it is acknowledged that anticholinergic drugs have an abuse potential. Anecdotally, in this study, the respondents recounted the potential 'street value'

of anticholinergic drugs (one procyclidine tablet was worth £1 in Hackney).

ii. Perceived effects of medication on symptoms

In hospital, when asked about the effects of medication on their symptoms, 52% of respondents acknowledged that medication had positive or beneficial effects. (These respondents were more likely to report that medication helped their symptoms ($p=0.05$) when asked a leading question later in the questionnaire). Others (13%) discussed both positive and negative effects of medication on their symptoms. About one-fifth of the respondents (21%) thought that their medication had negative or detrimental effects on their symptoms. Respondents who reported negative effects of medication were significantly more likely to be experiencing an involuntary admission (detained using the Mental Health Act) than those who reported positive or beneficial effects of medication (χ^2 test using Yates' continuity correction=4.157; $p=0.041$).

In the community, 54% of respondents (20; $n=37$) described their medication as having positive or beneficial effects on their symptoms. Again, these respondents were more likely to report that medication helped their symptoms ($p=0.004$) when asked a leading question later in the questionnaire, illustrating consistency in reporting. One respondent (3%) discussed both positive and negative effects of medication on their symptoms while 6 (16%) only reported perceived negative or detrimental effects of medication on their symptoms.

There was no relationship between the proportion of respondents who reported positive effects of medication in hospital and whether they reported positive or negative effects in the community. Similarly, no relationship was identified between those who reported that medication helped their symptoms in hospital and those who reported that medication helped their symptoms in the community.

Qualitatively, respondents' comments illustrated a spectrum of views on the effectiveness of their medication, both in hospital and in the community. Some respondents described the positive effects on specific symptoms while others were more global about recognising a calming effect or an enhanced coping ability. Other respondents recognised the limitations of their medication and the persistence of residual 'symptoms'. However, in some cases the

residual 'symptoms' described may have been adverse effects of their antipsychotic medication. Others suggested that the positive effects experienced were transient and that symptoms returned. A discrete group of respondents reported that the medication did not provide any benefit to their symptoms and in some instances made them feel worse.

iii. Perceived unwanted effects of medication and subsequent effects on activities

In hospital, 52 respondents (66%; n=79) reported unwanted effects with their medication. Most commonly sedation (17, 33%) and parkinsonian side-effects (17, 33%) were described. Of those respondents in hospital who described extra-pyramidal side-effects, 62.5% also reported taking an anticholinergic medication that may be prescribed to treat the extra-pyramidal side-effects (75% of their medical notes recorded the prescription of an anticholinergic drug). By comparison, in the community, 19 respondents (51%; n=37) reported experiencing unwanted effects from their medication. Again, parkinsonian side-effects were the most common type described (13, 68%). Two-thirds of the respondents who reported extra-pyramidal side-effects also reported taking anticholinergic medication and 80% of their medical notes had anticholinergic medication recorded. This data may suggest either that respondents were not taking the anticholinergic medication prescribed or that respondents were taking medication that was ineffective in managing the extra-pyramidal side-effects. Alternatively, the extra-pyramidal side-effects described may have been residual symptoms of the schizophrenia disorder. It is well-known that differentiating between some of the adverse effects of antipsychotic medication and the symptoms of schizophrenia can be difficult.

Respondents who reported unwanted effects of medication in hospital were significantly more likely to report unwanted effects in the community (χ^2 using Yates' continuity correction =4.79; p=0.029). The range of unwanted effects of medication was too large to compare the type of unwanted effect described in hospital and the community due to the small sample size.

About half the respondents that reported unwanted effects of medication both in the hospital (54%; n=52) and in the community (47%; n=19) also reported that subsequent activities were affected. When all respondents in the hospital (n=79) and in the community (n=37) were

asked about the consequences of both the symptoms of their illness and their medication, about half (39, 49%; 18, 49% respectively) reported that, in general, the way they spent their days was affected (e.g. hobbies, leisure time) and mostly in negative ways (36, 92%; 18, 100% respectively). No relationship existed between the hospital and community settings for those respondents who reported that their medication, its unwanted effects or their symptoms affected their activities. However, the community sub-sample was very small for further analyses.

Qualitatively, respondents discussed the effects of medication on their quality of life and subsequently, the negative impact on leading a productive life. In particular, the negative effects on personal activities such as reading, household chores, hobbies and activities and a working life. Some comments from the community questionnaire demonstrated a determination to cope and live their lives while tolerating the adverse effects of medication. Other comments simply described the potential extreme level of adverse effects with antipsychotic medication. A few respondents attributed their improved social functioning and coping to adhering with their medication regimes. Other comments made by respondents illustrated the lack of knowledge about the potential adverse effects of medication. Some respondents classified these effects as physical or other health problems.

For most people (70%), the benefits of antipsychotic medication versus placebo are well established (e.g. Davis, 1975). However, as discussed in Chapter 1, these benefits are not experienced by everyone, and the benefits that are measured are often recorded as the effect on positive symptoms and not as improvement in occupational or social functioning. The community care of people with schizophrenia has to go beyond the management of positive symptoms. Current government, in response to recent violent incidents in the community where it has been claimed that individuals have stopped their medication, is discussing the possibilities of compulsory drug treatment orders in the community. Consideration must be given to the ethical debate of coercively treating people with traditional antipsychotic medication when there are atypical drugs that have the same efficacy for positive symptoms, yet an improved side-effect profile. Given the range of responses to traditional antipsychotic drug therapy, the potential for adverse effects (including long term irreversible effects such as tardive dyskinesia) and the subsequent compromised occupational and social functioning,

(both from untreated symptoms and the adverse effects of medication), care must be taken in any recommendations. Issues, such as the identification of people for involuntary community drug treatment and the ethical issues of treating people with traditional antipsychotic medication instead of the newer atypical drugs with improved adverse effect profiles, would have to be addressed. Further, recommendations concerning the role of concomitant therapies (e.g. psychological techniques, family therapy) with drug therapy would also have to be examined.

iv. Experience of wanting to discontinue medication

Three-quarters of the hospital respondents (60, 76%) reported that they had wanted to stop their medication, irrespective of whether they had actually stopped their medication. This figure is near to the 71% reported in medical notes as stopping their medication before admission to hospital. The most common reason for wanting to stop their medication was the experience or fear of side-effects (33%) followed by the perception that medication was unnecessary or unhelpful (25%). However, when the 60 respondents who had reported that they had wanted to stop their medication were asked if they had stopped their medication, 38% (n=60) of the respondents reported that they had not.

Most commonly in-patient respondents who reported that they had stopped their medication, also reported that nothing had happened as a consequence of stopping their medication (21%). Alternatively, a further 18% recognised that their symptoms or illness had become worse. Some respondents had gained an informed insight to their illness and its drug management through experimentation by stopping their medication. Others focused on the positive impact of stopping their medication through perceived improved occupational and social functioning. Qualitatively, respondents gave vivid accounts of the negative impact of living with the symptoms of schizophrenia on every day functioning in the community.

During the community interview, 25 respondents (68%; n=37) reported that they had wanted to stop their medication. The lack of perceived therapeutic benefit (11, 44%; n=25) was the most common reason in the community, followed by a lack of motivation to adhere to their medication (8, 32%; n=25). On further exploration with these respondents (n=25), 10 respondents (40%) claimed that they had never stopped their medication in the past. Of those

who reported that they had stopped their medication in the past, the most commonly perceived outcome was that nothing had happened (6, 24%). A close second was the recognition of immediate feelings of benefit followed by illness (4, 16%). However, caution must be applied to these results due to the small numbers.

Experience of non-adherence gave some respondents an informed insight into the benefits and risks of adhering or not adhering to the medication. Other clients reported an improvement in their subjective well-being after stopping their medication. Feelings of wanting to stop medication in the hospital were not associated with feelings of wanting to stop medication in the community.

Medication-taking behaviours

From the explorative analysis of the descriptive comments made by the respondents throughout both hospital and community questionnaires, five types of medication-taking behaviour were identified: passive acceptance; active participation; ignored participation; reluctant acceptance; conditional acceptance. Behaviour-types were not mutually exclusive but identified individuals' expressions about how they interacted with their medication. All comments were analysed together and the behaviours 'emerged' from the data, with some individuals expressing more than one type of behaviour at different points in the data. Due to the lack of exclusivity of the behaviour-types, analysis of other factors that may be associated with particular behaviour types was not explored in detail. Although, behaviour types were considered with the level of insight of the respondents. Active participation had the greatest association with insight compared with the other behaviour types. Most of the other behaviour-types were associated with a lack of insight suggesting that the respondents who made the most comments in response to the open questions were those lacking insight into their illness.

The qualitative analysis was in response to comments made to the semi-structured questions and as such respondents were discussing issues according to the researcher's agenda. Future research may be aimed at corroborating these behaviour types by in-depth respondent-led interviews and then mapping associated factors such as voluntary or involuntary admissions and medication adherence rates.

Evidence of validity of the classification of behaviour-types was pursued was by comparing the behaviour types post-analysis with the literature. Szasz and Hollender (1956) described three basic models of interaction of the doctor-patient relationship: activity-passivity, guidance-cooperation and mutual participation. They discussed the temporary nature of the categories and suggested that as a patient's needs change then so will the doctor-patient relationship. Diamond (1985) divided his psychiatric patients into four groups depending on their reactions to their medication: '1) patients who are actively symptomatic and agree that drugs help, 2) those who stay on medication because it has stabilized them, 3) those who are currently symptomatic but refuse to take medication, and 4) currently asymptomatic patients who deny the need for medication'. He also found that patients did not fit precisely into anyone group but that the reactions were based on a continuum. Comparisons may be drawn between the literature and the types of medication-taking behaviour identified in this study described above providing some evidence of validity for the qualitative descriptions.

Respondents' views of the hospital and its staff were of particular importance to those who exhibited ignored or reluctant participation. Respondents identified a coercive factor describing hospital staff with a controlling role. Individuals expressed a lack of autonomy and involvement in decisions about their medicines. These feelings of mistrust associated with the medication and health care staff remained with the respondents after discharge to the community.

The majority of respondents interviewed in the hospitals (80%) reported that they intended to take their medication after they were discharged. In the community, on average five months after discharge, 23 (54%) were regularly receiving their depot medication, 14 (32%) were irregularly receiving their depot medication and 6 (14%) had stopped their depot medication. A similar range of medication-taking behaviours was identified in clients' responses when discussing behaviour after discharge from hospital: passive acceptance, active participation; reluctant acceptance, conditional acceptance and autonomous management. Autonomous management was a new behaviour type identified when discussing medicine management after discharge compared with medicine management in hospital. It seemed obvious to some respondents that discharge from hospital signalled autonomy and that now they could decide whether they wanted to take their medication,

irrespective of health care practitioners' views and opinions. In these instances, the 'controlling' power had been shifted to the individuals. This finding suggests that for some individuals, who see the management of medicines as an expression of power between health care professionals and themselves, it may be beneficial to give them the 'control' when still in hospital. This would alleviate the need to stamp their autonomy when they were discharged, which seems to be represented by stopping their medication. At the time of the study, the hospitals involved did not have any self-medication schemes by which people were given the opportunity to manage their own medication while still in hospital. It has been shown that self-medication schemes on psychiatric wards can enhance a patient's ability to cope with their own medicines after discharge (Pratt and Dunnett, 1985). Similarly, in many other patient groups, 'patient own drugs' studies are taking place to measure the effects, in terms of understanding, medication adherence and costs, of patients bringing in their own supplies of medication from home when they are admitted to hospital.

During the community interview, respondents discussed the consequences of living in the community with schizophrenia, in particular the negative impact on their quality of life, characterised by sadness, loneliness, poor social functioning, a lack of activities and a feeling of not reaching society's expectations. As for the recruitment interview, the community interview schedules were analysed for evidence of the respondents' perceived behaviour in managing their medicines. In comparison to the recruitment interview, most respondents were now responsible for taking their own medicines. A few respondents remained under section (of the Mental Health Act, 1983) or guardianship orders in the community and were therefore, legally bound to take their medication (Cases 02, 26, 40).

Passive acceptance was not identified as a behaviour of the community respondents. However, it is likely that this particular behaviour-type was under-represented since identification of behaviour-type was from the clients' responses to open questions. The behaviour-types were an indirect finding from the data and therefore, respondents who passively accepted their medication may have been less likely to make comment. In general, respondents demonstrated greater autonomy and active participation in managing their medication in the community by giving examples where they were involved and instigated changes to the medication regime according to adverse and subjective effects. Also, they

demonstrated their autonomy by reporting instances of titrating ‘as required’ medication (e.g. anticholinergic therapy) according to their needs. Others mentioned occasions of becoming non-adherent and then restarting therapy due to their perceived decline in mental health.

Some participants still felt that their contribution to medication therapy was discounted: ignored participation. Within this category of behaviour, some respondents questioned the long-term need for medication suggesting that there would be a time when they would stop all medication. Identification of this type of behaviour could highlight those patients most at risk of discontinuing therapy and may be targeted for educational or behavioural intervention or increased health personnel involvement. Others demonstrated more of a reluctant acceptance, highlighting their displeasure at having to take medication but their comments were not suggestive of stopping their medication. Some comments illustrated a risk-benefit analysis of their medication. Others suggested different strategies that may help with accepting their medication such as receiving their injection from the general practitioner instead of the nurse. Other comments discussed their current acceptance of medication but laid down conditional reasons for this behaviour to continue: conditional acceptance.

Patterns of behaviour in relation to insight categories were less clear than with the in-patient data. Half of those respondents demonstrating active participation and half of those demonstrating ignored participation had some insight into their illness. Feelings of being ignored in the community while showing some insight into their illness, may present respondents with a perception of coercion concerning their medication and a lack of control.

Community mental health staff were identified as having an influential role in the medication-taking behaviour of the respondents. On occasions this was reported in a positive way. Conversely, other discussed a lack of communication with staff concerning information and reasons for changing medication regimes. The respondents who were in the community while still under a section of the Mental Health Act (1983) were resentful of the control the staff members had over their medication and its management. Others, who were not formally expected to take their medication, reported that community mental health care staff made home visits to respondents who had not attended for their medication.

Unmet need for information about medication and illness

Qualitatively, analysis of respondents' additional comments in hospital clarified the therapeutic information gaps alluded to during the quantitative analysis of the data. Respondents demonstrated many worries and misconceptions about their illness and the drug therapy. Comments illustrated a lack of knowledge about their illness and the effectiveness of medication. The confusion among respondents between the effects of medication and the symptoms of illness fuelled the respondents' feelings of mistrust with the medication. Medication provided a convenient focus on which to blame the illness. Other respondents worried about relying on the medication too much.

Many respondents expressed a need for more information about their depot medication and its alternatives during the community interview. Again, other respondents' comments demonstrated a level of misinformation about their medication. Long term aims of therapy and the chronic nature of the illness were rarely understood. The respondents were confused by other health worries and whether the causes of these were linked to their mental health or their antipsychotic medication. Clearly, there is a need for more information and a need to correct misinformation. Individuals wanted varying amounts of information and different levels of involvement in the management of their illness. The ways in which information can be best delivered (e.g. by whom, where) need to be explored. Future work should evaluate different models of information provision. Currently, there is research in progress exploring the effects of a 'link-pharmacist scheme' where community pharmacists are matched with clients with mental health problems for providing individualised medication-related information.

Non-attenders for depot medication at the time of the community interview

The non-attenders were those respondents who, at the time of the community interview, were no longer receiving their depot (intramuscular) antipsychotic medication. Reasons for non-attendance were explored with each respondent. Qualitative information was gathered from the questionnaires to explore their experiences. It must be noted that while these non-attenders had stopped their depot (intramuscular) antipsychotic medication, two respondents were prescribed oral antipsychotic drugs. Adherence rates to oral therapy were not explored.

Reasons for discontinuing the depot antipsychotic medication did not differ from the problems identified by respondents who were still taking their medication. For example, unwanted effects associated with medication (e.g. adverse effects, painful administration) and the negative consequences of adhering to the medication. Although, one respondent claimed that the hospital had stopped her medication (medical notes did not confirm this information). Again, confusion arose between the adverse effects of medication and the potential residual symptoms of illness. Other respondents expressed the need to take control of their own lives and to move away from mental health services. One respondent was more concerned with finding a job. Another respondent justified stopping his medication because he lacked the choice in hospital when he was formally detained. His comments suggested that he did not understand the need for medication and by stopping the medication, he was expressing autonomy and taking control. He talked of the staff controlling his decisions.

Consequences of stopping the depot antipsychotic medications were explored. The non-attenders described their experiences since stopping their depot antipsychotic medication. Some focused on the remittance of the adverse effects of the medication. Case 09 conceded that she had benefited from receiving the medication but she expressed an underlying mistrust of the medication. Case 11 had stopped his medication and because there had been no adverse consequences, he perceived no need to recommence it. His comments suggested that he perceived his illness and its treatment as preventing him getting on with his life and therefore, it was preferable to ignore the illness. Case 45 was keen to stop his medication to increase his autonomy. However, he also acknowledged an increase in anxiety and subsequent negative consequences. He expressed a need for greater information about medication. Case 58 conceded to go back to an oral form of antipsychotic medication, but he preferred to be medication-free. Case 64 talked of his clarity of thought without medication. He acknowledged that during an in-patient stay, medication may have its place when an individual has problems, but he challenged the use of medication in correcting illness.

CHAPTER 8 QUALITY OF LIFE IN THE COMMUNITY

Quality of life was measured in the community using two approaches. First, respondents were asked to identify the five most important areas of life that contributed to their quality of life (adapted from the Schedule for the Evaluation of Individual Quality of Life (SEIQoL) (O'Boyle, 1994). Respondents then rated each area of life and their overall quality of life using a seven-point scale (Section 8.1). Subsequently, a known disease-specific quality of life instrument, the Lancashire Quality of Life Profile (Oliver, 1991) was administered (Section 8.2). Quality of life was only measured in the community due to the problems of definition and making relevant comparisons between different settings. For example, items such as the safety of the neighbourhood, travelling on public transport and visiting friends are included in the Lancashire Quality of Life Profile and are obviously not appropriate for administration in a hospital setting. Section 8.3 reports on the psychometric properties of the Lancashire Quality of Life Profile with the study sample (n=41) and comments on the content validity of the instrument through comparison of both approaches.

The primary aim of administering the adapted SEIQoL questions was to determine their value in assessing respondent-led quality of life with people with a diagnosis of schizophrenia. This was a novel method of measuring quality of life with this population group. Secondly, the content validity of the Lancashire Quality of Life Profile was explored by using the areas of life nominated by respondents using the respondent-led approach. Purposefully, the respondent-led approach was administered before the Lancashire Quality of Life Profile in order not to bias (by prompting) responses to the former.

8.1 Respondent-defined quality of life

8.1.1 Introduction

Respondents were asked to name the five most important areas of life (both good and bad) that they felt determined their quality of life, using adapted questions from the SEIQoL (Schedule for the Evaluation of Individual Quality of Life) (O'Boyle, 1994). The aim of these questions was to inform the validity of current quality of life measures for the severely

mentally ill living in the community. The respondents were asked to give a priority rating to each of the named areas and to rate their 'quality of life' in relation to each area, using the 'Delighted-Terrible Faces' Scale' (Andrews and Withey, 1976). The faces show clear expressions and were labelled 1 to 7. The extreme points were labelled as 'worst life imaginable' (face 1) and 'best life imaginable' (face 7). The interim faces were labelled as 'very bad' (face 2), 'bad' (face 3), 'all right' (face 4), 'good' (face 5) and 'very good' (face 6). Respondents also reported a global rating for their overall quality of life. The questions were repeated asking the respondents to name the five most important areas of life that their illness had affected. Again, respondents were asked to rate the relative priority to each area of life named. One respondent (Case 23) had withdrawn his consent to participate in the study from this point onwards (n=42).

8.1.2 Quality of life: five most important areas of life in rank order of importance

An open-ended question first asked the respondents (n=42):

"What are the five most important areas of your life at present, the things which make your life a relative happy or sad one at the moment... the things you feel determine the quality of your life?"

Respondents were asked to place each item in rank order of importance. Open quotes were coded according to the area of life they most accurately reflected. The area of life codes were formulated after all the interviews had been completed. (For a complete list of area of life codes with the respondents' quotes, see Appendix Twelve).

Some respondents experienced difficulty answering this question. Two respondents (5%) were unable to answer (Cases 02, 67).

"No, I don't experience none of that."

(Case 02)

A further 2 respondents (5%) (Cases 49, 54) answered the question by naming the important areas of their lives but they were unable to place the areas in rank order of importance.

Twenty-five (59%) respondents named five different areas of life; 3 (7%) named four; 8 (19%) named three; 2 (5%) named only one area of life. For those cases where they named

only one area of life as important to their quality of life, both cases named their children (Cases 30, 31).

“Seeing my son makes me happy. That’s all. I don’t see him often.”
[Quality of life rating in relation to seeing his son] Bad (face 3).

(Case 30)

“Seeing my children. Nothing else. They live with my mother.”
[Quality of life rating in relation to seeing her children] Good (face 5).

(Case 31)

Table 8.1 shows the domains that represent the areas of life that the respondents mentioned as most important in their current lives, in order of importance. Respondents were most likely to mention relationships with family and relatives as the first most important area of life (10, 26%), followed by work/education (6, 15%). The second most important area of life was relationships with others (which included intimate relationships) (9, 25%). In relation to the third, fourth and fifth most important areas of life, respondents were most likely to name leisure activities/social life (8-11, 27-38%).

The most frequently mentioned areas of life, across all ranks 1-5, (n=173) were leisure activities/social life (41, 23%), followed by relationships with family and relatives (23, 13%) and relationships with others (including intimate relationships) (18, 10%). Areas of life named by Cases 49 and 54 (who were unable to prioritise their areas of life) were included in the analysis for all areas of life.

Table 8.1 First to fifth most important areas of life named by respondents

	1st most important (n=38) No. (%)	2nd most important (n=36) No. (%)	3rd most important (n= 36) No. (%)	4th most important (n=28) No. (%)	5th most important (n=25) No. (%)	All areas of life[†] (n=173) No. (%)
Relationships with family, relatives	10 (26)	3 (8)	6 (16)	0 (---)	1 (4)	23 (13)
Work / Education	6 (15)	3 (8)	3 (8)	1 (4)	0 (---)	14 (9)
Own health (incl. unwanted effects of medication)	4 (11)	2 (6)	2 (6)	2 (7)	3 (12)	13 (8)
Leisure activities / social life	4 (11)	7 (18)	10 (27)	11 (38)	8 (32)	41 (23)
Religion / spiritual life	3 (8)	0 (---)	0 (---)	2 (7)	2 (8)	7 (4)
Finances / standard of living	2 (5)	2 (6)	2 (6)	5 (17)	0 (---)	12 (7)
Living situation	2 (5)	4 (11)	3 (8)	1 (4)	4 (16)	14 (9)
Safety and legal	2 (5)	1 (3)	0 (---)	0 (---)	0 (---)	4 (2)
Relationships with others (incl. intimate relationships)	1 (3)	9 (25)	4 (11)	1 (4)	2 (8)	18 (10)
Self-care / looking after oneself	1 (3)	1 (3)	1 (3)	2 (7)	1 (4)	7 (4)
Pets	1 (3)	1 (3)	1 (3)	0 (---)	0 (---)	3 (2)
Contact with mental health services/staff	0 (---)	2 (6)	2 (6)	1 (4)	2 (8)	7 (4)
Conversation / communication	0 (---)	1 (3)	2 (6)	1 (4)	0 (---)	4 (2)
Other areas [‡]	2 (5)	0 (---)	0 (---)	1 (4)	2 (8)	6 (3)

[†] Cases 49 and 54 were each unable to prioritise their five areas of life but their items were added to 'All areas of life'. [‡] Case 08: "Ambition, you've got to have goals."; Case 49: "Christmas."; Case 64: "Living in the first world as opposed to the third world; an awareness of others; to be progressive in one's thinking"; Case 70: "Seeing the sunshine."

8.1.3 Current quality of life status

Respondents were then asked to rate their quality of life in relation to each of the areas of life they had mentioned, using the seven-point 'Delighted-Terrible Faces' Scale' (Andrews and Withey, 1976). Case 53 was unable to rate the three most important areas he had named. Table 8.2 shows the positive and negative feelings expressed by the respondents in relation to the most important areas of life named.

Respondents were asked to think about the areas of life they had named and how they had rated each of them. They were then asked to rate their overall quality of life using the same ordinal scale (Table 8.2). Two respondents (Cases 02, 62) reported that they were unable to complete this task. Twenty-one (52%) respondents rated their overall quality of life as good, very good or best life imaginable. The remaining respondents were divided between their overall quality of life being 'all right' (10, 25%) or bad, very bad or worst life imaginable (9, 23%).

Ratings were combined at a domain-specific level for all areas of life named (ranks 1-5) (including Case 49 who could rate her current quality of life in relation to each area of life but could not prioritise them). (For a table of quality of life ratings by domain see Appendix Thirteen). Cases 53 and 54 did not make ratings. Respondents more often reported some areas of life as good, very good or best life imaginable; although numbers of respondents per domain were small. For example, leisure activities/social life (30, 75%; n=40), religion (6, 86%; n=7), communication with others (3, 75%; n=4) including mental health services/staff (6, 86%; n=7) and pets (3, 100%; n=3) were more often reported as contributing positively to quality of life. Alternatively, the three respondents who named safety/legal issues, all reported this area as detracting quality from their lives. For other areas of life, there was no majority rating among respondents about whether the area contributed positively or negatively to quality of life. For example, relationships with family and relatives, relationships with others, work/education, living situation, personal health/consequences of taking medication, finances/standard of living and self-care/looking after oneself.

Table 8.2 Feelings about life in relation to the most important areas of life named and life as a whole

	1st most important area (n=38)		2nd most important area (n=36)		3rd most important area (n=36)		4th most important area (n=28)		5th most important area (n=25)		Life as a whole (n=40)	
	No. (%)		No. (%)		No. (%)		No. (%)		No. (%)		No. (%)	
Best life imaginable	7 (19)	20 (54)	2 (6)	19 (54)	5 (15)	22 (63)	5 (18)	16 (57)	0 (---)	12 (48)	9 (22)	21 (52)
Very good	6 (16)		10 (28)		10 (28)		6 (21)		5 (20)		2 (5)	
Good	7 (19)		7 (20)		7 (20)		5 (18)		7 (28)		10 (25)	
All right	3 (8)	3 (8)	8 (23)	8 (23)	3 (9)	3 (9)	6 (21)	6 (21)	3 (12)	3 (12)	10 (25)	10 (25)
Bad	6 (16)	14 (38)	2 (6)	8 (23)	6 (16)	10 (28)	5 (18)	6 (22)	4 (16)	10 (40)	7 (18)	9 (23)
Very bad	2 (6)		2 (6)		3 (9)		0 (---)		3 (12)		2 (5)	
Worst life imaginable	6 (16)		4 (11)		1 (3)		1 (4)		3 (12)		0 (---)	
Total number of respondents [†]	37		35		35		28		25		40	

† Case 53 did not rate his current life for his 1st, 2nd and 3rd most important areas. Cases 02 and 62 did not rate their life as a whole.

8.1.4 Quality of life: five most important areas of life affected by illness

All respondents were diagnosed with schizophrenia, using DSM-III-R criteria (American Psychiatric Association, 1987) (Section 6.2.3). However, all respondents did not acknowledge their illness (see Section 7.2.2 for measurement of insight in the community).

Respondents were asked an open question:

“In relation to your illness, what would you say are the five most important areas of your life that have been affected by this? These may be the same as you have already named or different.”

Respondents' comments were recorded verbatim and coded as before, after all interviews were complete (n=42). Twelve respondents (29%) did not answer this question: one case had withdrawn consent for the study (Cases 53); three cases thought that their illness did not affect any specific areas of life (Cases 26, 29, 30); three cases reported that they were unable to answer the question or that they did not know (Cases 45, 46, 67); five cases had no insight to their illness and deemed this question inappropriate (Cases 02, 08, 21, 24, 59), e.g. “There’s nothing wrong with me.” (Case 24). A thirteenth respondent (Case 79) identified one area of life in response to the urinary tract infection she was experiencing, and denied any mental illness. This case was excluded from the analysis.

Table 8.3 shows the areas of life affected by illness that respondents mentioned as most important in their current lives, in order of importance. Respondents were most likely to report personal health issues including consequences of taking antipsychotic medication (6, 21%), work and education (6, 21%) and everything, life in general, (6, 21%) as the joint first most important area of life affected by their illness. One respondent named five areas of life affected by her illness but could not prioritise them in order of importance (Case 49).

The most frequently mentioned areas of life (all ranks 1-5) affected by illness, were personal health issues including consequences of taking medication (14, 20%), followed by work/education (13, 18%) and leisure activities/social life (11, 15%). Case 49 (who could not prioritise the areas of life affected by illness) was included in the analysis for all areas of life. Eight respondents (11%), in total, reported that their illness affected everything, life in general.

Table 8.3 First to fifth most important areas of life affected by illness named by the respondents

	1st most important (n=28) No. (%)	2nd most important (n=15) No. (%)	3rd most important (n=12) No. (%)	4th most important (n=8) No. (%)	5th most important (n=4) No. (%)	All areas of life† (n=72) No. (%)
Own health (incl. unwanted effects of medication)	6 (21)	2 (13)	3 (25)	2 (25)	1 (25)	14 (20)
Work / Education	6 (21)	1 (7)	3 (25)	3 (36)	0 (---)	13 (18)
'Everything' - life in general	6 (21)	2 (13)	0 (---)	0 (---)	0 (---)	8 (11)
Living situation	2 (7)	1 (7)	1 (8)	0 (---)	0 (---)	4 (6)
Leisure activities / social life	2 (7)	2 (13)	1 (8)	0 (---)	1 (25)	11 (15)
Relationships with others (incl. intimate relationships)	2 (7)	5 (33)	1 (8)	1 (13)	1 (25)	10 (14)
Religion	1 (4)	0 (---)	0 (---)	0 (---)	0 (---)	1 (1)
Relationships with family, relatives	1 (4)	0 (---)	2 (18)	0 (---)	1 (25)	4 (6)
Self-care	1 (4)	1 (7)	0 (---)	1 (13)	0 (---)	3 (4)
Finances / standard of living	0 (---)	1 (7)	0 (---)	1 (13)	0 (---)	2 (3)
Conversation / communication	0 (---)	0 (---)	1 (8)	0 (---)	0 (---)	1 (1)
Independence	1 (4)	0 (---)	0 (---)	0 (---)	0 (---)	1 (1)

† Case 49 was unable to prioritise her five areas of life but they were included in the analysis for all areas of life.

8.2 Quality of life as measured by the Lancashire Quality of Life Profile

8.2.1 Introduction

The Lancashire Quality of Life Profile (LQoLP) (Oliver, 1991) (see Section 2.4.3.3 and Appendix One) was administered to the respondents, after they had answered the open questions that identified their quality of life areas and ratings (see Section 8.1). Two respondents (Cases 26, 28) were unable to use the Life Satisfaction Scale (LSS) (for the subjective ratings in each domain of the Profile) due to reading difficulties and asked to use the 'Delighted-Terrible Faces' Scale' (Andrews and Withey, 1976) (used for rating the respondent-led areas of life). At this stage of the community interview, two respondents had withdrawn consent for participation in the study (Cases 23, 53) (n=41).

The objective indicators of quality of life (QoL) (for each domain) will be presented first, followed by the measures of subjective well-being: perceived quality of life (satisfaction ratings in each domain); subjective global well-being; psychological well-being (Affect-Balance Scale (Bradburn, 1969)); self-concept (Self-Esteem Scale (Rosenberg, 1965)); Cantril's Ladder (Cantril, 1965); the Happiness Scale (Gurin *et al.* 1960).

8.2.2 Objective indicators of quality of life by domain

Objective indicators are measured in the nine life domains of the Lancashire Quality of Life Profile (LQOLP): work/education; leisure/participation; religion; finances; living situation; legal/safety; family relations; social relations; and health.

1. Work/Education

One respondent (Case 66) (2%) was in employment at the time of the community interview. Case 66 worked in the Department of Office Services for British Telecom, sorting messages. He worked 9.00 am to 5.00 pm each week day, and was paid £26.00 per week. Three other respondents (Case 40, 49, 60) (7%) attended daytime adult education classes.

Case 40: Tuesdays and Thursdays, 3 hours a day; Fridays, 2 hours.

Case 49: Attends college daily from 10.00 am until 2.00, 3.00 or 4.00 pm.

“Every day, but I’d like it to be cut down so I’ve got time to go shopping and to the launderette.”

Case 60: Daily, 10.00 am - 4.00 pm.

The remaining respondents (37, 90%) reported that they were unemployed and not attending any education classes.

2. Leisure/participation

Most people (33-41, 80-100%) reported that they had been involved in shopping, travelling in a bus, car or train, or watching television or listening to the radio, during the two weeks before the interviews (Table 8.4). A minority (5, 12%) had been out to play or watch a sport.

“I don’t like sport.”

(Case 01)

“I can’t afford it. Watched on tv. Don’t go out to events that I have to pay for.”

(Case 09)

Table 8.4 Activities of the respondents in the previous fortnight

	In the past fortnight have you:			
	Been out to play or watch a sport?	Been out shopping?	Been for a ride in a bus, car or train [†] ?	Watched television or listened to radio?
	No. (%)	No. (%)	No. (%)	No. (%)
Yes	5 (12)	33 (80)	33 (80)	41 (100)
No	36 (88)	8 (20)	8 (20)	0 (----)
Total number of respondents	41	41	41	41

[†] Other than transport to and from work.

Almost half of all respondents (20, 49%) reported that they would have preferred to have had more time for leisure activities during the past year. Two respondents (5%) were unsure, and 19 (46%) had not lacked time to pursue leisure activities. The additional comments did not always support ‘lack of time’ as the barrier to pursuing more leisure activities.

“I’d like to go the pictures. I haven’t been in years.”

(Case 08)

“I just wish I had a girlfriend. I would be able to enjoy life.”

(Case 01)

3. Religion

About half the respondents (22, 54%) reported following a current religion, with the remainder reporting no religion (19, 46%) (Table 8.5).

Table 8.5 Current religion of the respondents

What is your religion now?	Number of respondents (%)
Christian [†]	19 (46)
Muslim	2 (5)
Buddhist	1 (3)
None	19 (46)
Total number of respondents	41

[†] Christian includes Roman Catholic (8), Protestant (7), Rastafarian Christian (2), Pentecostal (2)

Of those respondents who reported following a religion, 12 (52%) had not attended religious meetings in the previous month. However, a third of the respondents (8, 34%) had attended at least 4 times (Table 8.6).

Table 8.6 Number of times the respondents attended religious service in the previous month[†]

How often have you attended religious services in the past month?	Number of respondents (%)
0	12 (52)
1	2 (9)
2	1 (5)
3	0 (---)
4	4 (17)
5 or more	4 (17)
Total number of respondents	23

[†] Only asked if respondents reported a current religion (one other person also responded since she attended church with her mother (Case 31))

4. Finances

The total weekly income reported by respondents ranged from £13.00 to £137.00 (n=38). Three respondents did not answer any of the finance questions: two of whom lived with their parents and did not manage their own money (Cases 22, 59); the third non-responder reported “None of your business. That’s my business.” (Case 07).

The most important determinant of the reported weekly income, was whether respondents were living independently or in hostel accommodation where they automatically deducted living expenses.

- Six respondents reported their ‘spending money’ (accommodation and food costs deducted) (Cases 28, 54, 66, 68, 72, 89). In these instances, they did not know the total amount deducted. Spending money ranged from £13.00 to £39.70 (£39.70 was for the person who was employed (Case 66)).

The mean income reported per week (accommodation and food costs deducted) was £19.67.

- Three respondents (Case 40: £65.00; Case 49: £65.15 and Case 67: £71.00) had their accommodation costs deducted but this was not inclusive of food.

The mean income reported per week (accommodation costs deducted) was £67.05.

- The remaining 29 respondents had to pay all their living expenses from their weekly income which ranged from £48.10 to £137.00.

The mean income reported per week (no deductions) was £74.88.

All but one of the respondents reported receiving state benefits at the time of the community interview (37, 97%). The remaining respondent (Case 89) was unsure and added “I am applying for disability allowance”. Nine respondents (24%) had been turned down for a benefit for which they had applied in the previous year and one respondent was unsure (Case 60).

Respondents were asked (n=38):

“About how much more money per week do you need to be able to live as you would wish?”

Thirty-three respondents answered this question, 7 (21%) of whom reported that they did not

require any extra money.

“None. I need people to live with me to love me.”

(Case 62)

The remaining 26 respondents reported additional money requirements ranging up to £250.00, with a mean value of £53.94 (median £40.50).

“£100. Don’t forget. I haven’t got any clothes or anything.”

(Case 08)

“£135. I want to work and then I would move from the hostel.”

(Case 40)

“I’d like to get a job earning £150 a week.”

(Case 70)

Of the five non-responders to this question, three said that they had ‘no idea’ (Cases 30, 45, 49) and the two other non-responders named unrealistic amounts of money.

“Millions to fulfill my dreams. I’d like to buy my white brother-in-law a big house.
I’d like to open a Reggae Record Shop.”

(Case 14)

“One billion.”

(Case 24)

From the ‘additional money’ information reported by the respondents, a ‘perceived wealth’ variable was calculated. Perceived wealth was an ordinal scale ranging from 0-5, with the extreme points labelled as ‘poor’ (0) and ‘well-off’ (5). ‘Poor’ was equivalent to additional money reported between £201 and £250. ‘Well-off’ was equivalent to no additional money requirements. The interim points were increments of £50 (Table 8.7). Two-thirds of all respondents (22, 67%) reported that they required £50 or less additional money per week, to live life as they wished.

Table 8.7 Perceived-wealth of the respondents[†]

Perceived wealth		Number of respondents (%)
0	Poor (additional money £201 ≤ £250)	1 (3)
1	(additional money £151 ≤ £200)	1 (3)
2	(additional money £101 ≤ £150)	2 (6)
3	(additional money: £51 ≤ £100)	7 (21)
4	(additional money: £1 ≤ £50)	15 (46)
5	Well-off (additional money: £0)	7 (21)
Total number of respondents		33

[†] Calculated using additional money required per week to be able to live life as they would wish. Only calculated for those respondents who reported 'additional money' required.

Adding income and additional money produced a 'total money' variable for each of the 33 respondents, illustrating the total money expected by respondents to live life as they would wish. The range of total income ranged from £13.00 to £387.00 per week.

- For the 6 respondents who reported their 'spending money' (accommodation and food costs deducted) (Cases 28, 54, 66, 68, 72, 89), the total money reported by respondents to live life as they would wish ranged from £13.46 to £113.00.

The mean total income expected per week (accommodation and food costs deducted) was £63.89.

- Three respondents (Cases 40, 49 and 67) who had already paid for their accommodation, not including food, expected relative total amounts of £200.00, (not answered), £81.00.

The mean total income expected per week (accommodation costs deducted) was £140.05.

- Twenty-five out of the remaining 29 respondents, who had to pay all their living expenses from their weekly income, reported a range of total money £65.00-£387.00 to live life as they would wish. The four other respondents did not answer the additional money question (Cases 14, 24, 30, 45).

The mean total income expected per week (no deductions) was £130.38.

During the last year, 25 respondents (66%; n=38) reported that they had lacked the money to enjoy everyday life as they would have wished.

5. Living situation

Most respondents lived in either flats rented from local authorities (16, 39%) or hostel accommodation (16, 39%) (Table 8.8). Respondents had lived in their current homes for between 1 and 360 months (mean=54 months; median=6 months; $n=39$). About half the respondents had lived in their current accommodation for 6 months or less (20, 51%). Almost one-third of the respondents lived alone (12, 29%) while 28 (69%) lived with others. Eight respondents (20%) shared their accommodation with family members.

Table 8.8 Living circumstances of the respondents

	Number of respondents (%)	
Type of tenure		
Hostel	16	(39)
Flat (rented from local authority)	16	(39)
Private house (owner occupied)	2	(5)
Private house (rented)	1	(2)
Other (e.g. housing co-operative)	6	(15)
Household composition		
Lives alone	12	(29)
Lives with up to 5 others	13	(32)
Lives with more than 5 others	15	(37)
Don't know how many other residents (Case 30)	1	(2)
Lives with family		
Yes	8	(20)
No	33	(80)
Length of time in current residence		
≤ 3 months	13	(32)
> 3 months ≤ 1 year	8	(19)
> 1 year ≤ 2 years	2	(5)
> 2 years ≤ 5 years	4	(10)
> 5 years	12	(29)
Unsure (Cases 22 and 56)	2	(5)
Total number of respondents	41	

Most respondents (26, 63%) reported that, during the past year, there had been times when they had wanted to move or improve their living conditions but they had been unable to do so.

“I wanted to buy a tv but I couldn't afford one.”

(Case 27)

“I want to live with my Mum so I can look after her. She should have a wheelchair but she doesn’t want one.”

(Case 28)

“...the stairs are becoming too much. My shower isn’t working. A man came to fix the taps but he didn’t fix the shower.”

(Case 68)

6. Safety/Legal issues

During the year before the community interview, 4 (10%) respondents had been accused of a crime (Cases 04, 22, 29, 46).

“Yes. Carrying a knife.”

(Case 22)

“One mate of mine got arrested for burglary and he gave the police my name instead of his.”

(Case 29)

No respondents reported that they had been victims of crime in the 12 months before the community interview. However, some respondents reported instances of more than a year ago when they had been victims of crime.

“Not in the last year but I used to get mugged for my giro.”

(Case 24)

“When I first moved in, they nicked my benefit book and they started a fire in the bedroom. I’d left the door on the latch.”

(Case 70)

Three respondents (7%) reported that during the past year, there had been times when they would have liked police or legal help but they had been unable to obtain it (Cases 24, 45, 62).

7. Family relations

Most of the respondents were single (35, 85%) and about one-third had children (14, 34%) (Table 8.9). Almost half the respondents (20, 49%) were in contact with relatives at least once a month (Table 8.10). Five respondents (13%) either had no contact with any relatives or did not have any relatives (Cases 08, 24, 50, 67, 72).

Table 8.9 The current marital status of respondents and their number of children

	Number of respondents (%)	
What is your current marital status?		
	35	(86)
Single	2	(5)
Married	2	(5)
Divorced	1	(2)
Separated	1	(2)
Widowed		
Number of children		
0	27	(66)
1	8	(20)
2	1	(2)
3	1	(2)
4	2	(5)
5	2	(5)
Total number of respondents	41	

Table 8.10 Frequency of contact with a relative

Frequency of contact	Number of respondents (%)
At least once a week	9 (22)
Less often than once a week, at least once a month	11 (27)
Less often than once a month, more often than once a year	13 (32)
Annually	1 (2)
Less often than once a year	1 (2)
Variable	1 (2)
Not in contact with relatives / No relatives	5 (13)
Total number of respondents	41

Out of the 39 respondents who had family, 16 (41%) reported that, during the last year, there had been times when they would have liked to have participated in family activities but they had been unable to do so.

“Yes. I’d like to get in touch with my cousins but I don’t know where they live. After my mother and father died, I haven’t seen them. They weren’t at the funeral. They didn’t write. Didn’t hear anything about them.”

(Case 24)

“Sometimes I feel out of the swing at times with my family, kind of awkward.”
(Case 34)

8. Social relations

About half the respondents (21, 51%) reported that they were the sort of person who could manage without friends while the remaining half (20, 49%) reported that they needed friends.

“I could do with one but I can’t do with plenty.”
(Case 49)

“From time to time yes but other times no.”
(Case 62)

Most respondents reported having a ‘close friend’ (24, 58%) and a friend to whom they could turn for help if they needed it (25, 61%). Occasionally this was the same person.

“I have one friend ... and that’s all I need.”
(Case 28)

“... [helper at the Luncheon Club] but she has her own problems and her own home.”
(Case 33)

However, about two-fifths of respondents did not have a ‘close’ friend (17, 42%) nor any friends on whom they could rely (16, 39%).

“I had a friend but he died”
(Case 01)

“I find it difficult to be close to people.”
(Case 34)

“I want one.”
(Case 66)

Less than half of all respondents (17, 42%) had visited a friend in the week before the community interview (Table 8.11).

9. Health

Most people (33, 80%) reported experiencing their first admission to a psychiatric hospital by the age of 29 years (Table 8.12). During the year before the community interview, 19 (46%) respondents reported that they had seen a doctor for a physical illness and 40 (98%) reported that they had seen a doctor for a mental health problem. All respondents (41, 100%)

acknowledged that they had been in a hospital for a mental health problem during the last year. Thirty-seven respondents (90%) reported taking medication for a mental health problem. One-fifth of people (8, 20%) reported having a physical handicap that affected their mobility.

“I do have a mobility problem with my weight. I can’t walk very far without getting exhausted.”

(Case 09)

“Yes. Diabetes affects circulation in leg and affects my walking.”

(Case 50)

Table 8.12 Age of respondents at their first admission to a psychiatric hospital or ward

Age	Number of respondents (%)
Less than or equal to 14 years	3 (7)
15 years ≤ 19 years	7 (17)
20 years ≤ 24 years	10 (24)
25 years ≤ 29 years	13 (32)
30 years ≤ 34 years	0 (---)
35 years ≤ 39 years	2 (5)
40 years ≤ 44 years	0 (---)
45 years ≤ 49 years	0 (---)
50 years ≤ 54 years	1 (3)
Don’t know	5 (12)
Total number of respondents	41

Eleven respondents (27%) reported that during the last year, there had been times when they had wanted help from a doctor or other health professional but they had not received it (Table 8.13).

“Doctor unavailable.”

(Case 30)

“Professor don’t want to know me.”

(Case 50)

“When I took sick in my bed and my tongue kept coming out.”

(Case 60)

Table 8.11 Respondents' perceived needs for social relations

People differ in how much friendship they need:	Would you say that you are the sort of person who can manage without friends?	Do you have anyone who you could call a 'close friend' (i.e. who knows you very well)?	Do you have a friend to whom you could turn for help if you needed it?	In the past week, have you visited a friend?
	No. (%)	No. (%)	No. (%)	No. (%)
Yes	21 (51)	24 (58)	25 (61)	17 (42)
No	20 (49)	17 (42)	16 (39)	24 (58)
Total number of respondents	41	41	41	41

Table 8.13 Health of the respondents during the last year

	During the past year have you seen a doctor for a physical illness?	During the past year have you seen a doctor for a mental health problem?	During the past year have you been in hospital for a mental health problem?	Do you take medication for a mental health problem?	Do you have a physical handicap which affects your mobility?	In the past year have there been times when you wanted help from a doctor or other professional for your health but were unable to get it?
	No. (%)	No. (%)	No. (%)	No. (%)	No. (%)	No. (%)
Yes	19 (54)	40 (98)	41 (100)	37 (90)	8 (20)	11 (27)
No	22 (46)	1 (2)	0 (-----)	4 (10)	33 (80)	30 (73)
Total number of respondents	41	41	41	41	41	41

8.2.3 Subjective well-being

The Lancashire Quality of Life Profile (LQoLP) includes six measures of subjective well-being: perceived quality of life; subjective global well-being; psychological well-being (Affect-Balance Scale (Bradburn, 1969)); self-concept (Self-Esteem Scale (Rosenberg, 1965)); Cantril's Ladder (Cantril, 1965); Happiness scale (Gurin *et al.* 1960). Respondents used the life satisfaction scale (Andrews and Withey, 1976) to assess their satisfaction in life domains (perceived quality of life) and life, overall (subjective global well-being).

8.2.3.1 Perceived quality of life by domain

1. Work/Education

The respondent (Case 66) who was working at the time of the community interview reported that he was pleased with the job but had mixed feelings (about equally satisfied and dissatisfied) about the pay he received. The 3 respondents that were students reported that they were mostly satisfied (Case 49) or pleased (Cases 40, 60) about attending adult education classes.

“Pleased that I’ve got out and about and I’m not stuck in my flat. The other time before I was sick, I was in my flat 24 hours a day. I was scared to come out.”
(Case 60)

The remaining 37 respondents were mostly unhappy about being unemployed (21, 57%) (see Table 8.14).

“You can’t get a job when you want a job. My brother can’t get a job and there’s nothing wrong with him.”
(Case 01)

“I don’t feel socially stable without work.”
(Case 45)

“It’s not that I don’t want to work, I can’t.”
(Case 50)

However, other respondents (9, 24%) were satisfied with being unemployed.

“I like to do the housework and keep house.”
(Case 07)

“Couldn’t cope with a job all week.”
(Case 54)

Table 8.14 Satisfaction with employment status

How satisfied are you with being unemployed or retired?		
Life Satisfaction Scale (LSS) rating	Number of respondents (%)	
Can't be better	2 (5)	9 (24)
Pleased	1 (3)	
Mostly satisfied	6 (16)	
Mixed (about equally satisfied and dissatisfied)	7 (19)	7 (19)
Mostly dissatisfied	7 (19)	21 (57)
Displeased	11 (30)	
Can't be worse	3 (8)	
Total number of respondents	37	

2. Leisure/participation

Most respondents were satisfied with the pleasure they gained from activities they did inside their home (27, 66%), from activities they did outside their home (24, 59%) and from listening to the radio or watching television (27, 66%) (Table 8.18). However, 10 respondents (25%) were dissatisfied with the pleasure they gained from activities outside their home.

3. Religion

The majority of respondents who reported following a religion (n=22) were satisfied with the religious faith and its teachings (16, 80%). However, less than half were satisfied with the frequency they attended religious service (9, 48%) (Table 8.16).

Table 8.15 Satisfaction with activities inside and outside the home

Life Satisfaction Scale (LSS) rating	How satisfied are you with the amount of pleasure you get from things you do at home?		How satisfied are you with the amount of pleasure you get from things you do outside your home?		How satisfied are you with the pleasure you get from radio or TV?	
	No. (%)	No. (%)	No. (%)	No. (%)	No. (%)	No. (%)
Can't be better	3 (7)	27 (67)	2 (5)	24 (58)	6 (15)	27 (66)
Pleased	8 (21)		10 (24)		10 (24)	
Mostly satisfied	16 (39)		12 (29)		11 (27)	
Mixed (about equally satisfied and dissatisfied)	9 (22)	9 (22)	7 (17)	7 (17)	6 (15)	6 (15)
Mostly dissatisfied	3 (7)	5 (11)	7 (17)	10 (25)	5 (12)	8 (19)
Displeased	1 (2)		1 (3)		2 (5)	
Can't be worse	1 (2)		2 (5)		1 (2)	
Total number of respondents	41		41		41	

Table 8.16 Satisfaction with religion[†]

Life Satisfaction Scale (LSS) rating	How satisfied are you with your religious faith and its teachings?		How satisfied are you with the frequency with which you attend services?	
	No. (%)	No. (%)	No. (%)	No. (%)
Can't be better	3 (15)	16 (80)	3 (15)	10 (48)
Pleased	2 (10)		2 (9)	
Mostly satisfied	11 (55)		5 (24)	
Mixed (about equally satisfied and dissatisfied)	2 (10)	2 (10)	6 (29)	6 (29)
Mostly dissatisfied	1 (5)	2 (10)	2 (9)	5 (23)
Displeased	1 (5)		2 (9)	
Can't be worse	0 (---)		1 (5)	
Total number of respondents	20 [‡]		21 [§]	

[†] Only asked if respondents reported a religion (also Case 31 who attended church with her mother). [‡] Missing - Case 62: "Not practising."; Case 66: "Not practising."; Case 70: "I haven't got faith in anything really. I'm reading the bible and learning from it." [§] Missing - Case 62: "Not practising."; Case 66: "Not practising."

4. Finances

Almost half of all respondents felt that their current financial status (19, 49%) and the amount of money that they had to spend on enjoyment (16, 43%) was unsatisfactory, displeasing or could not be worse (Table 8.17).

“Everything suffers when you’re not working. Every area of your life. I haven’t bought no new clothes.”

(Case 58)

“I’ve received a phone bill for £62 and some pence and I’m not at home using the phone. It’s my son. He doesn’t pay for anything.”

(Case 33)

However, about a third of respondents reported feelings of satisfaction about their financial status and the amount of money they had to spend on enjoyment (13, 35%; 14, 38%).

Table 8.17 Satisfaction with finances[†]

Life Satisfaction Scale (LSS) rating	How satisfied are you with how well-off you are financially?		How satisfied are you with the amount of money you have to spend on enjoyment?	
	No. (%)	No. (%)	No. (%)	No. (%)
Can't be better	1 (3)	13 (35)	0 (---)	14 (38)
Pleased	6 (16)		4 (11)	
Mostly satisfied	6 (16)		10 (27)	
Mixed (about equally satisfied and dissatisfied)	6 (16)	6 (16)	7 (19)	7 (19)
Mostly dissatisfied	7 (18)	19 (49)	6 (16)	16 (43)
Displeased	8 (21)		6 (16)	
Can't be worse	4 (10)		4 (11)	
Total number of respondents	38		37 [‡]	

[†] Only asked if respondents knew how much money they received.

[‡] Case 62 did not answer this question: “Can’t answer that one.”

5. Living situation

Most respondents reported that their general living arrangements (24, 60%), the amount of independence (30, 76%), the amount of influence (22, 61%), and the amount of privacy (33, 84%) in their current living situation was satisfactory, pleasing or couldn’t be better.

However, respondents expressed feelings of dissatisfaction when asked about the prospect of continued residence at their current housing (16, 39%) and the prospect of returning to live in a hospital (31, 76%). Respondents had mixed feelings when asked about their current living situation. Twelve people lived alone, of whom three were satisfied and 6 were dissatisfied. Twenty-eight respondents lived with other people, of whom 17 were satisfied and 7 were dissatisfied (Table 8.18). Respondents who were dissatisfied with their living situation were more likely to make additional comments.

“I don’t have no influence here.”

(Case 02)

“My son spoils it for me...You can’t leave your purse anywhere with money. He takes the money.”

(Case 33)

“[No privacy] Every few minutes there’s always someone knocking on your door.”

(Case 46)

“I’d like to cook my own meals so I could have what I wanted... Some people are nice. Some aren’t. Not my age group, all older than me.”

(Case 54)

6. Legal / safety

Most people were satisfied with their general personal safety (26, 63%) but, less people were satisfied with the safety of their neighbourhood (17, 41%). About a quarter of all respondents were dissatisfied with their personal safety and the safety of their neighbourhood (Table 8.19).

“Car window smashed last night.”

(Case 09)

“It’s rough around here.”

(Case 14)

“They’ve tried to break in twice but they haven’t got in.”

(Case 60)

Table 8.18 Satisfaction with living situation

Life Satisfaction Scale (LSS) rating	How satisfied are you with:													
	Current living arrangements?		Amount of independence?		Amount of influence?		Living with the people you do or living alone?		Amount of privacy?		Prospect of continued residence at current housing?		Prospect of returning to live in hospital?	
	No. (%)	No. (%)	No. (%)	No. (%)	No. (%)	No. (%)	No. (%)	No. (%)	No. (%)	No. (%)	No. (%)	No. (%)	No. (%)	No. (%)
Can't be better	2 (5)	24 (60)	5 (13)	30 (76)	3 (8)	22 (61)	4 (10)	20 (50)	5 (13)	33 (84)	5 (12)	16 (39)	1 (2)	5 (12)
Pleased	10 (25)		10 (25)		9 (25)		4 (10)		11 (28)		5 (12)		1 (2)	
Mostly satisfied	12 (30)		15 (38)		10 (28)		12 (30)		17 (43)		6 (15)		3 (8)	
Mixed (about equally satisfied and dissatisfied)	8 (20)	8 (20)	7 (18)	7 (18)	7 (19)	7 (19)	7 (17)	7 (17)	1 (3)	1 (3)	9 (22)	9 (22)	5 (12)	5 (12)
Mostly dissatisfied	3 (8)	8 (20)	1 (3)	2 (6)	1 (3)	7 (20)	3 (8)	13 (33)	1 (3)	5 (13)	3 (7)	16 (39)	4 (10)	31 (76)
Displeased	3 (8)		0 (---)		4 (11)		4 (10)		3 (7)		7 (17)		9 (22)	
Can't be worse	2 (5)		1 (3)		2 (6)		6 (15)		1 (3)		6 (15)		18 (44)	
Total number of respondents	40 [†]		39 [‡]		36 [§]		40 [¶]		39 [¥]		41		41	

† Case 59 did not answer.

‡ Cases 07, 62 did not answer.

§ Cases 07, 22, 24, 30, 54 did not answer.

¶ Case 45 did not answer.

¥ Cases 01, 07 did not answer.

Table 8.19 Satisfaction with personal safety and the safety of the neighbourhood

Life Satisfaction Scale (LSS) rating	How satisfied are you with:			
	Your general personal safety?		The safety of this neighbourhood?	
	No. (%)	No. (%)	No. (%)	No. (%)
Can't be better	4 (10)	26 (63)	2 (5)	17 (41)
Pleased	10 (24)		8 (19)	
Mostly satisfied	12 (29)		7 (17)	
Mixed (about equally satisfied and dissatisfied)	5 (12)	5 (12)	14 (34)	14 (34)
Mostly dissatisfied	5 (12)	10 (25)	4 (10)	10 (25)
Displeased	2 (5)		2 (5)	
Can't be worse	3 (8)		4 (10)	
Total number of respondents	41		41	

7. Family relations

About half those respondents who had family and were in contact with family, were satisfied with the relationships (20, 52%) and the amount of contact (21, 56%) (Table 8.20). Of the remaining respondents, about half felt mixed (equal feelings of satisfaction and dissatisfaction) and the other half had feelings of dissatisfaction. Two respondents were each married (Cases 07, 29) and both reported that they felt mixed (about equally satisfied and dissatisfied) with their marriages.

Table 8.20 Satisfaction with family relations

Life Satisfaction Scale (LSS) rating	How satisfied are you with:			
	Your family in general?		The amount of contact you have with your relatives?	
	No. (%)	No. (%)	No. (%)	No. (%)
Can't be better	1 (3)	20 (52)	4 (11)	21 (56)
Pleased	5 (13)		5 (13)	
Mostly satisfied	14 (36)		12 (32)	
Mixed (about equally satisfied and dissatisfied)	8 (20)	8 (20)	8 (21)	8 (21)
Mostly dissatisfied	4 (10)	11 (28)	2 (5)	9 (23)
Displeased	2 (5)		5 (13)	
Can't be worse	5 (13)		2 (5)	
Total number of respondents	39 [†]		38 [‡]	

[†] Cases 50,72 had no relatives.

[‡] Cases 50, 72 had no relatives. Case 59 could not answer this question.

8. Social relations

Most people were satisfied with the way they got on with other people (27, 66%). However, about a quarter of respondents (10, 24%) had mixed feelings (equal satisfaction and dissatisfaction). About half the respondents were satisfied with the number of friends they had (23, 56%), but a further 12 respondents (29%) were dissatisfied (Table 8.21). Additional comments were mainly reported by those respondents who were dissatisfied with their social relationships.

“Don’t get on with other people. Find it hard to communicate. Doesn’t bother me.”
[Respondent had hearing difficulties and wore a hearing aid].

(Case 30)

“They don’t speak to me and don’t want to know me.”

(Case 50)

“Wish I had more [friends].”

(Case 26)

“I want to make more friends.”

(Case 33)

Table 8.21 Satisfaction with social relations

Life Satisfaction Scale (LSS) rating	How satisfied are you with:			
	The way you get on with other people?		The number of friends you have?	
	No. (%)	No. (%)	No. (%)	No. (%)
Can't be better	4 (10)	27 (66)	3 (7)	23 (56)
Pleased	11 (27)		7 (17)	
Mostly satisfied	12 (29)		13 (32)	
Mixed (about equally satisfied and dissatisfied)	10 (24)	10 (24)	6 (15)	6 (15)
Mostly dissatisfied	2 (5)	4 (10)	8 (20)	12 (29)
Displeased	0 (---)		3 (7)	
Can't be worse	2 (5)		1 (2)	
Total number of respondents	41		41	

9. Health

The majority of respondents were satisfied with their general health (24, 58%), the frequency with which they saw the doctor (27, 68%) and their mental health well-being (22, 55%) (Table 8.22). However 22-25% (9-10) of respondents were dissatisfied with their general health and mental health. Of those dissatisfied with the frequency with which they saw the doctor (5, 12%), some wanted to see the doctor more and others, less.

“I’d like to see him more often so he could find a way of curing it”

(Case 28)

“Like to see him less.”

(Case 56)

Table 8.22 Satisfaction with health

Life Satisfaction Scale (LSS) rating	How satisfied are you with:					
	Your general state of health?		How often you see a doctor?		Your mental health well-being?	
	No. (%)	No. (%)	No. (%)	No. (%)	No. (%)	No. (%)
Can't be better	1 (2)	24 (58)	1 (2)	27 (68)	4 (10)	22 (55)
Pleased	10 (24)		10 (26)		8 (20)	
Mostly satisfied	13 (32)		16 (40)		10 (25)	
Mixed (about equally satisfied and dissatisfied)	8 (20)	8 (20)	8 (20)	8 (20)	8 (20)	8 (20)
Mostly dissatisfied	5 (12)	9 (22)	4 (10)	5 (12)	4 (10)	10 (25)
Displeased	3 (8)		1 (2)		4 (10)	
Can't be worse	1 (2)		0 (---)		2 (5)	
Total number of respondents	41		40 [†]		40 [‡]	

[†] Case 59: “Don’t know.”

[‡] Case 08: “Don’t know much about it. I’ve never experienced anything.”

8.2.3.2 Subjective global well-being

● General well-being I

Respondents were asked about their general well-being at the start of the Lancashire Quality of Life Profile (GWB-I). Almost half of all respondents (19, 47%) felt satisfied about their

life on the day they were interviewed. However, a further third felt mixed (about equally satisfied and dissatisfied) (14, 34%) (Table 8.24). Some people made additional comments in response to this question:

“We don’t know what tomorrow will bring.”

(Case 07)

“I wish my Dad was alive. He died of cancer.”

(Case 28)

“I’m pleased with myself. It could be better but I’m pleased with myself because I don’t create no trouble. I always run away from trouble.”

(Case 33)

Respondents were asked if there may be any reason why they may feel different on the day of interview. Almost one quarter of respondents (10, 24%) reported that there were reasons why they felt different ‘today’ compared with other days (Table 8.23).

Table 8.23 Do you feel different today?

Are there any particular events/reasons why you feel different today from any other day, in general?	Number of respondents (%)
Yes	10 (24)
No	31 (76)
Total number of respondents	41

Six of the 10 respondents reported that they thought it was a better day than usual (Cases 09, 34, 36, 40, 64, 66).

“Good today, because I’m going out to buy a book and meet a friend at 12 but we’ll finish the questionnaire first.”

(Case 09)

“Better day than usual because I’ve come to get my injection and that’s the only way I get out.”

(Case 36)

“Today, I have met somebody from the outside, that is you, so it is better.”

(Case 40)

“The weather is getting better. It has a beneficial effect.”

(Case 64)

Three of the remaining respondents reported that it was a worse day than usual (Cases 04, 30, 49).

“I’ve got nothing to do today. I came to do pottery this afternoon but it was cancelled.”

(Case 04)

“I’ve started gambling again.”

(Case 30)

“I feel a bit sick.”

(Case 49)

The final respondent who reported that the interview day was different to his usual day, would not comment in what way he felt different (Case 45).

- **General well-being II**

A general well-being item was repeated at the end of the Lancashire Quality of Life Profile (GWB-II). Some additional comments in response to this question are reported below.

“Cos I haven’t got out to the country, no money in the bank, not corresponding with my family back home, not seeing my family here, not going to college.”

(Case 14)

“Life is nice but certain people aren’t nice. Life is all right.”

(Case 46)

“I’ve got no future. I know that as I’m sitting here now. I’m not going to be any different for the rest of my life.”

(Case 50)

On this occasion, 15 (36%) respondents felt satisfied about their life as a whole. Table 8.24 compares responses between both items.

Table 8.24 General well-being of respondents pre- (GWB-I) and post- (GWB-II) Lancashire Quality of Life Profile

Life Satisfaction Scale (LSS) rating	Can you tell me how you feel about:			
	your life as a whole today? (Start of questionnaire: GWB-I)		life as a whole? (End of questionnaire: GWB-II)	
	No.	(%)	No.	(%)
Can't be better	9	(22)	5	(12)
Pleased	6	(15)	5	(12)
Mostly satisfied	4	(10)	5	(12)
Mixed (about equally satisfied and dissatisfied)	14	(34)	15	(36)
Mostly dissatisfied	3	(7)	6	(15)
Displeased	3	(7)	3	(8)
Can't be worse	2	(5)	2	(5)
Total number of respondents	41		41	

8.2.3.3 Psychological well-being: the Affect-Balance Scale

Psychological well-being or happiness, was measured using the Affect-Balance Scale (Bradburn, 1969). The Affect-Balance Scale is composed of ten items, five items representing positive-affect and five items representing negative-affect. Each item of the Affect-Balance Scale is scored 1 for a yes or 0 for a no answer. The positive-affect and negative-affect subscores are the sums of the five items for each subscale. Each subscore ranges from 0-5 where 0 represents low positive/negative affect and 5 represents high positive/negative affect with the desirable subscores being a high positive affect (5) and a low negative affect (0). The affect-balance total score is a positive value ranging from 0-10 where a higher score represents greater psychological well-being. The negative-affect subscore is subtracted from the positive-affect subscore and a constant of 5 is added. The positive and negative subscales are independent of each other but both correlate with the Affect-Balance Scale total score (Bradburn, 1969).

Table 8.25 illustrates the respondents' answers to the individual items of the Affect-Balance

Scale, grouped under the positive and negative-affect subscales. Feelings of accomplishment sometimes reflected a demonstration of autonomy.

“When I left hospital they kept pressuring me to go to Open House for coffee mornings but I’d rather go to the Wimpy if I want a coffee. I’m not that sort of person.”

(Case 27)

Excitement or feelings of interest in something often reflected a respondent’s participation in activities.

“Machine knitting at the day centre.”

(Case 60)

“My course-work.”

(Case 49)

The restless feelings described by some respondents may be attributed to an unwanted effect of their antipsychotic medication.

“I was walking up and down and didn’t want to sit down on me settee. I kept changing seats.”

(Case 60)

Similarly, comments reported as examples of times when respondents had feelings of depression or were unhappy, were sometimes linked with their medication.

“Anxious, but I think it was because they were cutting me off the Valium. I was addicted to it.”

(Case 72)

“When my tongue was horrible.”

(Case 60)

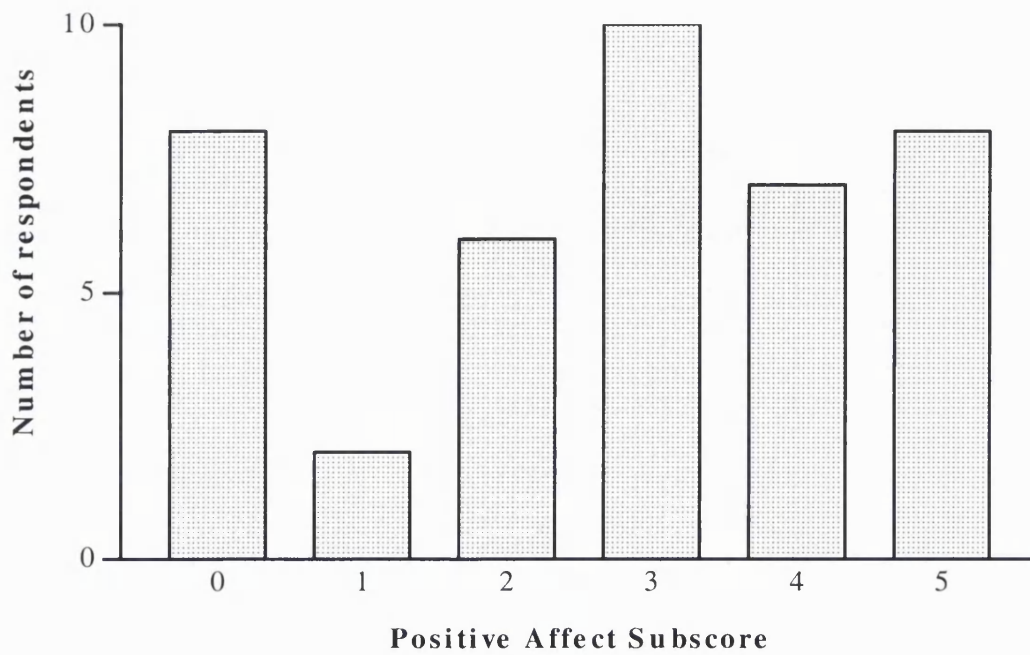
Figures 8.1a and 8.1b show the distribution of subscores for each of the positive and negative-affect subscales. The mean score for the positive affect subscale was 2.73 and 2.87 for the negative affect subscale. Figure 8.1c shows the distribution of total scores for the Affect-Balance Scale. The mean score was 4.85. The subscore for positive-affect and the affect-balance total score were significantly positively correlated (Pearson $r=0.797$, $p<0.001$, $n=41$). The subscore for negative-affect and the affect-balance total score were significantly negatively correlated (Pearson $r=-0.607$; $p<0.001$, $n=41$).

Table 8.25 Respondents' psychological well-being

During the past month, did you ever feel:	Positive Affect					Negative Affect				
	Pleased about having accomplished something?	That things were going your way?	Proud because someone complimented you on something you had done?	Particularly excited or interested in something?	"On top of the world"?	Too restless to sit in a chair?	Bored?	Depressed or very unhappy?	Very lonely or remote from other people?	Upset because someone criticised you?
	No. (%)	No. (%)	No. (%)	No. (%)	No. (%)	No. (%)	No. (%)	No. (%)	No. (%)	No. (%)
Yes	28 (68)	25 (61)	21 (51)	26 (63)	12 (29)	22 (54)	31 (76)	24 (58)	26 (63)	15 (37)
No	13 (32)	16 (39)	20 (49)	15 (37)	29 (71)	19 (46)	10 (24)	17 (42)	15 (37)	26 (63)
Total number of respondents	41	41	41	41	41	41	41	41	41	41

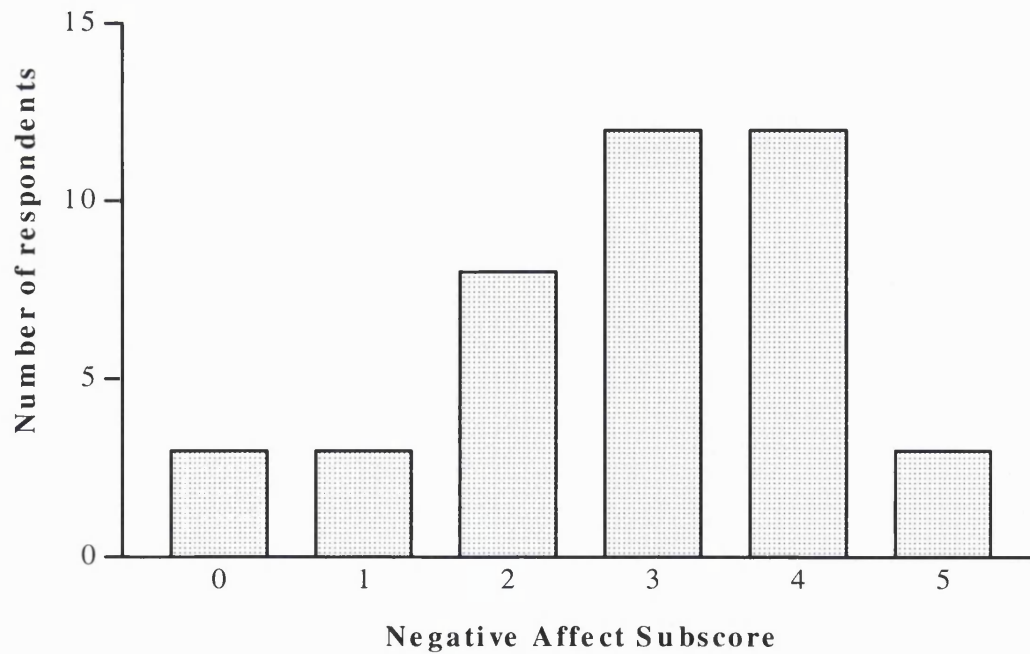
Note: Psychological well-being was measured by the Affect-Balance Scale (Bradburn, 1969)

Figure 8.1a Positive affect subscores for the Affect-Balance Scale (n=41)

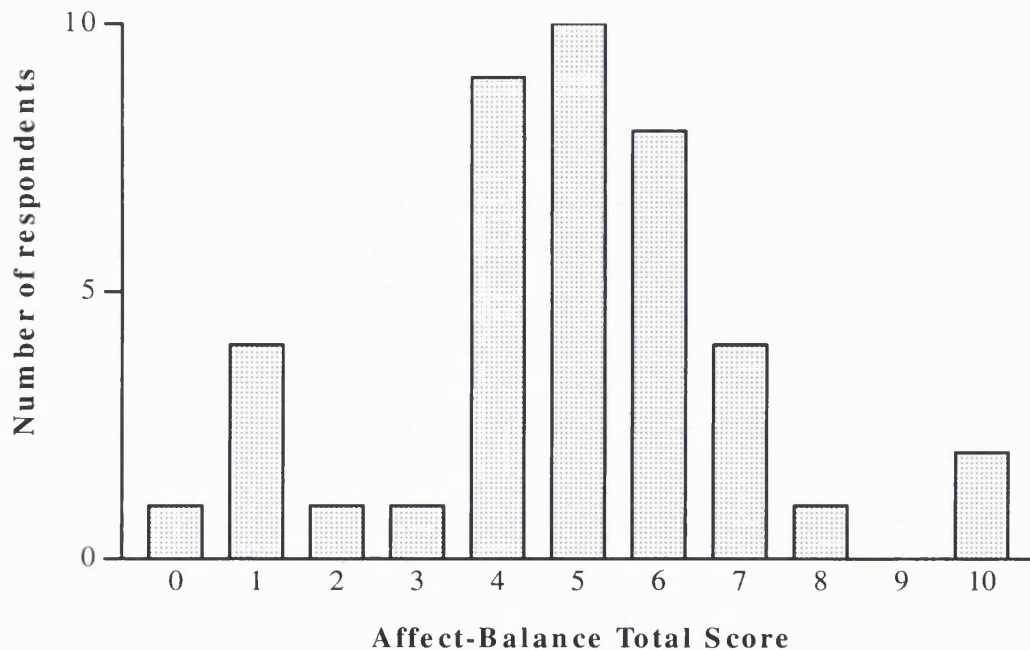


Note: High positive affect subscore (5) is desirable for greater psychological well-being.

Figure 8.1b Negative affect subscores of the Affect-Balance Scale (n=41)



Note: Low negative affect subscore (0) is desirable for greater psychological well-being.

Figure 8.1c Total scores of the Affect-Balance Scale (n=41)

Note: High affect-balance total score (10) represents greater psychological well-being.

8.2.3.4 Self-Concept: the Self-Esteem Scale

Self-concept was measured using Rosenberg's Self-Esteem Scale (1965). The scale comprises 10 items that may be divided into 5-items of positive self-esteem and 5-items of negative self-esteem. Respondents were asked to agree or disagree to each of the 10 statements and the dichotomous responses were scored as 1 or 0, respectively. Currently, there is no agreement over the method of scoring for this scale (Bowling, 1991:168). For the purposes of this study, the scale was scored using the same method as the Affect-Balance Scale (Bradburn, 1969) (see Section 8.2.3.3). Each item score was summed for each subscale. Each subscore ranged from 0-5 where 0 represents low positive/negative self-esteem and 5 represents high positive/negative self-esteem with the desirable subscores being a high positive self-esteem (5) and a low negative self-esteem (0). The self-esteem total score is a positive value ranging from 0-10 ([positive self-esteem subscore - negative self-esteem subscore] + 5) where the higher score represents greater self-esteem.

Table 8.26 illustrates the respondents' answers to the 10 items of the Self-Esteem Scale

grouped under positive and negative self-esteem items. Comments reflecting negative feelings of self-esteem either were associated with the respondents' feelings about their illness or being unemployed.

"[On the whole, you are satisfied with yourself.] No. Could do better like getting a part-time job or going to college."

(Case 14)

"[All in all, you are inclined to feel that you are a failure.] Failure being in St. Clement's [hospital]"

(Case 26)

"[All in all, you are inclined to feel that you are a failure.] Definitely in my working life."

(Case 31)

"[You wish you could have more respect for yourself.] I've got respect for myself, but I'd be much better if I could get rid of this illness."

(Case 28)

"[You feel that you're a person of worth, at least on equal plane with others.] No because I don't work. *[You certainly feel useless at times.]* Yes, sometimes I feel I am living a futile life. I've attempted suicide twice but not in recent years."

(Case 72)

Figure 8.2a and 8.2b show the distribution of subscores for each of the positive and negative self-esteem subscales. The mean score for positive self-esteem was 3.71 (median=4.00). The mean score for negative self-esteem was 2.49 (median=2.00). Figure 8.2c shows the distribution of the total scores for the Self-Esteem Scale. The mean score was 6.21 (median=6.5). Three of the respondents (Cases 54, 62, 64) found some items difficult to answer (see footnote Table 8.26).

The positive and negative self-esteem subscores were significantly negatively correlated (Spearman's $\rho=-0.457$; $p=0.004$; $n=38$). Each subscore also correlated with the Self-Esteem Scale total score: positive self-esteem and self-esteem total score were significantly positively correlated (Spearman's $\rho=0.809$; $p<0.001$; $n=38$); negative self-esteem and self-esteem total score were significantly negatively correlated (Spearman's $\rho=-0.876$; $p<0.001$; $n=38$).

Table 8.26 Respondents' self-esteem

Do you agree that the following statements apply to you:	POSITIVE	POSITIVE	NEGATIVE	POSITIVE	NEGATIVE	POSITIVE	POSITIVE	NEGATIVE	NEGATIVE	NEGATIVE
	You feel that you're a person of worth, at least on equal plane with others	You feel that you have a number of good qualities	All in all, you are inclined to feel that you are a failure	You are able to do things as well as most others	You feel you do not have much to be proud of	You take a positive attitude towards yourself	On the whole, you are satisfied with yourself	You wish you could have more respect for yourself	You certainly feel useless at times	At times you think you are no good at all
	No. (%)	No. (%)	No. (%)	No. (%)	No. (%)	No. (%)	No. (%)	No. (%)	No. (%)	No. (%)
Yes	28 (74)	35 (87)	16 (40)	35 (85)	11 (28)	29 (71)	25 (61)	29 (71)	26 (63)	17 (42)
No	10 (26)	5 (13)	24 (60)	6 (15)	29 (72)	12 (29)	16 (39)	12 (29)	15 (37)	24 (58)
Total number of respondents	38[†]	40[‡]	40[§]	41	40[¶]	41	41	41	41	41

Note: Self-esteem was measured using the Self-esteem Scale (Rosenberg, 1965)

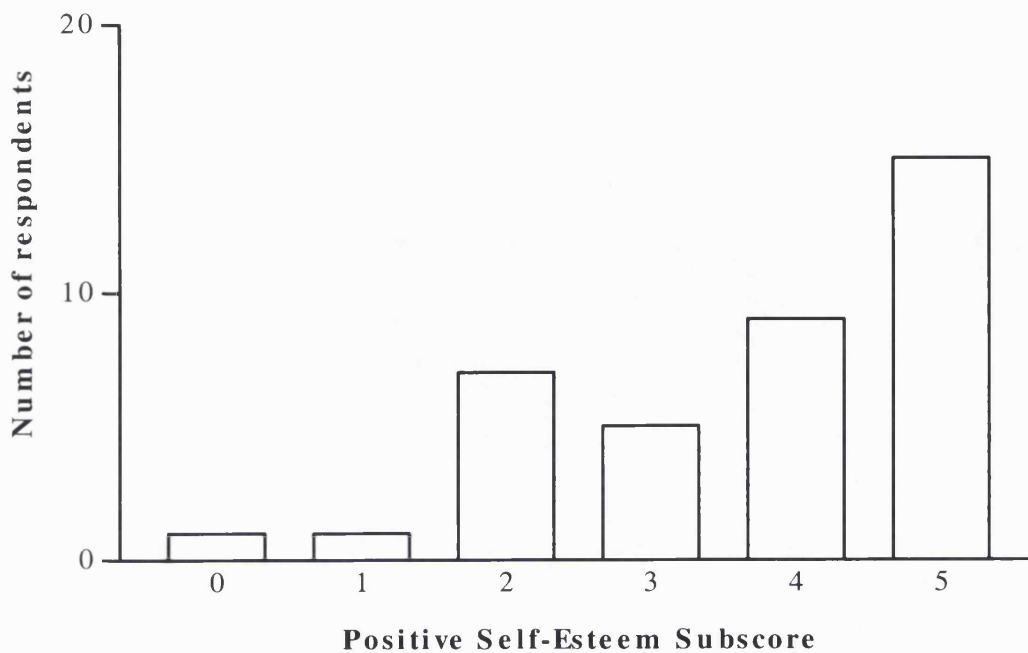
[†] Case 54: "Don't know."; Case 62: "Don't know."; Case 64: "Ambiguous. What I perceive as what I think is right may not be right in the future."

[‡] Case 64: "Ambiguous."

[§] Case 64: "I do not have a view point on that. Hospital alters your perception on what success or failure is."

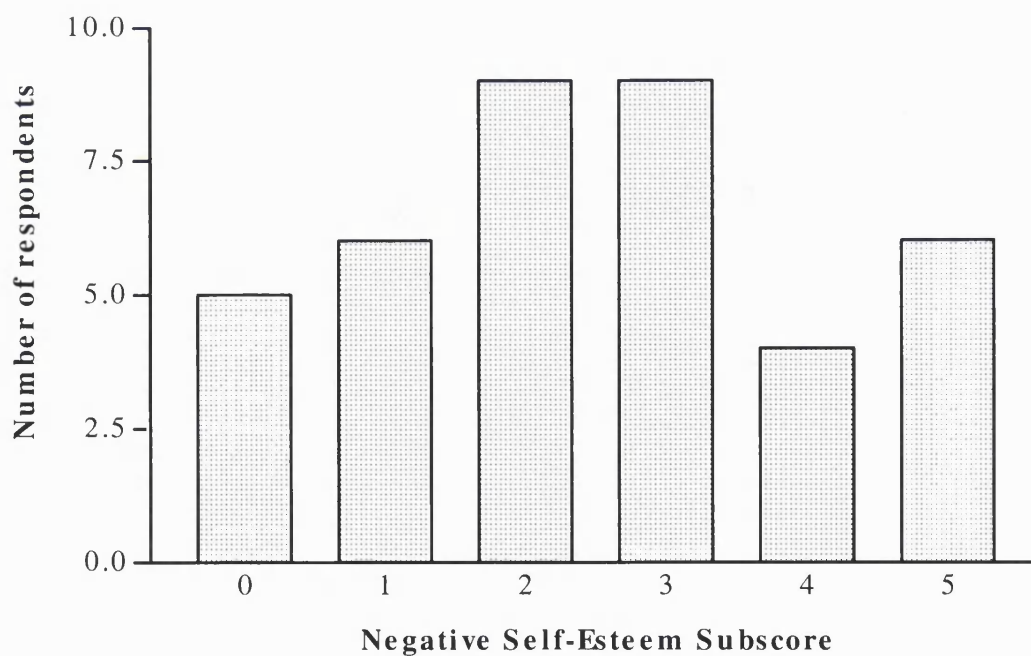
[¶] Case 54: "Don't know."

Figure 8.2a Positive self-esteem subscore for Self-Esteem Scale (n=38)

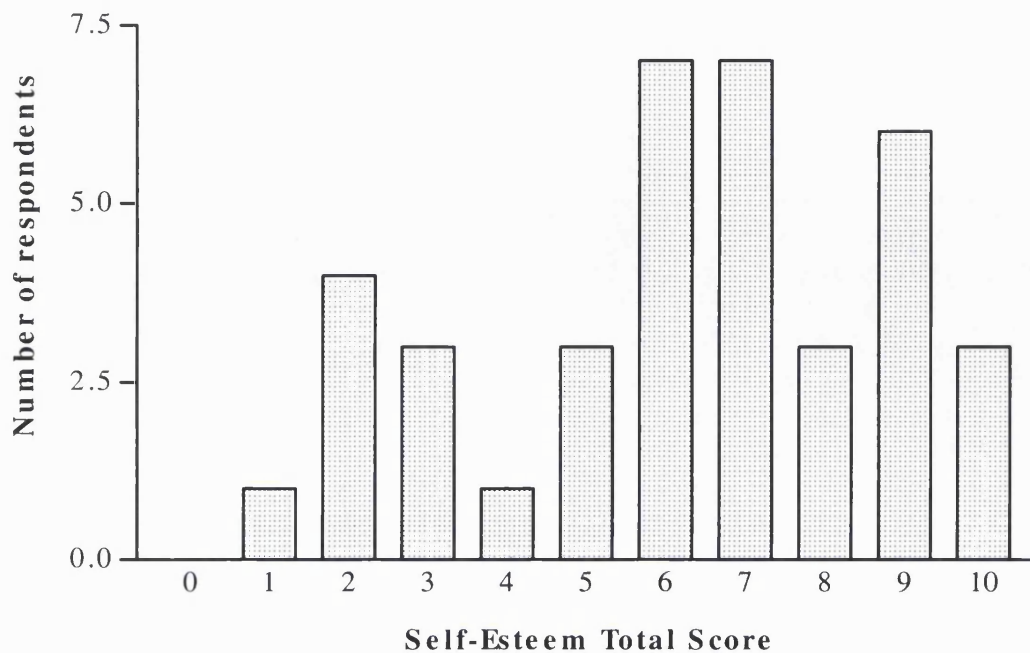


Note: High positive self-esteem subscore (5) is desirable for higher self-esteem.

Figure 8.2b Negative self-esteem subscore for Self-Esteem Scale (n=39)



Note: Low negative self-esteem subscore (0) is desirable for higher total self-esteem.

Figure 8.2c: Total score of the Self-esteem Scale (n=38)

Note: High self-esteem total score (10) represents higher self-esteem.

8.2.3.5 Cantril's Ladder (Cantril, 1965)

Cantril's Ladder (Cantril, 1965) is a single-item scale of life satisfaction. It is self-anchoring which allows the respondent to define the two extremes according to their own terms of reference. In the Lancashire Quality of Life Profile (Oliver, 1991) respondents were asked to imagine the bottom of the ladder to represent the very worst outcome they could have expected in life. The top of the ladder represented the best possible outcome the respondent could have expected. The respondents were asked to mark the stage on the ladder that they would put their life at the time of the interview. Cantril (1965) had ten stages to his original ladder. The Lancashire Quality of Life Profile version (Oliver, 1991) has thirteen rungs. This was so that the ladder represented a 70 mm scale and measurements (0-70) from the bottom of the ladder were used to represent the respondent's life satisfaction (personal communication, Dr Joseph Oliver). Respondents could mark anywhere on the scale and not just on a rung of the ladder.

Four respondents had difficulty understanding this concept and were unable to mark the ladder (Cases 02, 28, 46, 62).

“I can’t do that ‘cos I don’t see my life in a ladder.”

(Case 02)

“I can’t answer this because my life is in Jesus’ hands.”

(Case 46)

The mean measurement on the scale was 41mm (n=37) (median=37mm) and the measurements ranged from 3.5mm-68mm (see Figure 8.3). Almost one-third of the respondents (12, 32%) marked below the midpoint of the scale (35mm).

8.2.3.6 Happiness: The Happiness Scale

The Happiness Scale (Gurin *et al.* 1960) was employed as an indicator of subjective well-being. It is associated with satisfaction and mental health but remains independent of these measures (Oliver *et al.* 1996:61). It is a three-point scale that asks ‘How happy has your life been overall? Very happy; Pretty happy; Not happy’.

Respondents most often reported that their lives had been ‘pretty happy’ (19, 53%) (n=36). A further 13 respondents (36%) reported that their lives had been ‘not happy’. Five respondents were unable to answer this question (Cases 08, 14, 45, 49, 62).

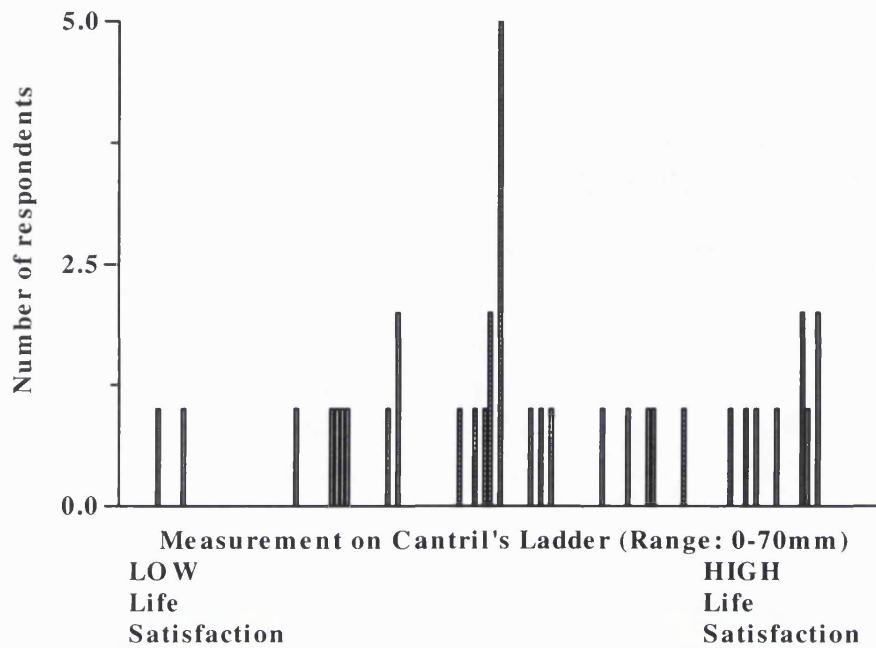
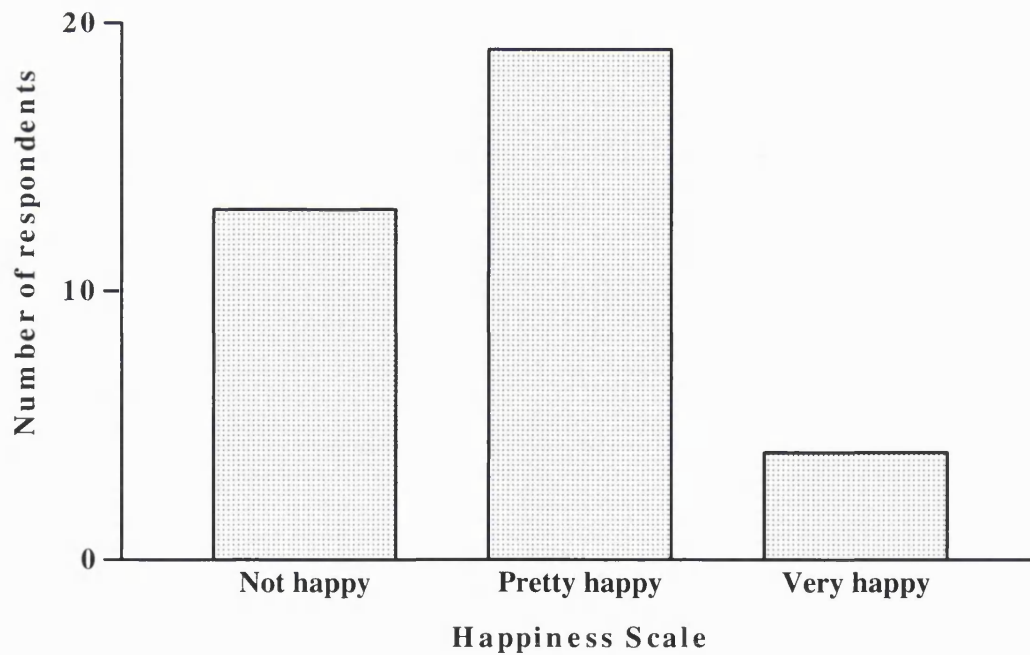
“Mixed. Up and down.”

(Case 14)

“Mixed.”

(Case 49)

Figure 8.4 illustrates the distribution of the respondents’ replies on the Happiness Scale.

Figure 8.3 Respondents' scores using Cantril's Ladder (n=37)**Figure 8.4** Respondents' scores on the Happiness Scale (n=36)

8.3 Psychometric properties of the Lancashire Quality of Life Profile

The psychometric properties of the Lancashire Quality of Life Profile (LQoLP) have been explored and tested by its authors (Oliver *et al.* 1996:65-83) (see Chapter 2 for a review of the profile). Data from the community questionnaire were analysed to determine the reliability and validity of the LQOLP with the sample in this study (n=41). For a wider discussion of the reliability and validity of the information collected throughout the study, see Section 8.4.

8.3.1 Reliability

Reliability is concerned with the consistency of measurement and its susceptibility to error, in particular, with the same respondents, under the same conditions, at different times. The reliability coefficient is a measure of the reproducibility achieved by a measure under a given set of conditions (Bowling, 1991:16; Freeman and Tyrer, 1992:145).

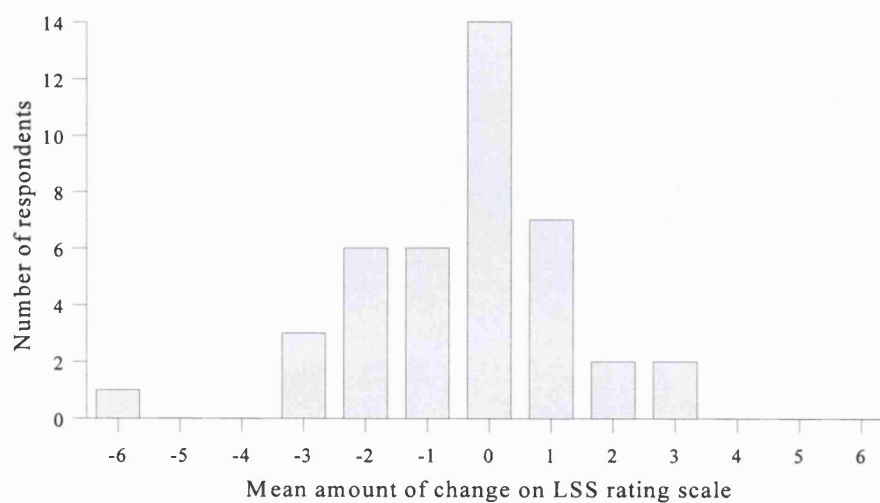
8.3.1.1 Test-retest reliability

The Lancashire Quality of Life Profile includes a pre- (GWB-I) and post-profile (GWB-II) general well-being item (see Sections 8.2.3.2) to provide a measure of stability (a reliability trend) for the report of client information throughout the profile (Oliver, 1991). In this study, the variables were moderately, but significantly, correlated (Pearson's $r=0.471$; $p=0.002$). The difference between the mean scores for GWB-I and GWB-II was not significant, i.e. mean general well-being did not significantly differ between the start and the end of administering the LQOLP, thus demonstrating no evidence of systematic bias ($t=1.44$, $p=\text{not significant}$) (Table 8.27).

Figure 8.5 shows that the mean amount of change per respondent approached a normal distribution. Changes in scores ranged between 1 and 3 points on the LSS scale except for one client (Case 36) who had adjusted her subjective general well-being score down 6 points. Most commonly, there was no change in the LSS ratings of GWB-I and GWB-II (14, 34%).

Table 8.27 Test-retest reliability measured using the general well-being ratings of the respondents pre- and post-Lancashire Quality of Life Profile

	LSS Scale Pre- and Post-Profile
<i>Pre-profile (GWB-I)</i>	
Mean	4.68
Standard deviation	1.75
<i>Post-profile (GWB-II)</i>	
Mean	4.29
Standard deviation	1.60
<i>Paired differences</i>	
Mean	-0.39
Standard deviation	1.73
95% C.I. of the difference:	
lower	-0.94
upper	0.16
t	1.44
p (two tail)	0.156
r (p=0.002)	0.47
Total number of respondents	41

Figure 8.5 Mean changes in general well-being LSS ratings per respondent, pre- and post-profile (n=41)

8.3.1.2 Reliability of scale scores

Three multi-item scales contribute to the measurement of subjective well-being in the LQOLP: perceived quality of life using the life satisfaction scale ratings for each domain (Andrews and Withey, 1976), the Affect-Balance Scale (Bradburn, 1969), and the Self-Esteem Scale (Rosenberg, 1965). Internal consistency and split-half methods were used to measure the reliability of the subjective well-being scales' scores with the study sample (n=41) (Table 8.28).

Table 8.28 Inter-item reliability for the three multi-item subjective well-being scales[†]

Scale	Inter-Item Mean Correlation	Standardised Item Alpha	Guttman Split-Half Correlation
Perceived QoL [‡] (n=16)	0.06	0.61	0.64
Perceived QoL [§] (n=25)	0.07	0.62	0.55
Positive Affect (n=41)	0.40	0.77	0.73
Negative Affect (n=41)	0.13	0.43	0.34
Positive self (n=38)	0.26	0.64	0.55
Negative self (n=39)	0.26	0.68	0.62

[†] Perceived Quality of Life, Affect-Balance Scale (Positive and Negative Affect) and Self-Esteem (Positive and Negative Self-Esteem).

[‡] Three items rated on the LSS scale were omitted from the analysis since item sample size < 20 (satisfaction with employment; salary; marriage).

[§] Five items rated on the LSS scale were omitted from the analysis since item sample size < 22 (satisfaction with employment; salary; marriage; religion; frequency attending religious services).

Twenty-four out of the 27 perceived quality of life items rated on the LSS scale were analysed for 16 respondents. A second analysis was performed using 22 perceived quality of life items for 25 respondents. Due to the small number of respondents for whom certain items applied, satisfaction with employment (n=4), salary (n=1) and marriage (n=2) were omitted from the first analysis while satisfaction with religion (n=20) and the frequency of attendance at religious services (n=21) were also omitted from the second analysis. The mean inter-item correlation was very low on each occasion (0.06; 0.07). Low mean inter-item correlations would be expected due to the variety of items being tested across the nine life domains. Cronbach's alpha (0.61; 0.62) and Guttman split-half coefficients (0.64; 0.55)

achieved weak but acceptable levels of reliability.

The Affect-Balance Scale was analysed according to its component subscales of positive and negative affect. Positive affect showed greater reliability in this sample compared with the reliability information generated for the negative affect subscale. The Self-Esteem Scale was also analysed according to its subscales (positive self-esteem and negative self-esteem). Each subscale showed comparable reliability data with negative self-esteem demonstrating slightly greater reliability (Table 8.28).

8.3.2 Validity

‘Validity is concerned with whether the indicator actually does measure the underlying attribute or not’ (Bowling, 1991:14). Bowling discusses the difficulty of establishing validity in health status measurement since there is no gold standard of health (criterion) with which to compare the indicator. Consequently, content and construct validity are the most appropriate methods for testing the degree of confidence with which a health status scale measures what it purports to measure.

8.3.2.1 Content Validity

As discussed in Chapter 2, there is a lack of empirical evidence supporting an agreed operational definition of quality of life (QoL). The Lancashire Quality of Life Profile (Oliver, 1991) is dependent on previously developed scales and measures of subjective well-being thought to be related to QoL. Oliver (1991) argues that the approach used to develop the LQOLP shows face validity and is in concordance with current informed opinion. However, he also states a need for empirical validation.

Oliver *et al.* (1996:72) claim that the LQOLP has an internal method for assessing content validity through the final item of the questionnaire that asks respondents:

‘Can you name anything(s) which would improve the quality of your life?’.

Five respondents reported that they could not name anything that would improve the quality of their lives (Cases 04, 21, 22, 31, 67). Four of these respondents (Cases 04, 21, 22, 67)

measured above the midpoint on Cantril's Ladder and reported either that overall, life had been 'pretty happy' or 'very happy' on the Happiness Scale. The remaining respondent (Case 31) measured in the lowest third of Cantril's Ladder and reported that overall, life had been 'not happy' on the Happiness Scale.

Thirty respondents (73%) could name at least one item. The verbatim responses were office-coded as before (Section 8.1). Table 8.29 shows the domains representing the areas of life that would improve QoL as identified by the respondents. One respondent (Case 45) gave an unrateable response.

Respondents most often mentioned relationships with others (including intimate relationships but excluding relationships with family and relatives) as the first life area that could improve their QoL (7, 20%). The most frequently mentioned life areas were work/education (15, 18%), followed by relationships with others (including intimate relationships but excluding relationships with family and relatives) (13, 16%) and living situation (12, 15%).

Table 8.29 Areas of life that would improve quality of life as reported by the respondents

Area of life that would improve quality of life	1st area of life named (n=35) No.	2nd area of life named (n=27) No.	3rd area of life named (n=14) No.	4th area of life named (n=6) No.	All areas of life (n=82) No. (%)
Relationships with others (including intimate relationships)	7	5	0	1	13 (16)
Work / Education	6	6	2	1	15 (18)
Finances / standard of living	6	2	1	0	9 (11)
Living situation	5	5	2	0	12 (15)
Own health including unwanted effects of medication	3	2	1	0	6 (8)
Leisure activities / social life	2	2	5	1	10 (12)
Relationships with family, relatives	1	4	0	0	5 (6)
Looking after oneself / self-care	1	0	1	1	3 (4)
Contact with mental health services / staff	0	1	0	0	1 (1)
Conversation / Communication	0	0	1	0	1 (1)
Spiritual life / religion	0	0	1	0	1 (1)
Domestic activities	0	0	0	1	1 (1)
Other areas [†]	4	0	0	1	5 (6)

[†] Case 08: "Having a surprise, something totally out of the blue."; Case 30: "Stop gambling, couldn't keep off it."; Case 49: "Personality, to have one."; Case 59: "Imagination."

Section 8.1 reported the domains representing the five most important areas of life that contributed to the respondents' QoL (n=41) using the adapted SEIQoL questions. Respondents identified these components of QoL before they answered the Lancashire Quality of Life Profile. Table 8.30 compares the domains used to code the verbatim responses of the respondent-defined QoL areas, the domains of the Lancashire Quality of Life Profile and the free response items identified to improve the QoL of the respondents at the end of the Lancashire Quality of Life Profile.

Table 8.30 Respondent-defined important areas of life compared with the domains of the Lancashire Quality of Life Profile and the free response items at the end of the Lancashire Quality of Life Profile

DOMAIN	Respondent-defined areas of life [†] (up to 5)	Lancashire Quality of Life Profile (105 items)	Final item of Lancashire Quality of Life Profile: free response items that would improve quality of life
Work/Education	Yes	Yes	Yes
Leisure / Participation	Yes	Yes	Yes
Religion	Yes	Yes	Yes
Finances	Yes	Yes	Yes
Living situation	Yes	Yes	Yes
Legal and safety	Yes	Yes	No
Family relations	Yes	Yes	Yes
Social relations	Yes	Yes	Yes
Health	Yes	Yes	Yes
Medication (including unwanted effects)	Yes	----	Yes
Intimate relationships	Yes	----	Yes
Self-care / looking after oneself	Yes	----	Yes
Contact with mental health services / staff	Yes	----	Yes
Pets	Yes	----	No
Conversation / Communication	Yes	----	Yes

[†]The respondent-led items were identified using questions adapted from the SEIQoL before administering the Lancashire Quality of Life Profile.

The respondent-defined areas of life (identified before administering the LQoLP) incorporated all the domains covered by the LQoLP. However, there were additional life areas identified by the respondents as contributing to their QoL that were not included in the LQoLP: medication issues, intimate relationships, self-care, contact with mental health services/staff, pets and communication/conversation (see Section 8.1). Table 8.30 shows that

the final item of the LQoLP, which offers the respondents an opportunity to name any areas of life that would improve their QoL, generated similar additional domains. However, at the end of the questionnaire there are problems such as interviewee fatigue, and if the domain had already been discussed would respondents feel able to discuss additional items.

Although all the domains of the Lancashire Quality of Life Profile were represented in the responses to the open questions, at an item-specific level, the domains often inadequately measured the respondent's life area. Forty-four per cent of the items ranked within the five most important areas of life (as defined by the respondents) were not measured by the LQoLP. For example, in the domain 'Leisure/Participation', the items included in the Lancashire Quality of Life Profile (Oliver, 1991) are detailed below.

In the past fortnight, have you:

been out to play or watch a sport?

been out shopping?

been for a ride in a bus, car or train?

watched television or listened to the radio?

In the past year, have there been times when you would have liked more leisure activity but were unable?

How satisfied are you with:

the amount of pleasure you get from things you do at home?

the amount of pleasure you get from things you do outside your home?

the pleasure you get from radio or tv?

Items included in the verbatim responses of the equivalent domain of 'leisure activities /social life' but judged as not included at an item specific level of the Lancashire Quality of Life Profile are detailed below.

"Playing the piano."

(Case 03)

"Playing drums. My poetry."

(Case 04)

"Going on holidays."

(Case 11)

"Reading."

(Case 14)

"Going to the launderette."

(Case 22)

"I like going to seaside places. I'm going to Margate this Sunday on a coach."

(Case 28)

“Smoking. Drinking.”

(Case 35)

“Library. Could be [better] if services were improved. Leisure services.”

(Case 45)

“Playing music. Roller skating. Dancing. Not much opportunity.”

(Case 46)

“Paul McCartney, John Lennon, Elvis and Rock ‘n’ Roll. Turkish Delight. I love Turkish Delight. Arnold Schwarzneger in the films. Cinema. I like going to the Lyceum Theatre.”

(Case 59)

“Smoking.”

(Case 72)

While it is acknowledged that one could not hope to include all items specific to all respondents, the inclusion of a generic ‘hobby/past-time’ item (which respondents may specify at the time of interview) may increase the content validity of this domain.

Respondents also made additional comments at the time of asking the ‘Leisure/Participation’ items that question the relevance of these items to all respondents. For example, in response to the first item of this domain, *‘In the past fortnight, have you been out to play or watch a sport?’*, 36 (88%) respondents replied ‘No’, but what does this tell us?

“I don’t like sport.”

(Case 01)

“I don’t go watching no sport.”

(Case 07)

“I can’t afford it. Watched on tv. Don’t go out to events that I have to pay for.”

(Case 09)

Similarly, at the time of administering the Lancashire Quality of Life Profile, almost half of all respondents (19, 46%) reported not following a religion and that this domain was irrelevant to them.

8.3.2.2 Construct Validity

The Lancashire Quality of Life Profile includes different measures of subjective well-being: Cantril’s Ladder (Cantril, 1965); subjective global well-being (the LSS average scores for

GWB-I and GWB-II), the Happiness Scale (Gurin *et al.* 1960), the Affect-Balance Scale (Bradburn, 1969) and the Self-Esteem Scale (Rosenberg, 1965). Inter-correlations between these scales were tested to determine the construct validity of the scale with the sample in this study (n=41) (Table 8.31). Included in this analysis was the subjective general well-being rating of 'overall quality of life' determined by respondents using the 'Delighted-Terrible Faces' Scale' (Andrews and Withey, 1976) (Section 8.1.3).

There were 2 non-significant Spearman correlations:

- Affect-Balance Scale (Bradburn, 1969) and Cantril's Ladder (Cantril, 1965) (Spearman's $\rho=0.21$; $p=0.22$; $n=37$)
- Faces QoL rating and Cantril's Ladder (Cantril, 1965) (Spearman's $\rho=0.31$; $p=0.058$; $n=37$)

The correlation between the Affect-Balance Scale (Bradburn, 1969) and Cantril's Ladder (Cantril, 1965) was re-analysed according to the positive and negative affect subscales.

- Positive affect and Cantril's Ladder showed a weak, but significant, correlation (Spearman's $\rho=0.335$; $p=0.043$; $n=37$).
- No correlation was detected, however, between negative affect and Cantril's Ladder (Cantril, 1965) (Spearman's $\rho=-0.047$; $p=0.784$; $n=37$).

Table 8.31 Spearman Inter-Correlations for Subjective Global Well-Being (GWB) Measures[†] and Psychological Well-Being (PWB) Measures[‡]

	GWB				PWB	
	Cantril's Ladder	LSS average (GWB-I and GWB-II)	Happiness	FACES QoL rating	Self-Esteem	Affect-Balance
Cantril's Ladder	1.00					
LSS average (GWB-I and GWB-II)	0.51*** (n=37)	1.00				
Happiness	0.62*** (n=34)	0.52*** (n=36)	1.00			
FACES QoL rating	0.31 (n=37)	0.43** (n=39)	0.41* (n=35)	1.00		
Self-Esteem	0.58*** (n=35)	0.55*** (n=38)	0.41* (n=34)	0.57*** (n=37)	1.00	
Affect-Balance	0.21 (n=37)	0.37* (n=41)	0.50** (n=36)	0.36* (n=39)	0.45** (n=38)	1.00

* $p \leq 0.05$ for 2-tailed test; ** $p \leq 0.01$ for 2-tailed test; *** $p \leq 0.001$ for 2-tailed test.

[†]Subjective Global Well-Being measures: Cantril's Ladder (Cantril, 1965); average LSS rating for General Well-Being pre- and post-profile; Happiness Scale (Gurin *et al.* 1960); FACES QoL rating administered pre-profile.

[‡]Psychological Well-Being measures: Self-Esteem Scale (Rosenberg, 1965); Affect-Balance Scale (Bradburn, 1969).

8.4 Summary

This section summarises the quality of life of the respondents as measured by adapted questions from the Schedule for the Evaluation of Individual Quality of Life (SEIQoL) (O'Boyle, 1994) and the Lancashire Quality of Life Profile (Oliver, 1991). The responses were compared to population data where possible. Later in this section, the psychometric properties of the Lancashire Quality of Life Profile with this study sample of respondents with schizophrenia will be compared to published data.

The literature suggests that the purpose of quality of life (QoL) measurement is to facilitate patient involvement in contributing information to the assessment of health care or treatment and to provide information on the effects of treatment and outcome in terms that are relevant to people's lives (Hunt and McKenna, 1993; Fitzpatrick *et al.* 1992). Much literature supports the notion that QoL measurement should include the perspective of the individual. Joyce (1994) states that objective indicators of functioning cannot supersede an individual's assessment of that functioning.

The Schedule for the Evaluation of Individual Quality of Life (SEIQoL) (O'Boyle, 1994) is a qualitative approach to measuring QoL (see Section 2.4.3.1) and had not been previously used with a sample of people with schizophrenia. Its appropriateness for people with compromised cognitive abilities is unknown. For this study, respondent-led assessment of QoL was adapted from the SEIQoL approach. Respondents were asked to identify, and prioritise, five areas of life that were important to their QoL. Subsequently, they were asked to judge their current QoL in relation to each area of life using the 'Delighted-Terrible Faces' Scale' (Andrews and Withey, 1976). The Delighted-Terrible Faces' Scale was used in Baker and Intagliata's (1982) Satisfaction with Life Domains Scale and is commonly adapted in other scales (e.g. Lehman's Quality of Life Interview (Lehman, 1988); the Lancashire Quality of Life Profile (Oliver, 1991). This was an exploratory approach to measuring individual QoL with people with schizophrenia.

The 'Delighted-Terrible Faces' Scale' (Andrews and Withey, 1976) was chosen because of its known validity in measuring perceptions of well-being and satisfaction with life domains

(Andrews and Crandall, 1976). The choice of this scale permitted the inclusion of two respondents who had difficulty reading. While, there was no evidence to support the reliable use of the faces' scale with respondents who have difficulty reading, it did permit access to the study for all those who wished to participate. Oliver *et al.* (1996:63) had piloted the faces' scale during the development work of the LQoLP (Lehman had also employed this scale as reported above). However they discarded it '... as they made no real improvement on the worded version of the delighted-terrible scale'. (Although Oliver *et al.* (1996:63) did not report in what way there was no improvement, e.g. spread of response). Baker and Intagliata (1982) successfully use the faces' scale in their Satisfaction with Life Domains Scale.

Previously, researchers have documented difficulties with open approaches to QoL assessment with mentally ill respondents (Jones *et al.* 1986; Barry *et al.* 1993). However, these studies were with long-stay inpatients being resettled in the community or with the confused elderly. This current study used the open approach with a younger group of respondents (mean age=39 years; n=43), diagnosed with schizophrenia who had experienced repeated admissions to hospitals (mean total number of admissions=5) but were living in the community at the time of the interview.

Some respondents had difficulty identifying and prioritising the five areas of life that determined their QoL. Two out of the 42 respondents could not answer the question. A further two respondents were unable to prioritise their areas of life. Variation existed in the ability of respondents to provide the appropriate context to their comments for accurate coding. Twenty-five respondents could name five areas of life but the remaining 13 respondents named between one and four areas of life. One respondent was unable to rate their current QoL in relation to each of the areas of life named using the Faces Scale.

Of interest to this study were the important areas of life that schizophrenia had affected. It was intended that these may be compared with the important areas of life affected by other long-standing illnesses (Bowling, 1996). Therefore, respondents were also asked to name the five most important areas of their lives that their illness had affected. This question assumed that respondents had insight to their illness. However, at the time of the community

questionnaire (n=42), only 12 respondents (29%) had some insight into their illness according to the Present State Examination (PSE) (Wing *et al.* 1974) questions (Section 7.2.2). Respondents' lack of insight prevented 6 respondents from answering the question. Seven other respondents did not answer the question: consent was withdrawn (1); illness was reported not to affect any specific areas of life (3); unable to answer question (3). Respondents also had difficulty identifying those areas affected by their illness *per se*. Severe mental illness such as schizophrenia affects peoples' whole lives. Eight respondents (11%) reported that 'everything, life in general' had been affected. Hunt (1997) suggested that asking people about areas of life in relation to their health status can be misleading since respondents may have already adjusted their lives to account for their altered functioning. People's goals and expectations can be modified to respond to changes in their functioning due to illness and therefore, asking about areas of life in relation to health status one may be tapping modified areas of life and so the impact of ill health is under estimated. Therefore, this question gave variable additional information compared with the first question. It was dependent on respondents' insight to their illness and the length of time that they had their illness since there was an implicit need to make comparisons with pre-morbid areas of life.

At an item-specific level some respondents highlighted the negative consequences of adhering to medication in relation to the impact on important areas of their lives. However, methodologically, one cannot be sure that the opening questions of the interview that explored respondents' perceptions of their medication did not make these issues more accessible, encouraging respondents to report them again. Alternatively, other respondents may have under-reported medication issues in relation to QoL due to the assumption that the interview had moved on to other items and discussion about medication had finished. Also, it is evident from the results of the medication issues that respondents had difficulty identifying the adverse effects of medication.

The most common area of life that was prioritised as first most important was relationships with family and relatives (10, 26%; n=38), followed by work/education (6, 15%; n=36) and own health (including the unwanted effects of medication) (4, 11%; n=36). The most frequently mentioned area of life across all ranks 1-5 (n=173) was leisure activities/social life (41, 23%), followed by relationships with family and relatives (23, 13%) and relationships

with others (including intimate relationships) (18, 10%). The important areas of life identified by the respondents illustrated that QoL, for them, was more than health status and more than areas of life affected by illness.

Bowling (1996) used the same questions in an interview survey (with the Office of Population Census and Surveys (OPCS) Omnibus Survey) with a random sample of the general population in Great Britain (n=2,000). The research aimed to provide population norms on the dimensions of life that people perceived to be important, and to analyse and provide data on how different subgroups of the population (e.g. by longstanding illness) defined the important domains of life. Table 8.32 compares the sample of people with schizophrenia in this study with Bowling's findings for the total sample (Bowling, 1996) and a subgroup of the British sample who reported mental illness problems (mainly depression) (Bowling, 1996).

Results of the first most important area of life were compared among the 3 samples. Both the community schizophrenia sample (n=38) (from this study) and the British population sample (n=1968) (from Bowling's study) were most likely to report relationships with family and relatives. However, the mental illness British subgroup (n=31) (from Bowling's study) was most likely to report the availability and ability to work as joint first most important area of life with social life and leisure activities.

The 4 most common areas of life nominated as the first most important area of life were compared between groups. The schizophrenia community group and the mental illness British subgroup had all areas of life in common: social life/leisure activities, work/education, own health, relationships with family and relatives. The British population sample differed from the two mental illness samples by nominating the health of someone close and finance and living conditions. It perhaps is not unexpected that the samples with mental illness, while concerned about their own health, do not mention the health of others. Also, the general population mentioned finance and living conditions ahead of work/education which may suggest that the general population sample took work/education for granted and the focus for QoL were the consequences of work/education, i.e. finances and standard of living indicators. By comparison the samples with mental illness may have had

more dissatisfaction in the areas of life of work/education and therefore, these areas were more important as QoL indicators. Data from other parts of the interview provided more evidence to support this theory for the schizophrenia sample. The problems of the stigma of mental illness were discussed by respondents and its negative effect on leading a working life. Also, satisfaction with unemployment status was reported as the area of least satisfaction during the Lancashire Quality of Life Profile (24%).

When all areas of life (ranks 1-5) were combined and analysed in order of frequency, social life and leisure activities was the most frequent area of life named by the community schizophrenia sample (n=40). The British population sample (n=1968) named finances and standard of living most frequently and the mental illness subgroup of the British sample (n=30) named the availability and ability to work most frequently.

The rating exercise of current QoL in relation to each area of life named demonstrated the double-sided nature of QoL as defined by Bowling (1995:2). When all areas of life (ranks 1-5) were combined in order of frequency, social life and leisure activities was the most common area of life named (n=41). For 30 (75%) respondents, social life and leisure activities contributed positively to their QoL, 4 (10%) felt their QoL was negatively affected and 6 (15%) felt that their QoL was neither positively nor negatively affected. Relationships with family and relatives (the second most frequent area of life named when all areas of life were combined) (n=23) was rated as positively contributing to QoL for 55% (11), as negatively contributing to QoL for 25% (5) and for the remaining 4 respondents (20%), QoL was neither good nor bad in relation to relationships with family and relatives. Relationships with others (including intimate relationships) (the third most frequent area of life named when all areas of life were combined) (n=18) was rated as positively contributing to QoL by 53% (9), as negatively contributing to QoL for 41% (7) and for the remaining respondent (1, 6%), QoL was neither positively nor negatively affected by relationships with others.

When QoL ratings were considered for life as a whole, (n=40) about half the sample rated their QoL as good, very good or best life imaginable (21, 52%), while the remaining half felt that their QoL was either 'all right' neither good nor bad (10, 25%) or that it was bad, very bad or the worst life imaginable (9, 23%). These global ratings were significantly correlated

in a positive direction with other global measures of well-being taken from the LQoLP (see later).

Table 8.32 Rank order of areas of life compared between the community sample with schizophrenia (this study), the British Omnibus Sample (total) and the British Omnibus Sample (mental illness) (from Bowling 1996)

	Community sample with schizophrenia (this study)		British omnibus sample (total) (Bowling, 1996)		British omnibus sample (mental illness - mainly depression) (Bowling, 1996)	
	Rank 1st most important	Total frequency 1-5 combined	Rank 1st most important	Total frequency 1-5 combined	Rank 1st most important	Total frequency 1-5 combined
Social life & leisure activities	3 joint	1	7	5	1 joint	2
Relationships with family & relatives	1	2	1	2	4	4 joint
Relationships with others	9	3	5	7	5	4 joint
Work / (Education) [†]	2	4 joint	6 (8)	6 (10)	1 joint (unknown)	1 (unknown)
Living situation [‡]	6 joint	4 joint	4	1	6	4 joint
Own health	3 joint	6	2	3	3	3
Health of someone close / responsible for	---	---	3	4	---	---
Finances / standard of living [‡]	6 joint	7	4	1	6	4 joint
Base	38	40	1968	1968	31	30

[†] For the community schizophrenia sample, work & education were coded together; for the British omnibus samples, work & education were coded separately. The rankings for education are in parentheses.

[‡] For the British omnibus samples, finance and living conditions were coded together.

Immediately following the respondent-led questions about QoL, (in order not to bias, by

prompting responses to the former) the Lancashire Quality of Life Profile (LQoLP) (Oliver, 1991) was administered to the respondents.

Objective indicators

According to the objective indicators, the study sample with schizophrenia demonstrated that they were a disadvantaged group in many life areas compared with survey data of the general population. Currently, population norms for the LQoLP have not been published. However, the data generated from the objective indicators provided some information to make comparisons with the 1993 General Household Survey data (Office of Population Censuses and Surveys, 1995).

- Respondents were mostly single (35, **85%**) compared with 31% of people aged 16-64 years in Great Britain who were either single or cohabiting (Office of Population Censuses and Surveys, 1995:12).
- The sample was mainly (37, **90%**) unemployed. This figure is much higher than that for the general population: 8% of the population in Great Britain aged 18-64 years (n=13,846) were unemployed (looking for work in previous 4 weeks and available to start work) and 23% were inactive in 1993 (Office of Population Censuses and Surveys, 1995:58-59).
- The mean total income expected per week to live life as they would wish (no costs deducted) was **£130.38**. This was calculated from adding individual weekly incomes to the amount of additional money nominated by respondents to live life as they would wish. By comparison, the median gross weekly earnings for persons aged 20-69 years in 1993, without qualifications, were £220 for men and £149 for women (Office of Population Censuses and Surveys, 1995:171). Compared with social survey data, the figure expected by the study respondents was reasonable according to the income they may have expected if working.
- Most respondents lived either in a flat rented from local authorities (16, **39%**) or in

hostel accommodation (16, **39%**). In 1993, 22% of adults in Great Britain rented accommodation from local authorities (Office of Population Censuses and Surveys, 1995:30).

- Twelve of the study respondents (**29%**) lived alone compared with 8% of the general population aged 16-64 years in Great Britain in 1993 (Office of Population Censuses and Surveys, 1995:15).
- Half the respondents had lived in their current homes for 1 year or less (20, **51%**). This suggested that many had been placed in new accommodation since discharge from the hospitals. Also, in 1993 only 8% of the general population of Great Britain who rented accommodation from their local authority, had lived there for less than 1 year (n=2120).
- Only five respondents (**12%**) reported that they had been out 'to watch or play a sport' in the last 2 weeks. This compared poorly with general population data that showed 47% adults had participated in a sport or physical activities (excluding walking) in the previous 4 weeks (Office of Population Censuses and Surveys, 1995:138). This is an interesting paradox to the importance placed on the domain of leisure activities/social life in the respondent-led QoL items. However, this spurious finding may be due to the specificity of the item of the LQoLP that asks about sport and not other activities or hobbies (see later methodological discussion).

Subjective well-being

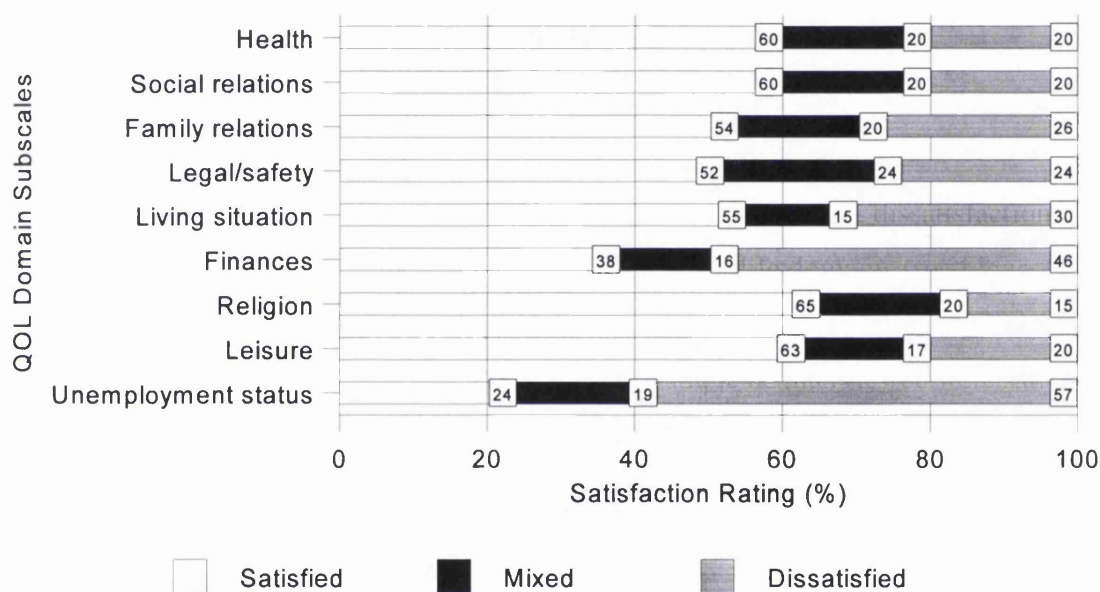
Throughout the subjective well-being measures, about half the respondents were satisfied with their lives though objectively, they appeared disadvantaged.

Perceived quality of life

According to perceived QoL, about half the respondents (52-65%) were satisfied with most domains with the exceptions of work/education (unemployment status) (24%) and finances

(38%). The remaining respondents were divided between feelings of dissatisfaction and feeling mixed (about equally satisfied and dissatisfied) about life domains (see Figure 8.6). Lehman published similar findings using the Quality of Life Interview upon which the LQoLP was based (Lehman *et al.* 1982). Over half the sample he interviewed were satisfied with their lives in most areas except that of work, finances and personal safety. Lehman's sample was 66% men, 75% Caucasian and 63% with a chart diagnosis of schizophrenia.

Figure 8.6 Average satisfaction ratings for domain data of perceived QoL



Besides dissatisfaction with the domains of work/education (unemployment) and finances, analysis at an item-specific level highlighted items of dissatisfaction in the areas of leisure, living situation, safety, relationships and health. These were domains that 8-23% of respondents had identified as important for their QoL in the respondent-led questions.

- Ten respondents (25%) were dissatisfied with the amount of pleasure they gained from activities outside their home.
- Sixteen (39%) were dissatisfied when asked about the prospect of continued residence at their current housing and thirty-one (76%) were dissatisfied at the

prospect of returning to live in the hospital. A third of the respondents (13, 33%) were dissatisfied with their current living arrangements (i.e. living with others (n=7) or living alone (n=6)). In response to an open question in both the recruitment and community interviews, respondents identified accommodation as the most common problem (17-18%) that made their symptoms worse.

- Ten respondents (25%) were dissatisfied with their personal safety and ten (25%) were dissatisfied with the safety of their neighbourhood.
- Eleven respondents (28%) were dissatisfied with their family relationships and 9 (23%) were dissatisfied with the amount of contact they had with relatives.
- Twelve respondents (29%) were dissatisfied with the number of friends they had.
- Nine respondents (22%) were dissatisfied with their general health and 10 (25%) were dissatisfied with their mental health well-being.

About half the respondents were satisfied in most domains while the most unsatisfactory item of the LQoLP was returning to live in hospital (76%). These findings support the current community care philosophy by highlighting their preferences for living in the community. Also, other items of dissatisfaction in the domains of work, finances, leisure, living situation, safety, relationships and health suggested that respondents' QoL in the community could be improved by both health and social services working together to meet their needs.

Subjective global well-being

The average rating of two single item measures of global well-being found that 22 (54%) respondents had feelings of satisfaction, 9 (22%) had mixed feelings and 10 (24%) had feelings of dissatisfaction about life as a whole.

Several national samples have also used this scale (n=4000) (Andrews and Robinson, 1991:89). By summing the two responses, the average score was 10.8 which was higher than

that for the schizophrenia sample (mean=**8.98**: 95% C.I. [8.07, 9.88]).

Psychological well-being: the Affect-Balance Scale (ABS)

Fifteen (37%) respondents scored above the midpoint on the Affect-Balance Scale (ABS) suggesting greater positive affect, i.e. positive feelings outweighed negative feelings. Ten (24%) scored the midpoint suggesting equal positive and negative affect and 16 (39%) scored below the midpoint of the scale suggesting greater negative affect, i.e. negative feelings outweighed positive feelings.

Compared with national data from the USA (Andrews and Robinson, 1991:83) the schizophrenia sample scored lower on psychological well-being. A national sample (n=1469) had an average score of 6.7 compared with **4.85** for the schizophrenia sample. In national samples of 2726 respondents, 13.5% scored +8 or +9 (top of the ABS) (**7%** for schizophrenia sample) and 6.6% scored +1 or +2 (bottom of the ABS) (**15%** for schizophrenia sample).

Oliver *et al.* (1996:170-178) analysed some of their pilot data by 3 clinical diagnoses: schizophrenia (n=133), manic-depressive (n=26) and chronic depressives (n=10). Oliver *et al.* (1996:170-178) found that a score of 4 or 5 on the negative affect subscale was a significantly better discriminatory measure than the single item asking about depression: chronic depression group (90%), manic group (42%) and schizophrenia group (22%). For the sample with schizophrenia reported here, 15 (**37%**) scored 4 or 5 on the negative affect scale suggesting that a third of respondents were depressed.

Self-concept: the Self-Esteem Scale (SES)

Twenty-six respondents (68%) scored above the midpoint suggesting greater positive feelings about self, 3 (8%) scored midpoint on the scale suggesting equal feelings of positive and negative self-esteem and 9 (24%) scored below the midpoint suggesting greater negative feelings about self.

Previous studies in adolescent populations have found the scores to be negatively skewed. However, it is suggested that respondents who do not endorse items of the SES, at least moderately, are probably clinically depressed (Blascovich and Tomaka, 1991:123).

Cantril's Ladder

Fifteen (68%) respondents marked above the midpoint of Cantril's Ladder suggesting positive life satisfaction and 12 (32%) marked below the midpoint of the scale suggesting poor life satisfaction.

Cantril (1965) reported that only 7% scored between 0-3 on the scale in his national studies. By comparison, 27% of this study's sample with schizophrenia scored at an equivalent point, illustrating that they were less satisfied with their overall life satisfaction.

Happiness Scale

Four (11%) respondents reported that life had been very happy, 19 (53%) reported that life had been pretty happy and 13 (36%) reported that their life had not been happy.

Compared with original data by Gurin *et al.* (1960) who reported that 89% of their national sample was very or pretty happy, the schizophrenia sample were less happy (23, 64%) with their overall life.

Psychometric properties of the Lancashire Quality of Life Profile with this study sample

This study contributes to the body of evidence relating to the use of the Lancashire Quality of Life Profile (LQoLP) with the severely mentally ill. Its authors have tested the instrument in a series of pilot studies both in the UK and USA (Oliver *et al.* 1996) involving patients of community mental health centres (n=24; n=68), physically disabled people (n=27), controls from a general health centre (n=15) and chronic mental health 'cases' (n=390). The proportion of respondents with a diagnosis of schizophrenia is unknown.

This study tested the psychometric properties with a small group of people with a DSM-III-R diagnosis of schizophrenia (n=41) living in the community in the UK approximately five months (on average) after discharge from hospital. The psychometric properties of the LQoLP with this sample is compared with the authors' data below.

- **Reliability**

Test-retest

In this study, global well-being-I (GWB-I) and global well-being-II (GWB-II) were modestly, but significantly correlated (**Pearson's $r=0.471$** ; $p=0.002$) and mean scores did not differ significantly indicating moderate external reliability. However, it is recognised that correlation coefficients of ≥ 0.8 are pursued for credible external reliability (Bryman and Cramer, 1997:63-64).

Test-retest reliability correlation coefficients for pilot studies by Oliver *et al.* (1996:70) ranged from 0.49-0.78. Mean scores were tested and significant differences were detected in one pilot study (n=390).

Scale scores

Reliability of the scale was tested using the three multiitem scales included in the Lancashire Quality of Life Profile (LQoLP): perceived quality of life, the Affect-Balance Scale and the Self-Esteem Scale. Table 8.33 compares the test statistics (inter-item mean correlation, standardised item alpha and Guttman split-half correlation) between the data presented here and Oliver's data of all surveys (Oliver *et al.* 1996:70). Acceptable levels of internal consistency were acknowledged with Cronbach's $\alpha \geq 0.5$ (Cronbach, 1951). Again it is recognised that some authors prefer a value of Cronbach's $\alpha \geq 0.8$ for credible internal reliability (Bryman and Cramer, 1997:63-64).

Perceived quality of life was analysed by combining all domain subscales. Due to the variation of items included throughout all domains, low mean inter-item and split half

correlations are not remarkable. Therefore, it seemed appropriate to calculate reliability coefficients (Cronbach's alpha) for each of the domain subscales where there was more than one item (Cronbach's alpha ranged 0.33-0.81 for all domains tested).

In the study reported here, the mean inter-item correlations for perceived QoL were difficult to compute due to small sub-sample sizes in some domains such as satisfaction with employment, salary, marriage and religion that had to be removed from the analysis. The values attained for the mean inter-item correlations suggest poor homogeneity for the construct 'perceived QoL' with this sample. Cronbach's alpha and the Guttman split-half coefficient were lower than those for the published data but were ≥ 0.55 .

The Affect-Balance Scale (ABS) was analysed by its separate components of positive affect (PA) and negative affect (NA). The PA subscale data from this study showed stronger reliability statistics (inter-item mean correlation, Cronbach's alpha and Guttman split-half correlation) than the published data. However, the converse was true of the NA subscale data with all values < 0.50 suggesting poor internal reliability.

Lehman (1983) also showed problems in the application of the ABS in this client group. The presence of specific NA features such as boredom and loneliness have been associated with inaccuracy (Oliver *et al.* 1996:80). However, Lehman (1983, 1988) also found that the level of psychopathology (measured as depression, anxiety, self-control, thought disorder) expressed by a client did not affect the multivariate QoL models. Although, depression and anxiety had consistent negative correlations with general life satisfaction across various patient populations. Oliver *et al.* (1997:81) in their analyses of their complete data set of over 1500 cases, agree with Lehman that 'mental health does not significantly alter the results derived from quality of life surveys'.

During piloting, Oliver *et al.* (1996:81) found that clients had difficulty answering the ABS. In response to this, the authors-reordered the items into response sets maintaining all the PA items together followed by the set of NA items. This reordering may have affected the psychometric properties of the scale.

The Self-Esteem Scale was analysed by its separate components of positive self-esteem and negative self-esteem. Positive self-esteem and negative self-esteem data produced low mean inter item correlations questioning the internal consistency of the scale. However, the items demonstrated more acceptable levels of internal reliability with the Cronbach's alpha and Guttman split half correlation coefficient ≥ 0.55 .

Table 8.33 Inter-item reliability for three multi-item subjective well-being scales[†] comparing this study data with published data (Oliver *et al.* 1996:70)

Scale	Inter-Item Mean Correlation		Standardised Item Alpha		Guttman Split-Half Correlation	
	Study data	Published data	Study data	Published data	Study data	Published data
Perceived QoL (26 items rated on the LSS scale)	0.06 (n=16) [‡]	0.21	0.61	0.75	0.64	0.75
	0.07 (n=25) [§]		0.62		0.55	
Positive Affect	0.40 (n=41)	0.35	0.77	0.75	0.73	0.66
Negative Affect	0.13 (n=41)	0.27	0.43	0.67	0.34	0.59
Positive self	0.26 (n=38)	0.36	0.64	0.76	0.55	0.72
Negative self	0.26 (n=39)	0.34	0.68	0.73	0.62	0.67

[†] Perceived Quality of Life, Affect-Balance Scale (Positive and Negative Affect) and Self-Esteem (Positive and Negative Self-Esteem).

[‡] Three items rated on the LSS scale were omitted from the analysis since item sample size < 20 (satisfaction with employment; salary; marriage).

[§] Five items rated on the LSS scale were omitted from the analysis since item sample size < 22 (satisfaction with employment; salary; marriage; religion; frequency attending religious services).

• Validity

Content validity

Oliver (1991) claimed that the Lancashire Quality of Life Profile (LQoLP) shows face validity and is in accordance with current informed opinion. However, he also stated a need

for empirical validation. Subsequently, Oliver *et al.* (1996:71-73) published more information on the content validity of the LQoLP. They referenced a study by Huxley (1994) who asked 25 mental health professionals the most important life domains for their personal life satisfaction. The cluster of domains produced were deemed all to be included in the LQoLP and did not produce any substantial additional areas. However, they did not justify using health professionals' views to validate the content of an instrument intended for sufferers of mental illness.

Oliver *et al.* (1996:72-73) also reported that the LQoLP has its own internal validity check by asking respondents to name anything that would improve their QoL at the end of the interview. A content analysis with large samples found that from 1575 interviews, 4725 responses were gained in response to this final question and that only a small proportion (138, 2.9%) did not apply clearly to an existing domain or scale (Oliver *et al.* 1996).

The responses to the final item (internal validity check) were analysed for the study reported here. Thirty respondents (73%) named at least one item. The most frequently mentioned life areas were work/education (15, 18%), relationships with others (including intimate relationships but excluding relationships with family and relatives) (13, 16%) and living situation (12, 15%). Relying on this method for assessing the content validity of the scale may present problems for the researcher. First, it is the final item of the LQoLP which takes about 35 minutes to complete and therefore respondents with severe mental illness may be reluctant to spend more time thinking about their QoL (respondent-fatigue). Secondly, the domains already discussed may be more accessible to respondents and lead the respondents into naming similar life areas. Third, the question wording may not be tapping current QoL. It asks respondents '*Can you name anything(s) which would improve the quality of your life?*'. Conceptually, this question is different to asking respondents about their current QoL; it provides the opportunity for a wish-list which may be subtly quite different to the life areas that contribute to current QoL.

An objective of the study reported here was to compare the life areas identified by the respondents using the respondent-led approach to QoL assessment (adapted Schedule for the Evaluation of Individual Quality of Life (SEIQoL) questions) with the domains and items of

the Lancashire Quality of Life Profile (LQoLP). The respondent-led approach was administered before the LQoLP and respondents were asked about life areas that were important for their current QoL. All the domains of the LQoLP were matched. Therefore, at a domain-specific level there is evidence to support the content validity of the LQoLP. However, respondents also identified additional items (similar to those in response to the final item of the LQoLP): self-care, contact with mental health services/staff (not just doctors), intimate relationships, conversation/communication, medication issues, domestic activities and pets. Therefore, on further analysis at an item-specific level, 44% of items identified by respondents during the open questions before administering the LQoLP were not subsequently covered by the LQoLP (e.g. girlfriend/boyfriend, pets, playing drums, smoking, drinking etc.) questioning the content validity of the instrument at this individual level.

Similarly, qualitative data generated by Barry *et al.* (1993) in a community resettlement study of long-stay inpatients, supported the inclusion of domains such as family, social relations and leisure but also recognised additional items pertinent to individuals' QoL such as cigarettes and coffee. Open-ended interviews were carried out with 20 respondents by Baker and Intagliata (1982) to elicit more detailed information regarding QoL. The areas identified by this sample (55.9% diagnosis of schizophrenia) were social contacts, satisfying relationships with families or acquaintances, financial security, functional limitations, personal preferences and interests.

Oliver (1991) suggests that the LQoLP can be used to generate individual profiles for each respondent to use as baseline measurement or for comparison with population norms. However, the issue of the item-specific content validity is of crucial importance at this level of measurement. Respondents are less likely to be motivated to work on areas of life that they are dissatisfied with but are of little importance compared to those areas of life that are of higher importance (Hickey *et al.* 1996). It is acknowledged that all instruments cannot be expected to include all items specific to all respondents. However, consideration should be given to supplementing scales with more open qualitative approaches that allow respondent-specific items to be measured alongside survey instruments.

Construct validity

Construct validity was tested by intercorrelating the measures of subjective well-being included in the Lancashire Quality of Life Profile (LQoLP). For the published data (Oliver *et al.* 1996:73), all correlations reached significance at the $p \leq 0.001$ level. However, the weakest correlations were with the Happiness Scale.

Construct validity was tested with the data reported in this study and included testing the convergent validity of the rating of overall QoL generated using the respondent-led items and the 'Delighted-Terrible Faces' Scale' earlier in the interview. Spearman inter-correlations all reached significance at the $p \leq 0.05$ level except two bivariate correlations:

Cantril's ladder and Faces QoL;

Cantril's Ladder and Affect-Balance Scale.

On further investigation, Cantril's Ladder demonstrated a weak but significant correlation with the positive affect subscale (Spearman's $\rho = 0.335$; $p = 0.043$; $n = 37$) but there was no correlation with negative affect. However, each scale had significant correlations with other measures of subjective well-being and justified the inclusion of all scales. The results of the analysis from this study is presented in Table 8.34 (**in bold**) and compared with Oliver *et al.* (1996:73) published data.

Oliver *et al.* (1996:73) compared their data with that of Andrews and Withey (1976:85) from two surveys in the USA with 1,118 and 1,072 'normal' respondents. Andrews and Withey's global well-being thermometer scale correlated with:

- the 3-point happiness scale at 0.39 (Oliver *et al.* = 0.35; **this study = 0.62**)
- a 7-point satisfaction scale at 0.46 (Oliver *et al.* = 0.57; **this study = 0.51**)
- affect-balance scale at 0.32 (Oliver *et al.* = 0.56; **this study = 0.21**).

The data from this study with the sample of people with schizophrenia compared favourably with other published data for mental health respondents and normal populations, except for the affect-balance scale (ABS). The potential problems of using the ABS with mental health populations was discussed earlier. The presence of specific NA features such as boredom and loneliness have been associated with report inaccuracy (Oliver *et al.* 1996:80).

Table 8.34 Spearman Inter-Correlations for Subjective Global Well-Being (GWB) Measures[†] and Psychological Well-Being (PWB) Measures[‡]:
Study data (in bold) and published data (Oliver *et al.* 1996:73)

	GWB				PWB	
	Cantril's Ladder	LSS average (GWB-I and GWB-II)	Happiness	FACES QoL rating	Self-Esteem	Affect-Balance
Cantril's Ladder	1.00					
LSS average (GWB-I and GWB-II)	0.51*** (n=37)	1.00				
	0.57***					
Happiness	0.62*** (n=34)	0.52*** (n=36)	1.00			
	0.35***	0.43***				
FACES QoL rating	0.31 (n=37)	0.43** (n=39)	0.41* (n=35)	1.00		
	N/A	N/A	N/A			
Self-Esteem	0.58*** (n=35)	0.55*** (n=38)	0.41* (n=34)	0.57*** (n=37)	1.00	
	0.46***	0.54***	0.38***	N/A		
Affect-Balance	0.21 (n=37)	0.37* (n=41)	0.50** (n=36)	0.36* (n=39)	0.45** (n=38)	1.00
	0.56***	0.55***	0.35***	N/A	0.56***	

* $p \leq 0.05$ for 2-tailed test; ** $p \leq 0.01$ for 2-tailed test; *** $p \leq 0.001$ for 2-tailed test.

[†] Subjective Well-Being measures: Cantril's Ladder; average LSS rating for General Well-Being pre- and post-profile; Happiness Scale; FACES QoL rating administered pre-profile.

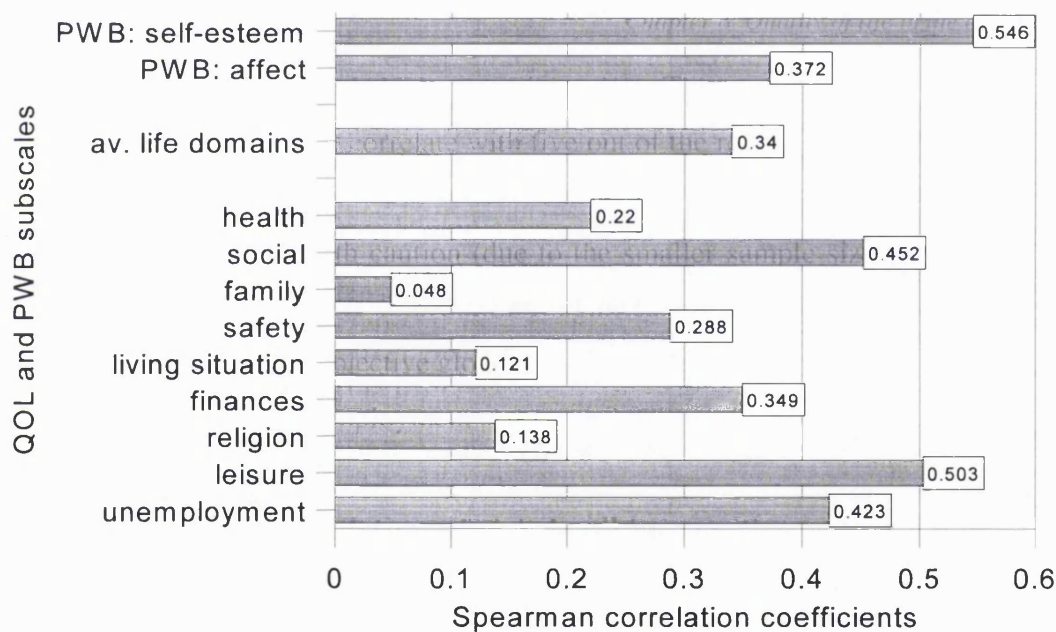
[‡] Psychological Well-Being measures: Self-Esteem Scale; Affect-Balance Scale.

Oliver *et al.* (1996:74) also correlated perceived quality of life domain scores with measures of GWB (Cantril's Ladder and the LSS average score). Much variation was observed across groups and between the UK and the USA. Most consistent findings were demonstrated with a UK sample (n=390). Due to inconsistent results that were most evident with the smaller samples, the authors questioned analyses with small samples and the stability of measures between settings and cultures. The authors claimed general support for construct validity by the pattern of significant positive bivariate correlations between the perceived quality of life

domain subscores for just over half the domain scales. This was in spite of religion, the weakest domain, which did not correlate with five out of the remaining 8 domain scores.

This analysis was repeated with caution (due to the smaller sample size) with this data. Figure 8.7 shows that there were four out of 9 significant bivariate correlations between perceived QoL domains and subjective global well-being (LSS average): leisure ($p=0.001$), social relations ($p=0.003$), unemployment status ($p=0.009$) and finances ($p=0.032$).

Figure 8.7 Spearman correlations of global well-being with perceived QoL domain subscales and psychological well-being



The average score for all life domains could only be calculated for 16 respondents and was found not to be significantly associated with subjective global well-being.

Inter-domain correlations were significant for the following domains:

Safety with social relations ($r=0.520$; $p=0.000$; $n=41$)

Health with religion ($r=0.591$; $p=0.006$; $n=20$)

Health with safety ($r=0.401$; $p=0.011$; $n=39$)

Health with social relations ($r=0.321$; $p=0.046$; $n=39$)

According to analyses with this sample, perceived QoL (9 life domains) does not seem to be measuring the same construct as global well-being. This finding may be dismissed due to the small sample size of this study; thereby agreeing with the inconsistent findings of Oliver *et al.*'s studies with small samples. However, Kemmler *et al.* (1997) completed similar analysis on data of a German version of the Lancashire Quality of Life Profile. This is the only published study found solely to include patients with a DSM-III-R diagnosis of schizophrenia (n=48). On analysis of their data, they also demonstrated poor evidence of construct validity for perceived QoL operationalised by the 8 life domains (the domain of religion was omitted from their study). They found that global well-being correlated only with housing, mental health and social relations (Spearman's $\rho \geq 0.35$). The average of all life domains score correlated at 0.18 (Spearman's ρ) with global well-being. On discussion of their findings they also question the existence of the construct 'subjective QoL' as represented by the life domains.

Criterion validity

Oliver *et al.* (1996:76) tested criterion validity by correlating respondent-rated Cantril's Ladder, global well-being (LSS average) and happiness with interviewer-rated quality of life using the Spitzer Quality of Life (QoL) Uniscale (Spitzer *et al.* 1981). They caution this test since the QoL Uniscale was not developed for use with people with mental illness and therefore it may be questioned whether it should be accepted as a criterion measure.

The QoL Uniscale was not used in this study. As O'Boyle (1994) reported, the terms of reference in judging QoL are specific to the individual influenced by their experiences, expectations and personal environment. By using an interviewer-rated QoL measure (QoL Uniscale), the researcher would be imposing her external value system on the judgements. The measure was attempted for the first few patients. However, this researcher (SAF) found that by using her value system all patients in this study were judged to have such a poor QoL that the scale did not discriminate between patients and all judgements clustered at the lower end of the scale. It was therefore decided to terminate the interviewer-rated QoL scale as the researcher was unsure of the value it contributed to the study.

Subsequently, Lehman (1983) and (Oliver *et al.* 1996:78) tested global well-being (GWB) as an independent criterion measure for the other QoL variables. Using multiple regression analysis, they tested personal characteristics, objective and subjective QoL on GWB (dependent variable). The total amount of variance explained was 58% by Lehman and 61% by Oliver *et al.* (1996:all survey data). Through concurrent analysis, Oliver *et al.* (1996:78) claim that the instrument demonstrates criterion validity.

The same analysis involving a large number of independent variables could not be performed on this study's data due to the small sample size ($n=41$). However explorative analysis considered a multiple regression stepwise model for global well being using the life domains and measures of psychological well-being that were significantly correlated with GWB (four covariates were entered at one time). Correlations > 0.55 were excluded to avoid multicollinearity. Objective data were not significantly related to GWB when tested as bivariate correlations. Subjective QoL in the domains of leisure, work (unemployment status), and social relations together with self-esteem (total score) explained 56.9% of the total amount of variance of GWB (adjusted r^2).

Kemmler *et al.* (1997) also carried out a multiple regression analysis and only the domains of social relations and health contributed significantly to global well-being. They found that the scales of psychological well-being (affect-balance scale and self-esteem scale) appeared to be more closely related to GWB than most domain scales. They also included measures of the positive and negative symptoms of schizophrenia which were significantly correlated to GWB. The total amount of variance explained was 60% when 3 independent variables were retained in the model (backward selection procedure): satisfaction with social relations, positive self-esteem, total score of positive and negative symptoms.

Due to the small sample sizes of both this study and Kemmler's study, little can be concluded about the criterion validity of the LQoLP for these samples.

CHAPTER 9 SOCIAL NETWORKS AND COMMUNITY CARE

9.1 Social networks

Respondents were presented with a predetermined list of three different types of contact: personal, professional carers and distant professionals. Personal contacts included friends, relatives, neighbours and religious figures. Professional carers included key workers, community psychiatric nurses (CPNs), social workers, occupational therapists, housing officers, counsellors/therapists, voluntary support organisations (e.g. MIND, PRA) and home helps. Distant professionals were the general practitioner (GP) and the psychiatrist (see Table 9.1). Respondents were asked to state if they were in contact with any of the types of contacts listed and if so, how frequent was the contact. The respondents were also asked if there was anyone else that they were in contact with that was not included on the list, and if so, how frequent was that contact. Initially, this chapter presents quantitative information on the total number of contacts. The quality of respondents' contacts with personal and professional carers are considered later in the chapter.

Tables 9.1 and 9.2 detail the type and frequency of contact with all others in the community, as reported by the respondents (n=42). Case 23 had withdrawn his consent for participation in the study at this stage. On most occasions, respondents reported face-to-face contact with others, however, family contact for four respondents was either by telephone (Cases 34, 45, 56) or by letter (Case 40). The most common types of contacts were families (33, 79%), general practitioners (GPs) (28, 67%), friends (24, 57%) and key workers (24, 57%). The most common types of contact according to frequency of contact are detailed below.

- **Daily contact** (n=26) was most common with families (8, 35%).
- **Weekly contact** (n=68) was most common with key workers (15, 24%).
- **Monthly contact** (n=78) was most common with the community psychiatric nurses (CPNs) to receive depot medication (20, 27%).
- **Three-monthly contact** (n=33) was most common with the GPs (10, 32%).
- **Six-monthly contact** (n=12) was also most common with the GPs (5, 42%), closely followed by the psychiatrists (4, 33%).

Table 9.1 Number and frequency of contacts with others in the community

SERVICE / INFORMAL CONTACT	IN CONTACT (n=42) No. (%)	FREQUENCY					
		daily	more than daily incl. weekly	more than weekly incl. monthly	more than monthly incl. 3 monthly	more than 3 monthly incl. 6 monthly	Not known [†]
		No. (%)	No. (%)	No. (%)	No. (%)	No. (%)	No. (%)
Family	33 (79) [‡]	8 (24)	10 (31)	6 (18)	5 (15)	1 (3)	3 (9)
GP	28 (67)	0 (---)	0 (---)	7 (25)	10 (36)	5 (18)	6 (21)
Friends	24 (57)	7 (29)	8 (34)	5 (21)	2 (8)	0 (---)	2 (8)
Key Worker	24 (57) [§]	2 (8)	15 (63)	4 (17)	2 (8)	0 (---)	1 (4)
Psychiatrist	23 (55)	0 (---)	1 (4)	8 (35)	9 (39)	4 (18)	1 (4)
CPN (to receive depot)	23 (55)	0 (---)	2 (9)	20 (87)	0 (---)	0 (---)	1 (4)
Social Worker	21 (50) [§]	1 (5)	3 (14)	10 (47)	2 (10)	2 (10)	3 (14)
Occupational therapist	12 (29)	1 (8)	9 (75)	2 (17)	0 (---)	0 (---)	0 (---)
Neighbours	11 (26)	4 (36)	3 (28)	2 (18)	0 (---)	0 (---)	2 (18)
Religious figure	10 (24)	0 (---)	6 (60)	4 (40)	0 (---)	0 (---)	0 (---)
CPN (not receiving depot)	6 (14)	0 (---)	2 (33)	3 (50)	0 (---)	0 (---)	1 (17)
Housing officer	4 (10)	0 (---)	0 (---)	3 (75)	1 (25)	0 (---)	0 (---)
Counsellor / therapist	2 (5)	0 (---)	1 (50)	1 (50)	0 (---)	0 (---)	0 (---)
MIND, PRA etc.	2 (5)	0 (---)	2 (100)	0 (---)	0 (---)	0 (---)	0 (---)
Home help	1 (2)	0 (---)	1 (100)	0 (---)	0 (---)	0 (---)	0 (---)
Psychologist	0 (---)	n/a	n/a	n/a	n/a	n/a	n/a
Other (see Table 9.2)	11 (26)	n/a	n/a	n/a	n/a	n/a	n/a

Notes: Percentages do not equal 100 since respondents may be in contact with more than one service. GP=General Practitioner; CPN=Community Psychiatric Nurse; MIND, PRA=voluntary support organisations. [†]Frequencies not specified. For example: Case 22 reported being in contact with friends "Once in a blue moon." [‡]Restricted contact with families - Cases 34, 45, 56 were in contact by telephone; Case 40 was in contact by letter. [§]Cases 22 and 60 were unsure if they were in contact with a social worker. Cases 22 and 59 were unsure if they were in contact with a key worker.

Table 9.2 Number and frequency of 'other' contacts in the community

CASE	TYPE OF CONTACT†	FREQUENCY OF CONTACT WITH 'OTHER' PERSON				
		daily	more than daily incl. weekly	more than weekly incl. monthly	more than monthly incl. 3 monthly	more than 3 monthly incl. 6 monthly
03	Hostel workers (PC)	✓				
	Diabetes specialist (DP)				✓	
08	Hostel worker (PC)		✓ (Mon. - Fri.)			
14	Others living in the hostel (PeC)	✓				
21	Day Centre (PC)		✓ (Mon-Fri)			
24	Nurses & hospital patients (PeC)	'Now and then.'				
28	Night school (PC)		✓			
	Out-patients clinic (DP)			✓		
30	Others living in hostel (PeC)	✓				
31	Day Centre (PC)		✓			
34	Others living in hostel (PeC)			✓		
	Staff & hospital patients (PeC)				✓	
60	Day Centre (PC)		✓			
62	Out-patients clinic (DP)			✓		

Note: ✓ signifies frequency of contact

† (PeC=Personal Contact; PC=Professional Carer; DP=Distant Professional)

Table 9.3 represents four different types of contact measure:

- Total number of individual contacts per respondent. This measure accounts for those contacts attributable to more than one group in the check list, e.g. if the social worker is also a respondent's key worker, this was counted as 1 contact for that respondent. All types of contacts are included: personal contacts, professional carers and distant professionals (see Table 9.1).
- Total number of individual contacts per respondent excluding distant professionals (i.e. psychiatrist, GP, diabetes specialist and hospital outpatient staff were omitted). Professional carers (including hostel workers, day centre and night school staff) remained in the analysis because of the different type of contact they have with respondents compared with the distant professionals. Professional carers were more likely to visit respondents in their own homes, be known on first name terms and were frequently called 'friends' by the respondents. This led to a different type of quality of contact. Personal contacts including cohabiters from hostels and hospital patients remained included.
- Total number of regular contacts, i.e. the number of individuals (as defined above) in contact with the respondent at least once every month (distant professionals were excluded).
- Total number of regular contacts (as defined above) not sharing the same accommodation as the respondent (distant professionals were excluded).

Table 9.3 Number and type of contacts in the community

Number of contacts	Total number of personal contacts, professional carers or distant professionals	Total number of contacts (excluding distant professionals) [†]	Total number of regular contacts (excluding distant professionals) [†]	Total number of regular contacts not sharing accommodation (excluding distant professionals) [†]
	No. (%)	No. (%)	No. (%)	No. (%)
0	0 (---)	0 (---)	0 (---)	3 (7)
1	1 (3)	2 (5)	3 (7)	5 (12)
2	1 (3)	6 (14)	8 (19)	11 (26)
3	3 (7)	7 (17)	13 (31)	10 (24)
4	8 (19)	11 (26)	5 (12)	3 (7)
5	8 (19)	6 (14)	10 (24)	9 (22)
6	9 (21)	9 (21)	3 (7)	1 (2)
7	6 (14)	0 (---)	0 (---)	0 (---)
8	5 (11)	1 (3)	0 (---)	0 (---)
9	1 (3)	0 (---)	0 (---)	0 (---)
Mean number of contacts‡	5.5 [4.90, 6.01]	4.1 [3.57, 4.57]	3.5 [3.03, 3.92]	2.9 [2.36, 3.36]
Total number of respondents	42	42	42	42

[†] 'Distant professionals' = psychiatrist, G.P., diabetes specialist, hospital outpatient staff.

Regular contact is defined as at least monthly.

‡ 95% confidence intervals in parentheses.

9.1.2 Social isolation (Personal contacts and professional carers)

Social isolation was considered by analysing the personal contact and professional carer networks of the respondents (contact with distant professionals was excluded). All respondents could name at least one type of personal contact or professional carer that they were in contact with at least monthly, however for two respondents (one female and one male) these contacts were only those with whom they lived in supported accommodation (Cases 03 and 24).

Of the 19 respondents who had less than the mean number of regular contacts not sharing the same accommodation (mean=2.9), 16 (84%) did not name any daily contacts and three male respondents (Cases 53, 67, 72) did not have any personal contacts. The mean number of personal contacts for these 19 respondents was 1.1 per person. These respondents lived in both supported (e.g. hostels) (12, 63%) and independent accommodation (7, 37%).

Of the 23 respondents who had three or more regular contacts that were not sharing the same accommodation, 13 (57%) did not name any daily contacts. All 17 respondents had at least one personal contact, with the mean number of personal contacts being 2.6. These respondents lived in both supported (e.g. hostels) (9, 39%) and independent accommodation (14, 61%).

Social isolation variables were analysed against a loneliness variable. Loneliness had no relationship with social isolation.

9.1.2.1 Personal contacts

Three respondents (7%) were without any personal contacts (Cases 53, 67, 72). All three respondents were single men who lived in hostel accommodation. Eighteen respondents (42%) had only one personal contact, who was most often a family member (n=12). The remaining respondents had either two (10, 23%), three (9, 21%) or four personal contacts (3, 7%).

9.1.2.2 Daily and weekly contacts

Twenty-one respondents (50%) (13 males (62%) and 8 females (38%)) were without any kind of daily contact (i.e. personal, professional carer or distant professionals). Three single male respondents (7%) (Cases 34, 50, 53) reported having neither daily nor weekly contacts. Cases 34 and 50 lived alone in independent accommodation and Case 53 lived in hostel accommodation.

Daily and weekly contacts mainly composed of personal contacts. If personal contacts were

removed from the analysis, fourteen respondents (33%) (8 males (57%) and 6 females (43%)) would be without any daily or weekly contacts.

There were no relationships between those who had daily contacts (n=21) and those who did not (n=21), with sex, age, marital status, ethnic group, country of birth nor severity of illness of the respondent.

9.1.2.3 Satisfaction with contacts

Perceived quality of life, measured using the Lancashire Quality of Life Profile (Section 8.2) assessed satisfaction with life domains including living situation, family relations and social relations (see Table 9.4).

Table 9.4 Number of respondents mixed or dissatisfied with perceived quality of life variables taken from the domains of living situation, family relations and social relations (Lancashire Quality of Life Profile)

Perceived Quality of Life (Lancashire Quality of Life Profile)	Number (%) of respondents with mixed or dissatisfied responses
Domain: Living situation	
How satisfied are you living alone? (n=12)	6 (50%)
How satisfied are you living with the people you do? (n=28)	7 (25%)
Domain: Family relations	
How satisfied are you with your family in general? (n=39)	19 (48%)
How satisfied are you with the amount of contact you have with your relatives? (n=38)	17 (44%)
Domain: Social relations	
How satisfied are you with the way you get on with others? (n=41)	14 (34%)
How satisfied are you with the number of friends you have? (n=41)	18 (44%)

Satisfaction with the domains of living situation, family relations and social relations were correlated with the objective measures of social isolation. Number of daily contacts was positively correlated with:

- the combined satisfaction with both family and the amount of contact with relatives (Spearman's $\rho=0.332$; $p=0.039$; $n=39$)

- the satisfaction with the way the respondents got on with other people (Spearman's $\rho=0.378$; $p=0.015$; $n=41$)

On further analysis, number of daily contacts were also positively correlated with greater positive affect (a measure of psychological well-being: Section 8.2.3.3) (Spearman's $\rho=0.313$; $p=0.046$; $n=41$). Also, respondents with the greater number of regular contacts, i.e. seen at least monthly (excluding distant professionals) were more likely to be dissatisfied with the amount of money they had to spend on enjoyment (Spearman's $\rho=-0.452$; $p=0.005$; $n=37$).

9.1.3 Further analyses with social contacts

- **Variations by age**

Variations in social contacts were analysed according to different age groups (19-29 years; 30-39 years; 40-63 years). Respondents aged 40-63 years were less likely than expected to be in contact with social workers compared with the other age groups ($\chi^2=7.034$; $p=0.030$; $n=41$). Both the 19-29 years and the 40-63 years age groups were less likely than expected to be in contact with key workers compared with the 30-39 years age group ($\chi^2=7.898$; $p=0.019$; $n=41$).

The mean rank of total number of contacts was lowest for 40-63 year-old respondents and next lowest for the 19-29 year-old respondents (Kruskal Wallis $\chi^2=6.610$; $p=0.037$; $n=42$). All classifications of number of contacts decreased with increasing age of the respondents (Spearman's $\rho= -0.326$ to -0.369 ; $p=0.016$ to 0.035 ; $n=42$).

- **Variations by severity of illness**

Severity of illness in the community was dichotomised into a mild/moderate illness group and a severe illness group. Respondents with severe illness were less likely to be in contact with a psychiatrist ($\chi^2=4.621$ using Yates' continuity correction; $p=0.032$; $n=43$) and less likely to be in contact with a CPN for depot medication compared with those respondents with either mild or moderate illness ($\chi^2=4.621$ using Yates' continuity correction; $p=0.032$; $n=43$).

The lower the severity of illness rating, the higher the number of contacts (all classifications) reported by respondents (Spearman's $\rho=0.396$ to 0.502 ; $p=0.010$ to 0.001 ; $n=36$ to 2). Respondents were also asked to report the level of improvement in symptoms since taking medication (see Section 7.3.3). The greater improvement in symptoms (self-report), the higher the number of total contacts reported by respondents (Spearman's $\rho=0.359$ to 0.376 ; $p=0.024$ to 0.031 ; $n=36$).

- **Variations by medication adherence**

Respondents who visited clinics for their depot medication were more likely than those who received their medication at home to be in contact with occupational therapy services (χ^2 using Yates' continuity correction= 3.921 ; $p=0.048$; $n=43$).

9.1.4 Summary

Respondents most frequent contacts were with family followed by the health care professionals, i.e. the key worker, community psychiatric nurse (to receive depot medication), general practitioners and psychiatrists. Respondents had a mean number of 5.5 total contacts, 4.1 contacts when distant professionals were excluded, 3.5 when regular contacts were counted (seen at least monthly) and 2.9 when regular contacts were counted but people who shared accommodation were excluded. This provided an understanding of the social network of respondents, an important aspect of social health, which is an essential component of quality of life (Bowling, 1991:8). Social isolation and schizophrenia were discussed in the introduction to this thesis (Section 1.5.1). The respondents had small social networks with some respondents without personal contacts. However, loneliness was not related to social isolation for this sample.

Equally important are the quality of the contacts and the social roles the contacts have in the community. Between 25-50% of respondents had mixed or dissatisfied feelings about the quality of their relationships with others. A greater number of contacts was significantly more likely with a younger age, with less severe illness and with greater improvement in symptoms since taking medication (respondent-defined). Respondents with the greater number of regular contacts were more likely to be dissatisfied with the amount of money they

had to spend on enjoyment (Spearman's $\rho=0.452$; $p=0.005$; $n=37$), suggesting that respondents with friends were more likely to engage in a social life and be more integrated into the community.

A relationship was also found between respondents who attended clinic for their depot medication and those who were in contact with occupational therapy services (compared with those who received their depot medication at home). The association suggests that respondents willing to access one type of community service were more likely to access another. Occupational therapy (OT) is regarded as an essential component of community care and rehabilitation. However, we cannot say from the relationship if receiving medication in the clinic encouraged the respondents to attend OT or the converse.

The prominent presence of the key worker, community psychiatric nurse, general practitioner and psychiatrist in the respondents' social networks were suggestive of the respondents' involvement with community mental health teams and the Care Programme Approach. The Care Programme Approach is discussed in the next Section.

9.2 Care Programme Approach

Section 1.4 briefly reviewed the main mental health policy changes in the provision of services for the mentally ill during the last decade. The intention of the 'Care Programme Approach' (Department of Health, 1990) was to promote a network of health and social care in the community that would decrease the risk of people with mental health problems losing contact with services. While it was recommended that the form of individual care programmes would be developed locally, key elements for inclusion in the care plans were stated. The health and social care needs of individuals, who could be potentially treated in the community, were to be systematically assessed and regularly reviewed. It was to be ensured that effective systems were set up to enable the provision of the agreed health and social care services. Specifically, the involvement of patients was outlined in the document.

‘It is important that proper opportunities are provided for patients themselves to take part in discussions about their proposed care programmes, so that they have the chance to discuss different treatment possibilities and agree the programme to be implemented.’

(Department of Health, 1990:82)

Also, the role of a key worker was seen as an essential contribution to the monitoring of service needs and the continuing care of the patient. This was described as a named person whose responsibility was ‘... to keep in close touch with the patient and to monitor that the agreed health and social care is given.’ (Department of Health, 1990:83).

In light of these recommendations (made at the same time as the planning of this research study) respondents were asked about their experience of the Care Programme Approach. Specifically, respondents were asked if there had been any special plans made for their care in the community before they were discharged from the hospital, if they had a named key worker and if there were any plans concerning their treatment, medication or injection (n=41) (Table 9.5). Cases 23 and 53 had each withdrawn their consent for participation at this stage of the study.

Table 9.5 Care Programme Approach plans reported by the respondents

	Were there any special plans made for your care in the community?	Do you have a named key worker?	Are there any special plans for your treatment, medication or injection?
	No. (%)	No. (%)	No. (%)
Yes	21 (51)	26 (63)	6 (15)
No	19 (46)	13 (32)	32 (78)
Don't know	1 (3)	2 (5)	3 (7)
Total number of respondents	41	41	41

The additional comments referring to plans in the community (detailed below) may be grouped (according to frequency of reporting) into three issues: living situation, daytime activities and professional contact.

- *Before you were discharged, do you know if there were any special plans made for your care in the community?*

Living situation

- “To be placed with a family.”
(Case 04)
- “To be taken to a hostel.”
(Case 21)
- “The social worker got me the hostel and now they’re trying to get me a place.”
(Case 49)
- “I was to live in my flat as usual...”
(Case 60)

Daytime activities

- “Going to art and getting me a place in building college. I haven’t got one yet.
We’re waiting until next term.”
(Case 28)
- “Referred to day care.”
(Case 35)
- “... and to go to the day centre.”
(Case 60)

Professional contact

- “They promised to get me a home help and they didn’t get me one.”
(Case 01)
- “Having a key worker and social worker. X visits every month.”
(Case 14)

Comments relating to medication were focused either on the medication regimen (e.g. dose, frequency) or the place for the injection. Some of the comments illustrated the respondents as taking a passive role. None of the respondents commented on any involvement with the decisions concerning arrangements about their medication after discharge from hospital.

- *Do you know if there are any special plans concerning your treatment, medication or injection?*

Medication regimen

- “Just got to keep having it.”
(Case 01)

“X is going to get in touch with the psychiatrist. I think they’re going to increase it. It won’t do any good. I’m sorry I’m so pessimistic but if you were me you would too. I wake up each morning with nothing to do. Sometimes I lie there for hours. I’m a miserable old sod.”

(Case 50)

“To allocate a CPN and the times of injection.”

(Case 66)

“Eighty milligrams every two weeks.”

(Case 68)

Place of receiving injection

“First of all they came to my flat for the injection.”

(Case 29)

“Coming here for my injection.”

(Case 35)

Respondents’ answers to whether they had a key worker at the end of the questionnaire were compared with the earlier responses given to the predetermined list of contacts that included a key worker (Section 9.1). Those respondents who reported that they were in contact with a key worker from the predetermined list (24, 57%; n=42) were more likely to report that they had a key worker in the questions about the Care Programme Approach (26, 63%; n=41) (χ^2 test using Yates’ continuity correction=14.747, $p<0.001$; n=39).

Respondents were then asked to rate each of the objective indicators of the Care Programme Approach using the LSS (Life Satisfaction Scale from the Lancashire Quality of Life Profile). Of those respondents who reported having care plans, between two-thirds and three-quarters were satisfied with the plans (Table 9.6). The remaining third to one quarter of respondents was either mixed or dissatisfied.

Table 9.6 Satisfaction with Care Plans

Life Satisfaction Scale (LSS) rating	How satisfied are you with:											
	the plans for your care in the community?		your named key worker?		the plans for your treatment, medication, injection?							
	(n=21)		(n=26)		(n=6)							
	No.	(%)	No.	(%)	No.	(%)						
Can't be better	1	(5)	15	(75)	3	(12)	17	(66)	0	(---)	4	(66)
Pleased	5	(25)		6	(23)	1		(17)				
Mostly satisfied	9	(45)		8	(31)	3		(49)				
Mixed (about equally satisfied and dissatisfied)	3	(15)	3	(15)	5	(19)	5	(19)	1	(17)	1	(17)
Mostly dissatisfied	0	(---)	2	(10)	4	(15)	4	(15)	0	(---)	1	(17)
Displeased	2	(10)			0	(---)			1	(17)		
Can't be worse	0	(---)			0	(---)			0	(---)		
Total number of respondents	20†				26				6			

† Case 27 did not answer.

The additional comments (detailed below) illustrate the closeness of some relationships between the key worker and the respondent. Consequently some of the comments suggested a clash of 'control/power' between the respondent and their key worker. Other comments showed a lack of contact between other respondents and their key workers.

• *How satisfied are you with your named key worker?*

Relationship issues

"He's a bit strict. I don't like strict people."

(Case 30)

"She has her ways. Sometimes she takes things the wrong way."

(Case 49)

"She won't let me handle my own money. I felt it could be better."

(Case 54)

"She got me the visits with my son. The social worker didn't do nothing."

(Case 62)

Limited contact

“Haven’t seen since October [now 08.12.94]. Don’t know if I’ll see again.”

(Case 36)

“Not too sure who he is. Had one but he left.”

(Case 89)

Of those respondents who did not have plans or were unsure, between 31-42% of respondents wanted plans to be made for them (Table 9.7). (Caution as small numbers).

Table 9.7 Care Programme Approach plans wanted by the respondents

	When you left hospital, would you have liked to have had special plans made for your care in the community? (n=20)	Would you have liked to have had a named key worker? (n=15)	Would you have liked to have had a treatment plan? (n=35)
	No. (%)	No. (%)	No. (%)
Yes	8 (42)	4 (31)	12 (39)
No	11 (58)	9 (69)	21 (61)
Total number of respondents	19[†]	13[‡]	33[§]

† Case 59 did not answer.

‡ Cases 22, 59 did not answer.

§ Cases 01, 59 did not answer.

Some additional comments in response to these questions highlight the great variation in the expectations of the respondents.

- *When you left hospital, would you have liked to have had special plans made for your care in the community?*

“Doesn’t bother me.”

(Case 30)

Professional contact

“Someone to call to check up on me.”

(Case 34)

Living situation

“I’d like a new flat.”

(Case 79)

Many more additional comments were made by the respondents concerning their medication. The majority of comments illustrated a perceived lack of autonomy and information about their medication. Undoubtedly, from these comments medication was an important aspect of the respondents' lives.

• *Would you have liked to have had a treatment plan?*

Lack of autonomy/information

"I'd like to stop taking it, all of it because it's not doing me any good."
(Case 02)

"Just cut it down to once every two weeks, instead of every week."
(Case 14)

"Medicines don't make a difference. I'm all right."
(Case 24)

"They've not discussed it with me but Dr X did say that I'd only be on the injection, in the end, that would be my only medication. I wished I knew more. They didn't tell me much. I was never as ill before as that day I missed my injection."
(Case 27)

"I'd like to get off it and learn how to cope without it."
(Case 34)

"I want it to be removed."
(Case 40)

"I'd like to come off it for good."
(Case 46)

"I'd like to have them cut down."
(Case 54)

"I would like it reduced, eventually stopping."
(Case 70)

"I'd like the Lorazepam back."
(Case 79)

Autonomy

"I tell them if I want it changed."
(Case 28)

"If I had a job after I leave college, I'd like to leave my medication and injection."
(Case 49)

“I’m only taking the ones I want to take.”

(Case 60)

9.2.1 Summary

Respondents were asked about any special plans made for their care in the community before they were discharged from the hospital, if they had a named key worker and if there were any plans concerning their treatment, medication or injection. During piloting, respondents were asked about the care plan approach but it was found that these words did not have much meaning for the respondents. Therefore ‘special plans’ were substituted. The researcher (SAF) acknowledges that these words were also open to interpretation by the respondents. However, additional comments illustrated that respondents were considering similar issues such as professional contact, living situation and daytime activities.

Half the respondents (46%) reported that they were unaware of any special plans, their key worker (32%) and any plans concerning their treatment (78%). All components of the Care Programme Approach that were meant to be in place at the time of the community interview. Of those who had plans and a key worker, most were satisfied with them (66-75%) illustrating the positive contribution of the approach to the respondents’ community care. Earlier in this chapter, the crucial role of health care professionals in the social network of respondents was also highlighted. Most of the other respondents would have liked to have had plans and a key worker (58-69%). Respondents made many comments in relation to medication and treatment plans, with many respondents wanting to reduce or stop their medication. The limited contact with key workers described by two respondents and the lack of a key worker for a third of respondents may illustrate the difficulty associated with staff retainment in the inner cities of London.

“A crisis in recruitment and retention of mental health professionals appears to have developed in London and threatens to be one of the most serious problems faced by London’s mental health services over the next ten years.”

(Lelliott *et al.* 1997:33)

Consideration should be given to increasing the involvement of respondents in decisions about local services and their medication. Such involvement could have a positive impact on the respondents’ perspectives of community care that could enhance their quality of life.

It may help to ensure that new policy initiatives have more meaning to the individuals for whose care they were designed to improve.

9.3 Postal questionnaire to significant others

Section 7.2.8 reported the significant others for whom permission was given to be sent a postal questionnaire (n=25). After the respondent had completed the community questionnaire, a postal questionnaire was sent to each of the nominated significant others with the aim of providing another source of data collection as a process of triangulation. Reminders were sent at two weeks and four weeks after the first mailing. After 6-weeks, where possible, significant others were also called by telephone to ensure that they had received the questionnaire and to respond to any problems. With consecutive mailings, the response rate increased from 16% (n=4) to 40% (n=10) to 60% (n=15). The information generated by these 15 significant others is reported here separately, rather than integrating it into the body of the results because of the low representation for all study respondents (n=41).

The information collected by the questionnaire was objective information about the effects of medication on the study respondents' lives, the significant others' opinions of the medication and whether they thought the study-respondents should be taking it, the social network contact list and the 21 objective indicators from the Lancashire Quality of Life Profile.

Twenty out of the 25 respondents (80%) who nominated a significant other, named a health team worker (see Table 7.13). Some questions asked the significant other for information based on the personal lives of the study-respondents and it was unlikely that all health team workers would know that information. For example, items such as the respondents' incomes, whether the respondent was in touch with a religious figure and how frequently they attended religious services.

Fifteen out of the 25 significant others replied to the questionnaire (60%). The main difference between the responders and non-responders was that all family members whom

the respondents nominated (n=4) were non-responders (see Table 9.8). Neither the sex of the significant other nor the sex of the study-respondent to whom the significant other belonged, influenced the response status of the significant other.

Table 9.8 Responders and non-responders of the significant other questionnaire

	RESPONDERS (n=15) No. (%)	NON-RESPONDERS (n=10) No. (%)
Health Team Workers [†] (eg CPN, GP, care workers, key workers, social workers)	14 (93)	6 (60)
Family	0 (---)	4 (40)
Friends	1 (7)	0 (---)
Significant other is male	8 (53)	4 (40)
female	7 (47)	6 (60)
Study-respondent is male	8 (53)	8 (80)
female	7 (47)	2 (20)

[†] CPN=Community Psychiatric Nurse; GP=General Practitioner

9.3.1 Medication issues

9.3.1.1 Effect of medication on respondents' symptoms of illness

Significant others were asked:

"Since [the respondent] has been taking medication, including the injection, how would you say their symptoms have been?"

Answers were based on a seven-point scale where 1 represented "substantially worse" and 7 "all better". The interim points were labelled as "much worse (2); somewhat worse (3); no change or same (4); somewhat better (5); much better (6)". Three significant others gave the same ratings as the respondents (Cases 27, 36 and 89). Four significant others gave lower ratings than the respondents. However, all significant others reported that the respondents' symptoms had improved but not as much as the respondents had reported (Case 26, 34, 54 and 68). The remaining 7 significant others gave higher ratings than those of the respondents (Cases 49, 56, 59, 62, 67, 72 and 79). Therefore, most commonly (7, 47%) study respondents

underestimated the improvement in their symptoms compared with the significant others.

Additional comments by significant others are reported below grouped under common issues. Most commonly the significant others recognised an improvement in the day-to-day functioning of the respondents with medication. However, significant others recognised that for some respondents there was a balance between an improvement in their symptoms and the adverse effects they experienced. One significant other described the lack of understanding that one respondent had in recognising the benefits of medication.

Improvement in functioning

“Calming, stability and enabling a better quality of life, in the day to day living and survival.”

(Significant other for Case 34)

“Medication helps him concentrate on practical things and he is better able to function independently and attend to cooking, bills etc. Also makes him less aggressive and threatening.”

(Significant other for Case 56)

“To my knowledge [Case 67] is more focused and currently presents no delusional symptoms.”

(Significant other for Case 67)

“[Case 68] seems to be much brighter and quite well self-sufficient.”

(Significant other for Case 68)

“The Lofepamine [antidepressant] has certainly allayed the frequency and severity of [Case 89]’s “panic attacks”.”

(Significant other for Case 89)

Risk-benefit trade

“The medication has been effective in resolving depressive features. However, while the Depixol has reduced the impact of delusional ideation and removed some delusional perception, bizarre thoughts remain. We are considering increasing the Depixol, but are mindful of possible side-effects.”

(Significant other for Case 26)

“The Pipartil’s [depot antipsychotic injection] effectiveness is questionable, but also, irrefutable.”

(Significant other for Case 89)

Unwanted effects

“The Modecate had to be slightly reduced because [Case 54] was dribbling.”

(Significant other for Case 54)

Improvement in symptoms

“Greatly reduced the psychotic symptoms, thus reducing the effects on his behaviour eg disinhibition.”

(Significant other for Case 59)

Respondent lacks understanding of illness/benefits of medication

“When [Case 11] was on depot injection, his mental state improved. [He] has a history of noncompliance and misunderstandably does not like taking injections. He has not been seen for a while.”

(Significant other for Case 11)

Two significant others reported that they had not known the respondents without medication and did not know the difference that medication had made on the symptoms of illness.

Not known without medication

“I have only known [Case 54] on medication.”

(Significant other for Case 54)

“Having not seen [Case 67] without medication I cannot comment.”

(Significant other for Case 67)

9.3.1.2 Respondents’ problems with the medication

Significant others were asked if the respondents had any problems with their medication and if so, did the problems affect anything the respondents did or would like to do (Table 9.9). One significant other’s judgement, in particular, seemed to underestimate the impact of blurred vision.

“Blurred vision - this annoys [Case 26] but she cannot read and is not interested in getting a television and that she does not have work responsibilities, it is not very disabling.”

(Significant other for Case 26)

Table 9.9 A comparison of the perceived problems with medication reported by the respondents and the significant others

RESPONDENT		RESPONDENT'S RATING	SIGNIFICANT OTHER	SIGNIFICANT OTHER'S RATING
Case 11	Any problems?	Stopped all medication	Social worker	Stopped all medication
Case 26	Any problems?	Blurred vision, pacing	Community psychiatric nurse	Blurred vision
	Affect anything?	Worried about going out		No
Case 27	Any problems?	Injection is painful	Social worker	Possible weight gain
	Affect anything?	No		No
Case 34	Any problems?	None	Friend	Parkinsonian type, blunted affect ++
	Affect anything?			Embarrassing and discomfort.
Case 36	Any problems?	None	General practitioner	None
Case 49	Any problems?	None	Community psychiatric nurse	None
Case 54	Any problems?	Too many tablets, want longer time between injections	Key worker	Headaches, biliousness, dribbling
	Affect anything?	No		No
Case 56	Any problems?	None	Community psychiatric nurse	Drowsy, over sedated
	Affect anything?			Sleeps most of the morning, limits social interaction

Table 9.9 (ctd.) A comparison of the perceived problems with medication reported by the respondents and the significant others

RESPONDENT		RESPONDENT'S RATING	SIGNIFICANT OTHER	SIGNIFICANT OTHER'S RATING
Case 59	Any problems?	None	Community psychiatric nurse	Slight tremor, restlessness, lethargy
	Affect anything?			Unable to do household chores, always tired, sleepy
Case 62	Any problems?	None	Key worker	Moody when she has her injection
	Affect anything?			No
Case 67	Any problems?	None	Key worker	None
Case 68	Any problems?	Shake, get fidgety	Care worker	None
	Affect anything?	Makes me feel different to other people cos they aren't fidgety		
Case 72	Any problems?	Obsessional thoughts	Key worker	None
Case 79	Any problems?	Giddiness	Community psychiatric nurse	None
Case 89	Any problems?	Jaw shake, loss of libido	Community psychiatric nurse	Mild tardive dyskinesia, increased akathisia
	Affect anything?	Not answered		Impaired social functioning, severely marked self-esteem

9.3.1.3 Respondents' non-adherence with medication

Significant others were asked if the respondents had ever stopped their medication in the past and if so, what were the consequences? Significant others of Cases 27 and 67 reported that the respondents had not stopped their medication. Case 68's significant other said that she did not know. Other responses were grouped under headings relating to admission to hospital,

negative feelings associated with taking long term medication, deterioration in mental and physical health and aggressive behaviour,. Comments were grouped and categorised in this way since a full content analysis was not deemed appropriate due to the quantitative approach of the postal questionnaire.

Most commonly, readmission to hospital was associated with respondents' non-adherence to medication. For five of the significant others, their comments demonstrated the difficulties associated with respondents' perceived needs for medication long-term.

Required admission to hospital

“[Case 26] was compulsorily admitted.”	(Significant other for Case 26)
“He became very unwell and needed hospitalisation, once again.”	(Significant other for Case 34)
“[Case 36] had a relapse.”	(Significant other for Case 36)
“She was admitted to Hackney Hospital.”	(Significant other for Case 49)
“He became unwell and required hospital admission.”	(Significant other for Case 56)
“Relapsed and needing readmission.”	(Significant other for Case 59)
“Admitted into hospital due to relapse.”	(Significant other for Case 79)
“Readmission.”	(Significant other for Case 89)

Negative feelings associated with taking long term medication

“[Case 34] dislikes chemical intervention and worry about its long term effects.”	(Significant other for Case 34)
“[Case 54] feels fed-up sometimes taking medication, as she has been taking medication for 20 years. [Not stopped it].”	(Significant other for Case 54)
“Feels they do not help and has been having them for a long time.”	(Significant other for Case 59)

“She’s fed-up of taking her injection and tablets but when we talk to her to explain how she’s improved, she’s ok.”

(Significant other for Case 62)

“Because of the above effects [problems with medication] and because he wants to be like me! - able to stay out of hospital without taking medication.”

(Significant other for Case 89)

More specifically some significant others focused on the increased symptoms of mental illness, aggression and physical ill health as consequences of respondents’ non-adherence to medication.

General deterioration in mental health

“[Case 11] has never wanted to have his depot injection. *[What happened after he stopped it?]* His mental state deteriorated.”

(Significant other for Case 11)

“She was frustrated, agitated and unstable when she forgot her tablets.”

(Significant other for Case 62)

“... complaining of suicidal ideation - repeated attempts to throw himself under cars. Complaining of increased anxiety +++ NOT psychotic.”

(Significant other for Case 89)

Aggressive behaviour

“[Case 26]... she attacked a CPN at home and would not attend a depot clinic.”

(Significant other for Case 26)

“[Case 49] says that the injection makes her “feel funny”, she gets agitated at people. *[What happened after she stopped it?]* She was... physically aggressive towards her mother.”

(Significant other for Case 49)

Deterioration in physical health

“... He also self-neglected himself.”

(Significant other for Case 11)

9.3.1.4 Opinions of the respondents’ medication

Significant others were asked if **they** thought that the respondents should be taking any medication. The majority (13, 87%) reported ‘yes’. Their reasons why, are reported below and grouped according to the frequency of common issues: effect of medication on symptoms of illness, improved daily functioning, improved social behaviour, improved overall life,

unwanted effects of medication, improved opportunities for community rehabilitation and improved interpersonal skills.

Most significant others focused on the effects of medication on improving the symptoms of mental illness, e.g. hallucinations, delusions, voices. Others reported the effects of medication in more general terms e.g. having a calming and stabilising effect.

Effect of medication on symptoms of illness

“He does not have any delusions or hallucinations.”

(Significant other for Case 11)

“... because she would likely have severe symptoms of mental illness without medication ... the Depixol has antipsychotic efficacy without the significant dystonia she said she experienced on Modecate and also it has an antidepressant effect.”

(Significant other for Case 26)

“... suffers from no hallucinations at the present.”

(Significant other for Case 36)

“Good in cancelling out positive symptoms of severe mental illness, like voices etc.”

(Significant other for Case 56)

“To prevent relapse of psychotic illness... Has good effect on his symptoms...”

(Significant other for Case 59)

“To keep her stable.. ”

(Significant other for Case 62)

“Its what has been prescribed by the Doctors, it is, sometime works better than others. Makes [Case 72] more calmer ...”

(Significant other for Case 72)

“It keeps her mentally stable.”

(Significant other for Case 79)

Some significant others thought of the beneficial effects of medication in terms of improved daily functioning. Significant others were concerned that respondents were happy when taking their medication and that they could carry out their activities and be independent.

Improved daily functioning

“As long as [Case 27] is happy with his current regime, significant other am I. Now able to function much better in his daily life.”

(Significant other for Case 27)

“Because of physical dependency over many years, appears unable to function without. The Piportil injection especially seems to give stability, and is unreliable to take oral medication regularly, and dose prescribed. Greater stability to every day living.”

(Significant other for Case 34)

“[Case 49] has full activities which she participates in very well. She has injection fortnightly given by a community nurse.”

(Significant other for Case 49)

“... allows him a measure of independence.”

(Significant other for Case 56)

“Since she takes the medication regularly, she appears to be less dependent.”

(Significant other for Case 36)

“... allowing [Case 59] to be living at home without having to be institutionalised... which does allow [Case 59] to be able to attend Day Care facilities.”

(Significant other for Case 59)

The effects of medication were also interpreted in terms of improving the respondents’ social behaviour. For example, socialising, self-care and appropriate behaviour.

Improved social behaviour

“... because his life improves. He is more sociable and copes very well with day-to-day activities. He socialises more where as without medication he becomes very isolated.”

(Significant other for Case 11)

“... without medication which would, on past evidence, lead to self-neglect and aggressive behaviour...”

(Significant other for Case 26)

“It improved [Case 49]’s behaviour.”

(Significant other for Case 49)

“It seems to keep him functioning at a reasonable level which is socially acceptable...”

(Significant other for Case 56)

“[Case 59] is less disinhibited and provocative to children in his neighbourhood, is able to attend day care facilities (whenever he feels like it).”

(Significant other for Case 59)

Medication was also discussed in a more global way, as enhancing respondents’ lives in general.

Improved overall life

“Because [Case 67] has always taken his injections and Procyclidine for as long as I have known him there is no bipolarity for comparison. [Case 67] now leads a relatively good quality of life in a communal environment, which he is an integral part of. He has responded well to medication and is focussed and generally at peace.”

(Significant other for Case 67)

“Life is much better for [Case 68], she needs the medication to keep this way.”

(Significant other for Case 68)

“Its what has been prescribed by the Doctors, it is, sometime works better than others. Makes [Case 72] more calmer and able to live among other people.”

(Significant other for Case 72)

“It suits her needs. It has kept her out of hospital, improved mental well-being, improved her quality of life.”

(Significant other for Case 79)

Two significant others mentioned negative aspects of medication and how unwanted effects affected the respondents.

Unwanted effects of medication

“Bad in making him drowsy and lethargic.”

(Significant other for Case 56)

“She has mood swings when she first receives it but then she’s fine.”

(Significant other for Case 62)

Finally, one significant other was quite specific about the improved opportunities for community rehabilitation that were a result of medication preventing the respondents being readmitted to hospital.

Improved opportunities for community rehabilitation

“... It has in the past 18 months kept [Case 26] out of hospital and given a team of workers opportunity to address improving her quality of life, such as considering hostel and day care placements.”

(Significant other for Case 26)

While another significant other reported that the improved communication skills of the respondent was due to the medication.

Improved interpersonal skills: verbal and non-verbal communication

“She is able to talk freely and has eye to eye contact.”

(Significant other for Case 36)

The comments of the two significant others who were unsure about whether the respondents should be taking their medication are reported below.

“Over 20 years is a long time to take medication, how would she be without it? I have not known [Case 54] when she was not on medication.”

(Significant other for Case 54)

“Because the effectiveness of any medication must be borne out in the remission of presenting symptomology. Otherwise, there can be no therapeutic identification. I feel the Piportil should be stopped. [Should continue taking the antidepressants]. Admittedly, medication affords [Case 89] a degree of mental stability that enables him to live as fuller life as possible.”

(Significant other for Case 89)

9.3.2 Respondents’ social networks

Significant others were presented with the same predetermined list of contacts as that given to the respondents (see Section 9.1) and asked to report with whom the respondents were in contact. Table 9.10 shows that the % agreement between respondents and significant others ranged from 29% to 88%.

Three significant others disagreed with the respondents on five or more contacts (Cases 34, 36, 49). The most common disagreements were contact with the CPN (to receive medication and at times other than receiving medication) social worker and religious figure.

Where possible Cohen’s kappa coefficient was calculated to test agreement between the respondent and significant other on individual contacts (Cohen, 1968). This was not possible with all contacts since a requirement of Cohen’s kappa test is that the same dichotomous categories of response are present in both variables. Care must be taken interpreting these results due to the small sample size of significant others. Also, the variable analysed (contact or no contact) was very crude. It is acknowledged that the sample of significant others was self-selecting and is not representative of the population. Table 9.14 shows that the best agreements between respondents and significant others concerned contact with housing officers, social workers and CPNs for depot medication. Poorest agreements were contact

with key workers, CPNs for reasons other than receiving depot medication and occupational therapists. However, both respondents and significant others have reported perceived contact and it is unknown who is correct.

Table 9.10 A comparison of the number of respondents' contacts reported by the respondents and the significant others

	TOTAL NUMBER OF FORMAL AND INFORMAL CONTACTS (n=17)		
	Respondent and significant other:		
	AGREE No. (%)	DISAGREE No. (%)	DON'T KNOW No. (%)
Case 11	9 (53)	2 (12)	1 (6)
Case 26	13 (76)	4 (24)	0 (---)
Case 27	10 (59)	4 (24)	3 (17)
Case 34	5 (29)	5 (29)	7 (42)
Case 36	10 (59)	5 (29)	2 (12)
Case 49	10 (59)	6 (35)	1 (6)
Case 54	13 (76)	3 (18)	1 (6)
Case 56	14 (82)	2 (12)	1 (6)
Case 59	8 (47)	4 (24)	5 (29)
Case 62	14 (82)	3 (18)	0 (---)
Case 67	14 (82)	3 (18)	0 (---)
Case 68	15 (88)	1 (6)	1 (6)
Case 72	5 (29)	1 (6)	11 (65)
Case 79	Not answered	Not answered	Not answered
Case 89	13 (76)	4 (24)	0 (---)

Table 9.11 Rate of agreement between the respondents and the significant others in reporting contact (or no contact) with others

Type of contact	Cohen's kappa coefficient		
In contact with housing officer.	Kappa=0.755	p=0.005	n=13
In contact with a social worker.	Kappa=0.698	p=0.008	n=13
In contact with a community psychiatric nurse (CPN) for depot medication.	Kappa=0.576	p=0.031	n=14
In contact with friends.	Kappa=0.441	p=0.137	n=11
In contact with family.	Kappa=0.409	p=0.140	n=13
In contact with neighbours.	Kappa=0.377	p=0.201	n=11
In contact with others.	Kappa=-0.333	p=0.273	n=6
In contact with a religious figure.	Kappa=-0.250	p=0.429	n=10
In contact with an occupational therapist.	Kappa=0.211	p=0.490	n=10
In contact with a CPN for a reason other than to receive depot medication.	Kappa=0.152	p=0.506	n=13
In contact with a key worker.	Kappa=-0.091	p=0.753	n=12

9.3.3 Objective indicators of the Lancashire Quality of Life Profile

Significant others were asked to report on the domain objective indicators of the Lancashire Quality of Life Profile (see Section 8.2.2): work/education, leisure/participation, religion, finances, living situation, legal and safety, family relations, social relations and health. Agreement between the respondents and significant others was expected to be exact except for income and time at current residence where responses had to be within 10% of the figure reported by respondents. Table 9.12 shows that the % agreement between the respondents and the significant others ranged from 33% to 86%. The lowest agreement rate (33%) was for a GP who was unable to respond to thirteen items.

The disagreement rates of $\geq 19\%$ were examined for the mistaken items (cases 27, 34, 54, 68, 79, 89). Significant others were least likely to agree with the respondents in the domain of living situation, contact with family relations and whether the respondent had played or

watched a sport in the previous two weeks.

Where possible Cohen's kappa coefficient was calculated to test agreement between the respondent and significant other on the objective indicators of the Lancashire Quality of Life Profile. This was not possible with all items since a requirement of Cohen's kappa test is that the same categories of response are present in both variables. Again, care must be taken interpreting these results due to the small sample size of significant others. It is acknowledged that the sample of significant others was self-selecting and is not representative of the population.

Table 9.13 shows that the best agreements between respondents and significant others were whether the respondents lived with their families or not and the respondents' marital statuses. Poorest agreements were with unsuccessful applications for benefits and whether respondents had played or watched a sport in the two weeks before the interview (care was taken to ask significant others about the same period as for the respondent).

Table 9.12 A comparison of the objective indicators of the Lancashire Quality of Life Profile reported by the respondents and the significant others

	TOTAL NUMBER OF OBJECTIVE INDICATORS (n=21)		
	Respondent and significant other:		
	AGREE No. (%)	DISAGREE No. (%)	DON'T KNOW No. (%)
Case 11	10 (48)	3 (14)	8 (38)
Case 26	15 (72)	3 (14)	3 (14)
Case 27	12 (57)	4 (19)	5 (24)
Case 34	11 (52)	5 (24)	5 (24)
Case 36	7 (33)	1 (5)	13 (62)
Case 49	15 (72)	3 (14)	3 (14)
Case 54	14 (67)	4 (19)	3 (14)
Case 56	16 (76)	2 (10)	3 (14)
Case 59	13 (62)	2 (10)	6 (28)
Case 62	18 (86)	3 (14)	0 (---)
Case 67	16 (76)	3 (14)	2 (10)
Case 68	13 (62)	6 (28)	2 (10)
Case 72	17 (81)	3 (14)	1 (5)
Case 79	12 (57)	7 (33)	2 (10)
Case 89	14 (67)	4 (19)	3 (14)

Table 9.13 Rate of agreement between the respondents and the significant others in reporting the objective indicators of the Lancashire Quality of Life Profile

Domain and objective indicator of quality of life	Cohen's kappa coefficient
Living Situation: Respondent living with family.	Kappa=0.762 p=0.002 n=15
Family Relations: Marital status of respondent.	Kappa=0.762 p=0.002 n=15
Leisure / Participation: Been for a ride in a bus, car or train in the last two weeks other than to and from work.	Kappa=0.639 p=0.021 n=13
Health: Seen a doctor for physical illness in the last year.	Kappa=0.474 p=0.057 n=15
Family Relations: Frequency of seeing relatives.	Kappa=0.321 p=0.037 n=12
Finances: Unsuccessful application for benefits.	Kappa=-0.154 p=0.598 n=10
Leisure / Participation: Played or watched a sport in the last two weeks.	Kappa=-0.125 p=0.640 n=12

9.3.4 Items that would improve the respondents' quality of life

Significant others were asked if they had any suggestions for improving the quality of life of the respondents or for helping the respondents to overcome their mental health problems. Eleven domains were mentioned: mental health community support, medication, social relations, leisure/participation, work, intimate relations, family relations, living situation, finances, motivation and health. All comments relevant to each domain are presented below, in order of frequency.

It was not surprising that the most frequently mentioned area of life reported to improve the quality of life was increased support from the community mental health professionals, since

the majority of respondents were representatives of these teams. However, the comments illustrated that the significant others thought that more support was required and from specific agencies.

Mental Health Community Support

“... support from the mental health team.”

(Significant other for Case 11)

“She needs also support from other agencies significant other that she does not feel isolated.”

(Significant other for Case 49)

“For [Case 59] to be able to attend Day Care facilities on a more regular basis.”

(Significant other for Case 59)

“... more of my [CPN] time.”

(Significant other for Case 89)

Again, it was not surprising that medication was high on the agenda for the significant others. They also highlighted that regular medication was important and improving respondents' understanding of their medication and its role in illness management.

Medication

“Regular medication ...”

(Significant other for Case 11)

“[Case 49] needs to have her fortnightly injections of Depixol to keep her condition stable.”

(Significant other for Case 49)

“To have a better understanding of the effects of medication...and relapse prevention.”

(Significant other for Case 59)

Significant others did not only focus on the medical aspects of helping the respondents with medical help but also mentioned the need for help with making social relations and participating in the community.

Social relations

“To continue contact with befriender to encourage her to go out more and have more involvement with the community.”

(Significant other for Case 26)

“... more friends, ways to make them ...”

(Significant other for Case 54)

“Work with his ... friends in order to reduce “expressed emotion” and significant other try to prevent relapse.”

(Significant other for Case 56)

Day-time and work-related activities were other features that could improve the respondents’ quality of life.

Leisure/participation

“... outings; holidays; socialising. [Case 54] thrives on these.”

(Significant other for Case 54)

“To have a better understanding of ... day time activities.”

(Significant other for Case 59)

“To go out a bit more to participate in the community.”

(Significant other for Case 62)

Work

“Part-time training in a suitable subject, academic and artistic, to use previous educational qualifications, and present abilities and many interests, which are many and well preserved.”

(Significant other for Case 34)

“... a part-time job ...”

(Significant other for Case 54)

“A job, a sense of purpose, the opportunity to earn a socio-economic role...”

(Significant other for Case 89)

Separate to social relationships, the needs for intimate relationships were also identified as important.

Intimate relations

“Get a permanent partner.”

(Significant other for Case 27)

“... a partner, great sex.”

(Significant other for Case 89)

Family relationships were mentioned from different perspectives. One significant other talked of the potential benefits of family therapy and another discussed the needs for the respondent to re-gain custody of her child.

Family relations

“... Work with his family ... in order to reduce “expressed emotion” and significant other try to prevent relapse.”

(Significant other for Case 56)

“Having her son full-time.”

(Significant other for Case 62)

Other areas of community living were identified such as specific housing needs and the need for more money.

Living situation

“Placement in sheltered type of accommodation.”

(Significant other for Case 34)

“... better access to housing ...”

(Significant other for Case 89)

Finances

“More money ...”

(Significant other for Case 54)

“Give [Case 56] the optimum access to benefits etc. in order to obtain good socio-economic conditions and reduce stress caused by adverse financial circumstances.”

(Significant other for Case 56)

Two significant others discussed the needs for increasing the respondent’s motivation to help them to do more for themselves.

Motivation

“Increase motivation in terms of finding a life direction.”

(Significant other for Case 27)

“If she herself could be motivated to do more.”

(Significant other for Case 68)

Finally, one significant other reported that to improve the respondent’s quality of life, a full

remission of their mental illness was the best solution.

Health

“A full remission of his mental ill-health ...”

(Significant other for Case 89)

9.3.5 Summary

Caution must be applied to the results of the postal questionnaire from significant others due to the small sample size (n=15) and the lack of representation for the whole study sample (n=41). However, the data collected provided an interesting and important additional aspect to the study results.

Methodologically, the exercise highlighted the difficulties associated with gaining supplementary information from significant others. In the first instance, only 61% (25) of the respondents gave permission for the researcher to approach someone else for information. Of these, a 60% response rate was gained (using three reminders). Response rates are known to be difficult with postal questionnaires and an interview approach may have resulted in a higher response rate. However, a postal questionnaire was necessary because of the time constraints in this study. It was disappointing that all of the relatives that were nominated were non-responders. The questionnaire was not piloted with relatives because of time constraints. All the questions were adapted from the respondents' questionnaires (which had been piloted) and colleagues reviewed the significant other questionnaire. However, the researcher acknowledges that piloting with relatives may have identified any problems that they may have had with the questionnaire. All the significant other respondents had professional relationships with the study respondents and therefore, had some difficulty answering some of the social network and quality of life items that asked about everyday life.

Respondents' subjective evaluation of their symptoms since taking medication was most commonly underestimating the benefits when compared with ratings made by significant others. The associated descriptions made by the significant others highlighted the benefits and the limits of medication. They provided greater detail in terms of the consequences of the respondents taking their medication in terms of improved functioning. While the

significant others could not comment on the subjective problems of taking medication, they provided useful objective information. For some respondents, the significant others noticed more problems with medication than the respondents themselves. However, for others, the respondents reported problems when the health care professional did not report any.

Essential information gained from the significant others were the consequences of the respondents stopping their medication. They highlighted the deterioration in mental and physical health and the aggressive behaviour. However, they also showed that they were aware of the respondents' negative feelings associated with taking medication long-term. When asked about whether they thought that respondents should be taking medication, two significant others were unsure. Their reasons were related to the very long-term use of medication without a break and the limited clinical effectiveness with some medication.

Significant others provided variable information that agreed with the respondents on the social networks and objective indicators of quality of life suggesting that they did not know about the everyday life of the respondents. The lack of relatives offered as significant others (n=4) may be indicative of the poor relationships that people with mental illness can have with relatives or it may suggest that the health professionals are the closest associates of the respondents.

Some of the most important information provided by the significant others were the items suggested to improve the respondents' quality of life. Of the 11 domains nominated (medication, mental health community support, social relations, intimate relations, family relations, living situation, work, finances, leisure/participation, motivation and health) 7 are currently included in the Lancashire Quality of Life Profile. Of the items mentioned by significant others that are not included in the Lancashire Quality of Life Profile, many agreed with items that respondents had reported earlier for their quality of life (Section 8.1): an understanding of medication, mental health teams, day care facilities, day time activities and a sexual partner.

Significant others provided an essential additional source of information that provided another perspective on the quality of life of the respondents.

10 FURTHER ANALYSES OF MEDICATION ISSUES AND FURTHER ANALYSES OF QUALITY OF LIFE

10.1 Introduction

This chapter reports on further analyses of medication issues (Chapter 10A) and quality of life issues (Chapter 10B). Differences and associations between variables were explored. Differences between categorical variables were examined using the Pearson Chi-Squared test of significance (χ^2), Fisher's Exact Test and Mann Whitney U test. Associations between interval and ordinal data were investigated using Spearman Rank Correlation coefficients. All significance levels were analysed as two-tailed. Bivariate relationships between medication issues (Section 10.2) and quality of life (Section 10.4) were each examined independently by sex, age, ethnicity, country of birth, severity of illness and Mental Health Act (1983) status (i.e. formal or informal status in hospital).

Multiple regression was used to explore predictive variables for three separate models. The first two are models of medication adherence (Section 10.3) and the third, a model of general well-being (Section 10.5). Multivariate analysis of three or more variables assumes that the underlying data are normally distributed, but this cannot be the case with ordinal data. In this study, the multivariate techniques have been employed in the spirit of experimental enquiry and in the knowledge that the robustness of the techniques to departures from multivariate normality makes any results obtained unlikely to be misleading, although quoted significance levels may be suspect (personal communication, Mr Colin Chalmers (principal consultant, DataStat Consultants)). This modelling work, therefore, will not be conclusive but will help inform the generation of new hypotheses worthy of further research.

Significant factors relating to the dependent variables (medication adherence and general well-being) were identified using correlation matrixes. The covariates were chosen according to the strength of their correlations with the dependent variable. To minimise multicollinearity, variables with correlation coefficients > 0.55 were excluded from the analysis. Attention was drawn not only to differences which achieved statistical significance

at least at the 5% level, but also to differences and trends in the expected or hypothesised directions. Given the small sample sizes (statistical significance is sensitive to small sample sizes) and the non-experimental design of this research, it would be inappropriate to over-rely on statistical significance (Pocock, 1983).

“... $P < 0.05$ has become unduly emphasised as the level needed to declare a positive finding... In practice, one must recognize that there is precious little difference between $P = 0.06$ and $P = 0.04$.”

(Pocock, 1983:205)

Variables that were worthy of entry due to theoretical significance were also included in the models (see Sections 10.3 and 10.5). The relative contribution of each covariate to each dependent variable was analysed using a stepwise multiple regression analysis (Statistical Package for the Social Sciences (SPSS)). A stepwise method of analysis was selected as it is data driven, supports the generation of new hypotheses and implicit by letting the knowledge of the researcher or the literature inform the choice of independent variables which adds weight to the conclusions of the models. Each variable is entered into the model in sequence according to its relative contribution to r^2 . This provides the advantage that variables that are unimportant for the final model will not remain in the model since a variable's importance is reviewed at each step, so deriving the best subset of independent variables.

This chapter is divided into chapter 10A and 10B. Chapter 10A will presents bivariate analyses involving medication issues (Section 10.2) followed by two multiple regression models of medication adherence (Section 10.3). Chapter 10B presents bivariate analyses involving quality of life issues (Section 10.4) followed by a multiple regression model of general well-being (Section 10.5).

10.2 Chapter 10a: Further analyses of medication issues

Frequencies of medication-related variables were reported in Chapters 6 and 7. In this Section (10.2), bivariate associations of medication issues by sex, ethnic group, country of birth, Mental Health Act (1983) Status, severity of illness and depot attendance are described. Analyses were performed by the age of the respondents; no relationships of

interest were found. The multiple regression models of medication adherence are presented in Section 10.3.

10.2.1 Variations by sex

In hospital, females reported a higher mean rank of negative effects of medication on symptoms (Mann Whitney U test: $z=-2.453$; $p=0.014$; $n=79$). During the community interview, males were more likely to be able to name all the medication they were taking ($\chi^2=5.437$ using Yates' continuity correction; $p=0.020$; $n=37$).

10.2.2 Variations by ethnic group

Ethnic groups were grouped according to 'white' (White English, White Irish, White Jewish, White Scottish, White Welsh) and 'black' (Black African, Black Caribbean, Black U.K./British and Black 'other' but excluding Asian) categories. The mean rank for the attendance rate for depot medication on the expected day according to the prescription was significantly higher for 'white' ethnic groups compared with 'black' ethnic groups (Mann Whitney U test: $z=-2.264$; $p=0.024$; $n=34$).

10.2.3 Variations by country of birth

Respondents were dichotomised into those who were born in the U.K. and those born outside the U.K.. Respondents born outside the U.K. were more likely to be taking 1 or 2 drugs in hospital, compared with U.K.-born respondents who were more likely to be taking 3-5 drugs ($\chi^2=4.348$ using Yates' continuity correction; $p=0.037$; $n=57$). At the time of discharge and the community interview, U.K.-born respondents had a higher mean rank of non-antipsychotic medications (Mann Whitney U test: $z=-2.202$; $p=0.028$; $n=68$) (Mann Whitney U test: $z=-2.049$; $p=0.040$; $n=27$).

10.2.4 Variations by Mental Health Act (1983) Status

Respondents were divided into those respondents whose admissions to hospital were

voluntary (informal) and those who had been detained formally under the Mental Health Act (1983).

Informal patients were more likely to be taking a higher mean rank of non-antipsychotic drugs in hospital (Mann Whitney U test: $z=-2.260$; $p=0.024$; $n=48$). On discharge, informal patients were more likely to be prescribed a higher mean rank of total number of medication (Mann Whitney U test: $z=-3.419$; $p=0.001$; $n=70$) and a significantly higher number of non-antipsychotic medication (Mann Whitney U test: $z=-3.265$; $p=0.001$; $n=71$).

According to medical notes, formal patients were significantly more likely to be recorded as having stopped their medication prior to their admission to hospital ($\chi^2=7.215$ using Yates' continuity correction; $p=0.007$; $n=73$). Formal patients were more likely to report medication as having a negative effect on their symptoms in hospital ($\chi^2=4.157$ using Yates' continuity correction; $p=0.041$; $n=59$). When all negative effects of medication were combined, formal patients were more likely to report a higher mean rank of negative effects in hospital (Mann Whitney U test: $z=-2.480$; $p=0.013$; $n=78$).

In the community, those patients who had experienced a formal admission were more likely to be taking less medication (Mann Whitney U test: $z=-2.191$; $p=0.028$; $n=34$). Also, formal patients were less likely to report that their medication or symptoms affected their day in the community ($\chi^2=6.827$ using Yates' continuity correction; $p=0.009$; $n=40$).

10.2.5 Variations by severity of illness

Severity of illness, as measured by the Global Assessment and Functioning Scale (see Sections 6.3.6 and 7.2.6) was dichotomised into respondents with severe illness and those with either mild or moderate illness. Respondents with severe illness in hospital had a higher mean rank of total number of medication in hospital (Mann Whitney U test: $z=-2.078$; $p=0.038$; $n=60$).

10.2.6 Variations by depot attendance

Variations by adherence to medication were analysed using two different methods:

- The first analysis compared regular attenders (100% on the day expected) with irregular attenders (< 100% on the day expected including those who had stopped their medication).
- The second analysis dichotomised respondents into those who required home visits to receive their depot medication and those who attended clinics.

Regular attenders were less likely to be able to know all of their medication by name ($\chi^2=6.680$; $p=0.035$; $n=43$) and more likely to belong to the severe illness group while in hospital ($\chi^2=6.772$ using Yates' continuity correction; $p=0.009$; $n=43$).

Irregular attenders were more likely to report feelings of wanting to stop their medication in the community (Fisher's Exact test $p=0.013$; $n=37$) and less likely to be in contact with community psychiatric nursing services ($\chi^2=8.249$ using Yates' continuity correction; $p=0.004$; $n=43$).

Respondents who received their depot medication at home were more likely to be prescribed depot medication alone when discharged from hospital. Respondents who visited a clinic to receive their depot were more likely to be prescribed both depot and oral medication when discharged from hospital ($\chi^2=4.141$ using Yates' continuity correction; $p=0.042$; $n=43$).

10.2.7 Summary of bivariate relationships with medication issues

Being able to name all medication was associated with being male and with irregularly attending for depot medication in the community.

- Does this mean that irregular attenders are more interested in their medication while regular attenders are more passive because they are less able to name all their medication? While regular attenders are more severely ill, there is no bivariate relationship between severity of illness and ability to name medication.

Reporting medication as having negative effects on symptoms in the hospital was associated with being female and with being formally admitted to the hospital. In the community, reporting that medication or symptoms affect their day was more likely for respondents who had experienced an informal admission to the hospital.

- Do respondents who experience formal admissions only criticise medication in hospital? Are formal respondents averse to medication or averse to the coercion of involuntary admissions? This could have important implications for community treatment orders.

Being recorded in medical notes as stopping medication before admission to hospital was more likely for formal patients.

- Are formal patients more likely to stop their medication or more likely to be recorded as stopping their medication in medical notes?

Psychiatrists prescribed less medication in hospital for respondents who were born outside the U.K., for formal patients and for patients with moderate or mild illness. At discharge and in the community, psychiatrists prescribed less medication for respondents born outside the U.K. and for respondents who had experienced a formal admission to hospital.

- Do psychiatrists prescribe fewer drugs for 'difficult' patients, i.e. patients born outside the U.K. who may have language and cultural problems, and for formal patients? Neither countries of birth nor formal/informal status were related to severity of illness.

Combined oral and intramuscular (depot) antipsychotic discharge medication were more likely prescribed at discharge for respondents who visited a clinic for their depot medication. Intramuscular (depot) antipsychotic medication only was more likely for respondents who required a home visit for their depot medication.

- As before, do psychiatrists prescribe fewer drugs for 'difficult' patients, i.e. patients who require outreach services for their depot medication? It is known that patients who receive outreach services are difficult to persuade to attend a clinic for their medication.

Regular attenders for depot medication were more likely to belong to the severe illness group in hospital. Lower attendance rates on the expected day for depot medication were more likely for black ethnic groups. Irregular attendance rates for depot medication were associated with respondents who reported that they wanted to stop their medication and who were in less contact with community psychiatric nursing services.

- Medication non-adherence was associated with moderate/mild illness in hospital, black ethnic groups, self-report of wanting to stop medication and a lack of contact with community psychiatric nursing services. How much variation in medication adherence can these variables predict? The next Section explores two multiple regression models of medication adherence.

10.3 Multiple regression analysis of medication adherence

Two multiple regression analyses were performed in order to assess the independent predictors of medication adherence. Medication adherence (the dependent variable) was operationalised using two different variables (see Section 7.3.1) resulting in two different multiple regression models:

- Model 1: the general attendance rate for the depot medication over the follow-up period (Section 10.3.1).
- Model 2: the attendance rate for the depot medication on the expected day according to the prescription (Section 10.3.2).

10.3.1 Model 1: General attendance rate for depot medication

Very few variables were significantly related to the general attendance rate for depot medication at the $p \leq 0.05$ level (see Table 10.1). No correlation coefficients were > 0.55 and multicollinearity was not an issue of concern.

Table 10.1 Correlation matrix of general attendance rate for depot medication (medication adherence) with other variables of interest

	General attendance rate for depot medication	Affect-Balance Total Score	Total weekly income	Severity of illness in hospital
General attendance rate for depot medication	r=1.000			
Affect-Balance Scale Total Score.	r= -0.398 p=0.011 n=40	r=1.000		
Total weekly income.	r= -0.402 p=0.014 n=37	r=0.188 p=0.258 n=38	r=1.000	
Severity of illness in hospital.	r= -0.310 p=0.045 n=42	r=-0.192 p=0.228 n=41	r=0.165 p=0.321 n=38	r=1.000

Cells detail Spearman's rho; two-tailed significance; number of respondents.

Other variables considered for entry to the multiple regression model were those of theoretical interest (listed below) but mainly of no statistical significance when tested in bivariate relationships with medication adherence at the $p \leq 0.05$ level. Different combinations of these variables were modelled.

- Ability to name all medication in hospital/community.
- Total number of medications prescribed in hospital/community.
- Prescription of anticholinergic medication (suppress adverse effects caused by antipsychotic medication) in hospital/community.
- Presence of positive or negative effects of medication on symptoms in hospital/community.
- Presence of unwanted effects of medication in hospital/community.
- Unwanted effects affecting activities in hospital/community.
- Feelings of wanting to stop medication in hospital/community.
- Intentions of taking medication after discharge from hospital.
- Medication reported as helping symptoms in hospital/community.
- Medication/symptoms affecting day in hospital/community.
- Level of educational and technical qualifications of respondents.

- Sex of respondents
- Age of respondents
- Ethnic groups of respondents ('white' or 'black' as defined in Section 10.2.2)
- Severity of illness in hospital/community
- Affect-Balance total score (psychological well-being)
- Self-Esteem total score (psychological well-being)
- Total weekly income (proxy measure for type of accommodation as those respondents with lower weekly incomes tended to live in supported accommodation where workers would be available as prompts to attend for medication or attendance for medication may be a prerequisite to live at the accommodation)

Four covariates were chosen due to the sample size of respondents ($n=41$) and according to their strength of relationship or theoretical significance with general attendance rate for depot medication. Different combinations of the above variables were explored and the adjusted r^2 was examined as an estimate of the amount of variance in depot attendance that was explained. The independent variables entered into the final model for depot attendance were those with the greatest adjusted r^2 and are listed below (Table 10.2):

- Severity of illness in hospital.
- Affect-Balance total score.
- Total weekly income.
- History of stopping medication according to medical notes.

Table 10.2 shows that the model accepted three variables as predictors of medication adherence: severity of illness in hospital, Affect-Balance total score and income. The other covariate (history of stopping medication according to medical notes) was excluded from the model. The total variation in depot medication attendance rates explained by the model was 54.7% (based on the adjusted r^2 value). The F statistic (reflects how well the model fits the data and provides evidence that there is a linear relationship between the variables) was significant ($F=13.895$; $p<0.001$).

With this small data set, it would be difficult to confirm that the regression is linear. However, violations of the assumptions of multiple regression were explored for model 1

(Statistical Package for the Social Sciences, 1990: B-79 to B-84).

- Residuals

The standardised residual mean and standard deviation are expected to be 0 and 1 respectively if the model is appropriate for the data. For model 1, the values were -0.110 and 1.138 respectively.

- Linearity

Linearity was checked by plotting predicted against residual values. Residuals were distributed horizontally about 0. However, for predicted values > 0 , residual values decreased. The residual values were plotted against the independent variables. For all plots, the residuals were randomly distributed horizontally about 0.

- Equality of variance

As stated above, for predicted values > 0 , residual values decreased. This may suggest a violation of the equality of variance assumption.

- Normality

A histogram of standardised residuals was plotted and assumed an approximate normal distribution (mean=-0.11, standard deviation=1.14).

‘... it is unreasonable to expect the observed residuals to be exactly normal - some deviation is expected because of sampling variation. Even if the errors are normally distributed in the population, sample residuals are only approximately normal.’

(Statistical Package for the Social Sciences, 1990: B-83)

The two cumulative distributions of expected and observed values were plotted. A close to straight line was produced suggesting normality.

Further evidence was gathered using different modelling approaches. It is valuable to note that by also using forward selection and backward elimination methods, the same model was produced.

Table 10.2 Model 1: Regression of general attendance rate for depot medication (medication adherence) on severity of illness in hospital, Affect-Balance total score and total weekly income

	B (1)	B (2)	B (3)
Severity of illness in hospital	-8.768 [-14.192, -3.344] (-3.297) p=0.002	-10.544 [-15.186, -5.903] (-4.639) p<0.001	-9.078 [-13.517, -4.639] (-4.183) p<0.001
Affect-Balance total score		-5.067 [-7.800, -2.333] (-3.785) p=0.001	-4.471 [-7.036, -1.906] (-3.565) p=0.001
Total weekly income			-0.253 [-0.457, -0.049] (-2.533) p=0.017
Constant	126.858 [100.02, 153.713]	160.795 [131.796, 189.794]	167.509 [140.237, 194.781]
R ²	0.260	0.499	0.590
Adjusted R ²	0.236	0.466	0.547
n	32	32	32

Note: 95% confidence intervals for the unstandardised coefficients are in square brackets. t values are presented in parentheses below the 95% confidence intervals for the unstandardised coefficients. All tests are two tailed.

Model 1 shows that all independent variables (severity of illness, Affect-Balance total score; total weekly income) were negatively related to the dependent variable (medication adherence). Respondents who had greater levels of medication adherence in general:

- were more severely ill in hospital
- scored lower on Affect-Balance scale (worse psychological well-being)
- reported a lower weekly income - which may be interpreted as a proxy measure for supported accommodation due to living expenses already being deducted. Staff would be able to remind respondents that they should attend for their injection and some supported residences have medication adherence as a prerequisite allowing individuals to stay.

Severity of illness explained 23.6% of the variance, Affect-Balance explained a further 23% and income explained the remaining 8.1%. Caution must be applied to these result due to the small sample size and the negative skew of the adherence data. However, hypotheses may be generated about medication non-adherence.

From this model, it appears that people with schizophrenia living in the community are more susceptible to medication non-adherence if they are less compromised in psychological, social and occupational functioning during an admission to hospital (severity of illness measured by GAF Scale), if they have better psychological functioning (Affect-Balance scale) and if they live independently. The relationship between medication non-adherence and severity of illness may support the concept of 'intelligent adherence', i.e. people who have been more ill in hospital are more likely to take their medication. Further work is required to test these hypotheses and model. However, these data do not support a quantitative relationship between medication adherence and QoL.

10.3.2 Model 2: Attendance rate for depot medication on the expected day according to prescription

Very few variables were significantly related to the attendance rate for depot medication on the expected day (medication adherence) at the $p \leq 0.05$ level. No correlation coefficients were > 0.55 and multicollinearity was not an issue of concern.

- Level of qualification was weakly negatively correlated with medication adherence (Spearman's $\rho = -0.320$; $p = 0.047$; $n = 39$).
- Respondents able to name all medication in hospital had a higher mean rank of rates of medication adherence (Mann-Whitney U test: $z = -2.387$; $p = 0.017$; $n = 42$).
- Respondents who reported problems in the community that made their symptoms worse (most commonly accommodation problems) had a lower mean rank of rates of medication adherence (Mann-Whitney U test: $z = -2.228$; $p = 0.026$; $n = 41$).

Other variables considered for entry to the multiple regression model were those of theoretical interest but mainly of no statistical significance when tested in bivariate relationships with medication adherence at the $p \leq 0.05$ level. The same variables of

theoretical interest as for multiple regression model 1 (Section 10.3.1) were considered. Different combinations of these variables were modelled.

Four covariates were chosen due to the sample size of respondents (n=41) and according to their strength of relationship or theoretical significance with attendance rate for depot medication on the expected day. Different combinations of the variables were explored and the adjusted r^2 was examined as an estimate of the amount of variance in depot attendance on expected day (dependent variable) that was explained. The independent variables entered into the final model for depot attendance on expected day were those with the greatest adjusted r^2 and are listed below (Table 10.3):

- Ability to name all medications taking in hospital (dummy variable: 1=all; 0=some or none).
- Level of educational and technical qualifications.
- Reported problems in the community making symptoms worse (dummy variable: 1=yes; 0=no).
- Ethnic groups of respondent (dummy variable: 1='white'; 0='black').

Table 10.3 shows that the model accepted all four variables as predictors of medication adherence on expected day. The total variation in depot medication attendance rates on the expected day explained by the model was 53.3% (based on the adjusted r^2 value). The F statistic was significant ($F=9.845$; $p<0.001$).

Table 10.3 Model 2: Regression of depot attendance on expected day on knowledge of medication by name in hospital, level of qualifications, problems making symptoms worse and ethnic group

	B (1)	B (2)	B (3)	B (4)
Ability to name all medication in hospital (0=some or none; 1=all).	22.515 [3.186, 41.844] (2.379) p=0.024	30.082 [12.183, 47.981] (3.437) p=0.002	25.001 [8.327, 41.675] (3.071) p=0.005	24.476 [9.213, 39.740] (3.290) p=0.003
Level of educational and technical qualifications.		-7.838 [-13.126, -2.550] (-3.032) p=0.005	-9.024 [-13.901, -4.148] (-3.791) p=0.001	-9.098 [-13.561, -4.635] (-4.183) p<0.001
Problems in community (0=no; 1=yes).			-20.844 [-36.551, -5.136] (-2.718) p=0.011	-19.078 [-33.521, -4.635] (-2.710) p=0.012
Ethnic group (0='black'; 1='white').				17.296 [3.431, 31.162] (2.560) p=0.016
Constant	66.818 [51.160, 82.476]	108.146 [76.994, 139.298]	129.559 [97.030, 162.089]	122.375 [92.057, 152.694]
R ²	0.159	0.361	0.495	0.593
Adjusted R ²	0.131	0.317	0.440	0.533
n	31	31	31	31

Note: 95% confidence intervals for the unstandardised coefficients are in square brackets. t values are presented in parentheses below the 95% confidence intervals for the unstandardised coefficients. All tests are two tailed.

As for Section 10.3.1, violations of the assumptions of multiple regression were explored for model 2 (Statistical Package for the Social Sciences, 1990: B79 to B-84). However, with such a small data set, confirmation that the regression is linear would be difficult..

- Residuals

For model 2, the standardised residual mean is 0.000 and the standard deviation is 0.933.

- Linearity

A scatterplot of standardised residuals against predicted values , showed residuals to be

scattered about the horizontal at 0. However, again, for predicted values > 0 , residual values decreased. The residual values were plotted against all independent variables (ability to name all medication; level of qualifications; problems in the community and ethnicity). For all plots, residuals are all randomly distributed horizontally about 0 .

- Equality of variance

As stated above, for predicted values > 0 , residual values decreased. This may suggest a violation of the equality of variance assumption.

- Normality

A histogram of standardised residual was plotted and assumed an approximate normal distribution with a mean of 0.00 and standard deviation of 0.93. The two cumulative distributions of expected and observed values were plotted. Less of a straight line was produced compared to model 1 (dependent variable: general attendance rate for depot medication).

Further evidence in favour of model 2 was generated using other modelling approaches (forward selection and backward elimination) which resulted in exactly the same model.

Model 2 showed that respondents who had greater levels of medication adherence on the expected day according to prescription:

- were able to name all their medication in hospital (suggesting an interest or involvement with their medication in hospital)
- had a lower level of educational and technical qualifications
- reported no other problems in the community making their illness worse
- identified themselves as 'white' rather than 'black'

Ability to name all medication in hospital explained 13.1% of the variance, level of educational and technical qualifications explained a further 18.6%, having a problem in the community making illness worse a further 13.3% and ethnic group explained the remaining 9.3%.

Again, caution must be applied to these results due to the small sample size and the negative skew of the adherence data. However, hypotheses may be generated for medication non-

adherence. From this model, it appears that people with schizophrenia living in the community are more susceptible to medication non-adherence on the expected day according to prescription, if they are unable to name all their medication in hospital, if they have a higher level of educational and technical qualifications, if they report having problems in the community that are making their illness worse, and if they identify themselves as 'black'. Further work is required to test this hypothesis. Further work may also wish to test if the ability to name medication represents a level of interest or involvement in medication management. Further work may explore medication-taking behaviour type, e.g. active participation, passive acceptance (discussed earlier) in association with ability to name medication.

Warner (1994:170) postulates that outcome of schizophrenia is worse among the better educated because of the greater labour market stresses that affect the educated. Is this theory a confounder in medication adherence? A study by Tunnicliffe *et al.* (1992) completed a retrospective analysis through nursing records to determine the effects of ethnicity on 'dropping out' from depot medication within one year. They found that respondents of an Afro-Caribbean origin were significantly more likely to drop out than non-Afro Caribbean respondents. However the contribution of ethnicity to non-compliant behaviour was modest compared to other variables. Overall, these data do not support a quantitative relationship between medication adherence and quality of life.

10.4 Chapter 10b: Further analyses of quality of life issues

Frequencies of quality of life variables are reported in Chapter 8. In the following section (10.4), bivariate associations of quality of life variables by sex, age, ethnic group, country of birth, Mental Health Act (1983) Status, severity of illness and depot attendance are described. The multiple regression model of global well-being is displayed in Section 10.5.

10.4.1 Variations by sex

Table 10.4 illustrates relationships of interest between quality of life issues and sex. Females were more likely than males to report physical or other health problems when in hospital ($\chi^2=4.723$ using Yates' continuity correction; $p=0.030$; $n=75$).

- Respondent-defined quality of life

In the community interview, the mean rank rating of quality of life for females was consistently higher (better) than males on all five of the respondent-defined quality of life areas. This was significant at the $p \leq 0.05$ level for the second, fourth and fifth life areas named. These were most likely to be relationships with family and relatives, relationships with others (including intimate relationships) and leisure activities/social life, respectively (see Section 8.1.2).

- Lancashire Quality of Life Profile: Perceived Quality of Life

The mean rank satisfaction ratings for personal safety, the domain of legal/safety (personal safety and neighbourhood safety combined) and the domain of family relations (family in general, contact with family and marriage (where applicable)) were all significantly lower for females.

Table 10.4 Variation of quality of life variables by sex

Test variable	Relationship with sex	Test statistic
Current quality of life status ratings for respondent-defined quality of life areas .	<u>First life area:</u> Females mean rank: 25.32 Males mean rank: 15.89 <u>Second life area:</u> Females mean rank: 25.81 Males mean rank: 13.81 <u>Fourth life area:</u> Females mean rank: 19.64 Males mean rank: 13.11	Mann Whitney U test: $z=-2.593$ $p=0.010$ $n=39$ Mann Whitney U test: $z=-3.407$ $p=0.001$ $n=37$ Mann Whitney U test: $z=-1.987$ $p=0.047$ $n=30$
Psychological well-being (Lancashire QoL Profile)		
Affect-Balance Scale: negative affect subscore	Females mean rank: 26.18 Males mean rank: 17.33	Mann Whitney U test: $z=-2.396$ $p=0.017$ $n=41$
Perceived Quality of Life (Lancashire QoL Profile)		
Domain: Legal/Safety Satisfaction with personal safety.	Females mean rank: 14.62 Males mean rank: 25.52	Mann Whitney U test: $z=-2.937$ $p=0.003$ $n=41$
Mean domain score for satisfaction with safety (personal safety and safety of neighbourhood).	Females mean rank: 16.32 Males mean rank: 24.31	Mann Whitney U test: $z=-2.127$ $p=0.033$ $n=41$
Domain: Family relations Mean domain score for satisfaction with family relations (family in general, contact with family and marriage (where applicable)).	Females mean rank: 15.71 Males mean rank: 23.32	Mann Whitney U test: $z=-2.085$ $p=0.037$ $n=39$
Subjective well-being (Lancashire QoL Profile)		
Global well-being: average score of general well-being I and general well-being II.	Females mean rank: 25.35 Males mean rank: 17.92	Mann Whitney U test: $z=-1.975$ $p=0.048$ $n=41$
Cantril's Ladder	Females mean rank: 24.50 Males mean rank: 14.81	Mann Whitney U test: $z=-2.702$ $p=0.007$ $n=37$

- Lancashire Quality of Life Profile: Psychological well-being and subjective well-being

The mean rank of the negative affect subscore of psychological well-being (measured using the Affect-Balance Scale) was significantly higher for females. A high score (4 or 5) on the negative affect subscale has been used as an indicator of depression. In terms of self-esteem, females were more likely to be satisfied with themselves than males ($\chi^2=4.148$ using Yates' continuity correction; $p=0.042$; $n=41$). Females had a higher mean rank on satisfaction rating with global well-being and on Cantril's ladder (a measure of subjective well-being).

10.4.2 Variations by age

Age was treated as an interval variable except in the analysis of nominal data, when the sample was divided into three age groups: 19-29 years; 30-39 years; and 40-63 years. It is acknowledged that these are arbitrary divisions, but it was assumed that each subgroup included people of similar experiences.

- Lancashire Quality of Life Profile: Perceived Quality of Life

The mean rank satisfaction with the frequency of attending religious services significantly increased with increasing age groups (Kruskal Wallis $\chi^2=8.157$; $p=0.017$; $n=21$).

10.4.3 Variations by ethnic group

Ethnic groups were grouped according to 'white' (White English, White Irish, White Jewish, White Scottish, White Welsh) and 'black' (Black African, Black Caribbean, Black U.K./British and Black 'other', but, excluding Asian) categories.

Respondents who belonged to the 'white' ethnic groups were more likely to belong to the severe illness group in hospital ($\chi^2=4.024$ using Yates' continuity correction; $p=0.045$; $n=56$) and more likely to report physical or other health problems in hospital ($\chi^2=4.229$ using Yates' continuity correction; $p=0.040$; $n=53$).

- Lancashire Quality of Life Profile: Objective indicators

In the community, the mean rank of additional money requested in order to live life as one would wish was higher for the 'black' ethnic groups (Mann Whitney U test: $z=-3.233$; $p=0.001$; $n=25$).

- Lancashire Quality of Life Profile: Perceived Quality of Life

The mean rank of satisfaction with mental health in the community was higher for the 'black' ethnic group (Mann Whitney U test: $z=-2.054$; $p=0.040$; $n=33$).

10.4.4 Variations by country of birth

Respondents were dichotomised into those who were born in the U.K. and those born outside the U.K.. Table 10.5 illustrates relationships of interest between quality of life issues and country of birth.

- Respondent-defined quality of life

Mean rank for U.K. born respondents was consistently higher than non-U.K. born respondents on the current quality of life status ratings for all five of the respondent-defined quality of life areas. The mean rank was significantly higher (more satisfied) for the third-ranked life area named (most commonly leisure activities/social life) (see Section 8.1.2).

- Lancashire Quality of Life Profile: Objective indicators

The mean rank of weekly income was higher for non-U.K. born respondents. The mean rank of age at first admission to psychiatric hospital or ward was also higher (i.e. older) for non-U.K. born respondents.

- Lancashire Quality of Life Profile: Perceived Quality of Life

The mean rank satisfaction with frequency of attendance at religious service and the domain of religion (satisfaction with religious faith and its teachings and the frequency of attendance at religious service, combined) were both higher (more satisfied) for non-U.K. born respondents.

Table 10.5 Variation of quality of life variables by country of birth

Test variable	Relationship with country of birth	Test statistic
Satisfaction ratings with third-ranked life area, (respondent-defined quality of life areas) most commonly leisure activities/social life.	U.K. born mean rank: 21.17 Non-U.K. born mean rank: 13.77	Mann Whitney U test: z=-2.062 p=0.038 n=36
Objective indicators (Lancashire QoL Profile)		
Domain: Finances Total weekly income.	U.K. born mean rank: 16.20 Non-U.K. born mean rank: 23.61	Mann Whitney U test: z= -2.027 p=0.043 n=37
Domain: Health Age at first admission to psychiatric hospital.	U.K. born mean rank: 15.20 Non-U.K. born mean rank: 23.38	Mann Whitney U test: z=-2.248 p=0.025 n=35
Perceived Quality of Life (Lancashire QoL Profile)		
Domain: Religion Satisfaction with frequency of attendance at religious services.	U.K. born mean rank: 7.25 Non-U.K. born mean rank: 13.75	Mann Whitney U test: z=-2.513 p=0.012 n=20
Mean domain score for religion (satisfaction with religious faith and its teachings and the frequency of attendance at religious services).	U.K. born mean rank: 6.95 Non-U.K. born mean rank: 14.05	Mann Whitney U test: z=-2.751 p=0.006 n=20

10.4.5 Variations by Mental Health Act (1983) Status

Respondents were divided into those respondents whose admissions to hospital were voluntary (informal) and those who had been detained formally using the Mental Health Act (1983). Table 10.6 illustrates relationships of interest between quality of life issues and Mental Health Act (1983) Status.

- Respondent-defined quality of life

In the community, informal respondents were more likely to report overall quality of life as negative while respondents who had experienced a formal admission to hospital were more likely to report overall quality of life as positive. The mean rank of overall quality of life for formal respondents was higher (i.e. more positive).

- Lancashire Quality of Life Profile: Objective indicators

The mean rank for weekly income was higher for those respondents who had experienced a formal admission. Formal respondents were also significantly more likely to have monthly or less frequent contact with relatives ($\chi^2=4.714$ using Yates' continuity correction; $p=0.030$; $n=35$). The mean rank of age on first admission to psychiatric hospital or ward was higher for those who had experienced a formal admission (i.e. they were older on their first admission).

- Lancashire Quality of Life Profile: Perceived quality of life

Respondents who had experienced a formal admission had higher mean rank satisfaction (i.e. more positive) with being unemployed, the way respondents got on with others, domain score for social relations (satisfaction with the way you get on with others and the number of friends you have, combined), general health, frequency of seeing doctor, mental health and for the domain score of health (previous three health items combined).

- Lancashire Quality of Life Profile: Psychological well-being

The mean rank for the negative affect subscore (measured using the Affect-Balance Subscale; high scores of negative affect have been used as an indicator for depression) and the negative Self-Esteem subscore (measured using the Self-Esteem Scale) were both higher for those respondents who had experienced an informal admission. The mean rank for the positive self-esteem subscore and the overall total Self-Esteem score (measured using the Self-Esteem Scale) were both higher (greater self-esteem) for those respondents who had experienced a formal admission. Respondents who had experienced a formal admission were significantly more likely to '... feel a person of worth, at least on equal plane with others' (Fisher's Exact test $p=0.021$; $n=38$).

Table 10.6 Variation of quality of life variables by Mental Health Act (1983) Status

Test variable	Relationship with Mental Health Act (1983) Status	Test statistic
Respondent-defined current quality of life status. All faces' ratings for overall quality of life (faces 1-7).	Formal mean rank: 23.94 Informal mean rank: 15.34	Mann Whitney U test: $z=-2.334$ $p=0.020$ $n=40$
Objective indicators (Lancashire QoL Profile) Domain: Finances Weekly income.	Formal mean rank: 23.90 Informal mean rank: 11.96	Mann Whitney U test: $z=-3.203$ $p=0.001$ $n=38$
Domain: Health Age first admitted to a psychiatric hospital/ward.	Formal mean rank: 23.50 Informal mean rank: 12.25	Mann Whitney U test: $z=-3.193$ $p=0.001$ $n=36$
Perceived Quality of Life (Lancashire QoL Profile) Domain: Work Satisfaction with being unemployed.	Formal mean rank: 22.32 Informal mean rank: 14.13	Mann Whitney U test: $z=-2.130$ $p=0.021$ $n=37$
Domain: Social relations Satisfaction with the way respondents got on with others.	Formal mean rank: 23.96 Informal mean rank: 16.38	Mann Whitney U test: $z=-2.039$ $p=0.041$ $n=41$
Mean domain score for social relations (satisfaction with the way you get on with others and satisfaction with the number of friends you have).	Formal mean rank: 24.68 Informal mean rank: 15.25	Mann Whitney U test: $z=-2.496$ $p=0.013$ $n=41$
Domain: Health Satisfaction with general health.	Formal mean rank: 25.56 Informal mean rank: 13.88	Mann Whitney U test: $z=-3.135$ $p=0.002$ $n=41$
Satisfaction with the frequency of seeing doctor.	Formal mean rank: 23.56 Informal mean rank: 15.40	Mann Whitney U test: $z=-2.238$ $p=0.025$ $n=40$
Satisfaction with mental health.	Formal mean rank: 24.96 Informal mean rank: 13.81	Mann Whitney U test: $z=-3.006$ $p=0.003$ $n=40$
Mean domains score for health (satisfaction with all above items combined).	Formal mean rank: 26.36 Informal mean rank: 12.63	Mann Whitney U test: $z=-3.620$ $p<0.001$ $n=41$

Table 10.6(ctd.) Variation of quality of life variables by Mental Health Act (1983) Status

Test variable	Relationship with Mental Health Act (1983) Status	Test statistic
Psychological well-being (Lancashire QoL Profile)		
Affect-Balance Scale: negative affect subscore	Formal mean rank: 17.78 Informal mean rank: 26.03	Mann Whitney U test: $z=-2.214$ $p=0.027$ $n=41$
Self-Esteem Scale: positive self-esteem subscore	Formal mean rank: 22.79 Informal mean rank: 13.86	Mann Whitney U test: $z=-2.496$ $p=0.013$ $n=38$
negative self-esteem subscore	Formal mean rank: 17.23 Informal mean rank: 24.43	Mann Whitney U test: $z=-1.934$ $p=0.051$ $n=39$
Total score for Self-Esteem	Formal mean rank: 22.83 Informal mean rank: 13.79	Mann Whitney U test: $z=-2.444$ $p=0.015$ $n=38$

10.4.6 Variations by severity of illness

Severity of illness, as measured by the Global Assessment and Functioning Scale (see Sections 6.3.6 and 7.2.6) was dichotomised into respondents with severe illness and those with either mild or moderate illness. .

- Lancashire Quality of Life Profile: Objective indicators

Respondents with severe illness had a higher mean rank of perceived wealth (see Section 8.2.2.5) i.e. they requested less additional money to live life as they would wish (Mann Whitney U test: $z=-2.218$; $p=0.027$; $n=33$). Respondents with moderate or mild illness were more likely to report barriers to moving or improving their living conditions in the last year ($\chi^2=4.063$ using Yates' continuity correction; $p=0.044$; $n=41$).

10.4.7 Variations by depot attendance

Variations by adherence to medication were analysed using two different methods:

- The first analysis dichotomised respondents into those who required home visits to receive their depot medication and those who attended clinics.
- The second analysis compared regular attenders (100% on the day expected) with irregular attenders (< 100% on the day expected including those who had stopped their medication).

Table 10.7 illustrates the relationships of interest between quality of life issues and depot attendance.

Irregular attenders were more likely to report one or more problems in the community that were making their illness worse ($\chi^2=6.196$ using Yates' continuity correction; $p=0.013$; $n=42$).

- Respondent-defined quality of life

The mean rank for those respondents who received their injection at home was higher (better) for overall quality of life faces' ratings (respondent-defined).

- Lancashire Quality of Life Profile: Objective indicators

The mean rank for those respondents who received their injection at home was higher for the age when they were first admitted to a psychiatric ward or hospital.

- Lancashire Quality of Life Profile: Perceived quality of life

Respondents who received their depot at home had higher mean rank satisfaction with the mean domain score for legal/safety (personal safety and safety of neighbourhood, combined), contact with relatives and the frequency of seeing the doctor.

- Lancashire Quality of Life Profile: Psychological well-being and subjective well-being

Respondents who received their depot at home also has a higher mean rank for the positive self-esteem subscore (measured using the Self-Esteem Scale).

Table 10.7 Variation of quality of life variables by depot attendance

Test variable	Relationship with depot attendance	Test statistic
Respondent-defined quality of life: overall quality of life (rated using the faces scale).	Injection at home mean rank: 25.03 Injection at clinic mean rank: 17.15	Mann Whitney U test: z=-2.139 p=0.031 n=40
Objective Indicators (Lancashire QoL Profile) Domain: Health Age when first admitted to a psychiatric hospital/ward.	Injection at home mean rank: 23.00 Injection at clinic mean rank: 15.29	Mann Whitney U test: z=-2.172 p=0.030 n=36
Perceived Quality of Life (Lancashire QoL Profile) Domain: Legal and safety Mean domain score for legal and safety (satisfaction with personal safety and satisfaction with safety of neighbourhood).	Injection at home mean rank: 25.42 Injection at clinic mean rank: 17.54	Mann Whitney U test: z=-2.111 p=0.035 n=41
Domain: Family relations Satisfaction with contact with relatives.	Injection at home mean rank: 24.35 Injection at clinic mean rank: 15.57	Mann Whitney U test: z=-2.480 p=0.013 n=38
Domain: Health Frequency of seeing the doctor.	Injection at home mean rank: 24.56 Injection at clinic mean rank: 17.18	Mann Whitney U test: z=-2.078 p=0.038 n=40
Psychological well-being (Lancashire QoL Profile) Self-Esteem Scale Positive self-esteem subscore.	Injection at home mean rank: 23.22 Injection at clinic mean rank: 16.15	Mann Whitney U test: z=-2.045 p=0.041 n=38

10.4.8 Summary of bivariate relationships with quality of life issues

From the data presented, it can be seen that the variables of sex, age, ethnicity, country of birth, Mental Health Act status, severity of illness and depot attendance are all related to different aspects of 'quality of life'.

Of particular interest were the relationships with respondent-defined quality of life (adapted

from the SEIQoL approach). Females generally scored higher on the satisfaction ratings with the respondents-defined life areas. Yet scored lower than males in the satisfaction scores with two life domains of the Lancashire Quality of Life Profile (safety and family relations). Similarly, U.K.-born respondents' satisfaction with respondent-defined life areas were higher than the non-U.K. born respondents.

- Does this suggest that given an open approach to QoL measurement, females and respondents born in the U.K. are more likely to name areas of life that they are highly satisfied with? Where as males and respondents born outside the U.K. are more likely to name areas that they are dissatisfied with?

Mean satisfaction with the domain of:

safety was higher for males and for respondents who received an outreach service for their depot medication;

religion were higher for non-U.K. born respondents;

social relations and health were higher for those respondents who had experienced a formal admission to hospital.

- Is perceived safety an influencing factor when respondents receive an outreach service for their depot medication?
- Does a formal admission to hospital allow mental health teams to treat the patient more effectively so that after discharge, they have a better quality of life with respect to social relations and their perceived health?

Greater psychological well-being was associated with females and with respondents who had experienced a formal admission to hospital. Greater self-esteem scores were also achieved by respondents who had experienced a formal admission to hospital and by respondents who received outreach services for their depot medication.

- As above, does a formal admission to hospital allow mental health teams to treat the patient more effectively so that after discharge, they have better psychological well-being and self-esteem? Similarly, does providing an outreach service to respondents for their medication facilitate improved self-esteem due to the individualised contact in the patient's own home?

Greater subjective well-being was associated with females, with respondents who had received a formal admission to hospital and with received outreach services for their depot medication.

- As above, does a formal admission to hospital allow mental health teams to treat the patient more effectively so that after discharge, they have better subjective well-being? Similarly, does providing an outreach service to respondents for their medication facilitate improved subjective well-being due to the individualised contact in the patient's own home?

10.5 Multiple regression analysis of global well-being

A multiple regression analysis was performed in order to assess the independent predictors of global well-being (Model 3). Global well-being (the dependent variable) was operationalised using the average LSS ratings for general well-being I and II from the Lancashire Quality of Life Profile (see Sections 8.2.3.2).

Significant factors relating to global well-being (dependent variable) for potential entry into the multiple regression model are listed below (Spearman's rho is detailed with two-tailed significance). To minimise multicollinearity, variables with correlation coefficients > 0.55 were excluded from the analysis.

• Affect-Balance Scale	$r=0.372$; $p=0.017$; $n=41$
• Cantril's Ladder	$r=0.507$; $p=0.001$; $n=37$
• Domain score for Finances	$r=0.349$; $p=0.032$; $n=38$
• Domain score for Leisure/participation	$r=0.503$; $p=0.001$; $n=41$
• Domain score for social relations	$r=0.452$; $p=0.003$; $n=41$
• Domain score for unemployed	$r=0.423$; $p=0.009$; $n=37$
• Self-Esteem Scale	$r=0.546$; $p<0.001$; $n=38$
• Negative self-esteem	$r=-0.376$; $p=0.018$; $n=39$
• Positive affect	$r=0.411$; $p=0.008$; $n=41$
• Satisfaction with independence	$r=0.331$; $p=0.039$; $n=39$
• Satisfaction with financial comfort	$r=0.328$; $p=0.044$; $n=38$
• Satisfaction with number of friends	$r=0.323$; $p=0.040$; $n=41$

- Satisfaction with employment status $r=0.423$; $p=0.009$; $n=37$
- Satisfaction with pleasure from outside acts $r=0.457$; $p=0.003$; $n=41$
- Satisfaction with neighbourhood safety $r=0.375$; $p=0.016$; $n=41$
- Length of hospital stay $r=0.386$; $p=0.013$; $n=41$
- Happiness $r=0.523$; $p=0.001$; $n=36$
- Severity of illness in hospital $r=-0.325$; $p=0.038$; $n=41$

Other variables considered for entry to the multiple regression model were those of theoretical interest but not necessarily of statistical significance when tested in bivariate relationships with global well-being at the $p \leq 0.05$ level. Different combinations of these variables were modelled.

- Age.
- Sex.
- Ethnicity.
- Intention to take discharge medication.
- Social network.
- Formal/informal admission to hospital.
- Experiencing problems in the community that are making symptoms worse.

Four covariates were chosen due to the sample size of respondents ($n=41$) and according to their strength of relationship or theoretical significance with general well-being. Different combinations of the above variables were explored and the adjusted r^2 was examined as an estimate of the amount of variance in general well-being that was explained. The independent variables entered into the final model for depot attendance were those with the greatest adjusted r^2 and are listed below (Table 10.8):

- Satisfaction rating for activities completed outside the home.
- Self-Esteem total score.
- Satisfaction rating for the amount of independence at current living situations.
- Severity of illness when in hospital.

Table 10.8 shows that the total variation in global well-being explained by the model was 63.1% (based on the adjusted r^2 value). The Table shows that the model accepted all four co-

variates in the global well-being model. The F statistic (reflects how well the model fits the data and provides evidence that there is a linear relationship between the variables) was significant ($F=16.358$; $p<0.001$).

As detailed earlier in Section 10.2, with such a small data set it would be difficult to confirm that the regression is linear. However, violations of the assumptions of multiple regression were explored for model 3.

- Residuals

For model 3, the standardised residual mean is 0.000 and the standard deviation is 0.943. Expected values are 0.000 and 1.000 respectively.

- Linearity

A scatterplot of standardised residuals against predicted values showed a random distribution about the horizontal point of 0 which suggests linearity. The residual values were also plotted against the independent variables. The resulting plots also supported the assumption of linearity since residuals were randomly distributed horizontally about 0 for all independent variables included in model 3.

- Equality of variance

There was no observable pattern when predicted values were plotted against residuals which is suggestive of equality of variance i.e. for every X value, there is a constant variance of Y.

- Normality

A histogram of standardised residuals was plotted and assumed an approximately normal distribution (mean=0.00 and standard deviation=0.94). As discussed before, it is unreasonable to expect an exact normal distribution due to sampling error. The two cumulative distributions of expected and observed values produced an approximate straight line providing evidence of normality.

Confirmatory evidence was provided by attempting the model using the different techniques of forward selection and backward elimination. On each occasion the same model was generated.

Model 3 showed that respondents who had greater levels of global well-being:

- had greater self-esteem
- had greater satisfaction from activities done outside the home
- had greater satisfaction with the amount of independence they had at their current living situation
- had a severe form of illness during their admission in hospital

Self-esteem explained 37.5% of the variance, satisfaction from activities done outside the home explained a further 14.9%, satisfaction with the amount of independence they had at their current living situation a further 5.5% and severity of illness in hospital during last admission explained the remaining 5.2%.

Again, caution must be applied to these results due to the small sample size. However, hypotheses may be generated for global well-being. From this model, it appears that people with schizophrenia living in the community have a better global well-being if they had high self-esteem, pursued satisfactory activities outside the home, had a satisfactory amount of independence at their home and had experienced a severe form of illness during their previous admission. Severity of illness may be linked to global well-being as an indicator of how people have adjusted their lives and expectations to account for their illness. Those respondents with moderate or mild impairment may have too high goals and therefore score lower on global well-being.

Table 10.8 Model 3: Regression of global well being[†] on satisfaction with activities completed outside the home, Self-Esteem total score, satisfaction with amount of independence at current residence and severity of illness in hospital

	B (1)	B (2)	B (3)	B (4)
Self-Esteem total score	0.351 [0.201, 0.501] (4.752) p<0.001	0.299 [0.165, 0.434] (4.517) p<0.001	0.290 [0.163, 0.417] (4.636) p<0.001	0.281 [0.162, 0.400] (4.793) p<0.001
Satisfaction with activities done outside home		0.432 [0.178, 0.686] (3.454) p=0.001	0.419 [0.180, 0.658] (3.560) p=0.001	0.395 [0.169, 0.620] (3.567) p=0.001
Satisfaction with the amount of independence at current residence			0.310 [0.040, 0.581] (2.332) p=0.026	0.313 [0.059, 0.567] (2.515) p=0.017
Severity of illness in hospital				-0.261 [-0.485, -0.037] (-2.375) p=0.024
Constant	2.254 [1.253, 3.254]	0.613 [-0.689, 1.916]	-0.886 [-2.679, 0.907]	0.505 [-1.556, 2.556]
R ²	0.392	0.550	0.614	0.672
Adjusted R ²	0.375	0.524	0.579	0.631
n	36	36	36	36

Note: 95% confidence intervals for the unstandardised coefficients are in square brackets. t values are presented in parentheses below the unstandardised coefficients. All tests are two-tailed.

[†] Computed from general well-being I and II ratings from the Lancashire Quality of Life Profile.

PART FOUR - CONCLUSIONS

CHAPTER 11 DISCUSSION AND CONCLUSIONS

The overall aim of the study was to investigate associations between the effects of antipsychotic medication and the quality of life of people with a clinical diagnosis of schizophrenia. Respondents were recruited in hospitals and followed-up, on average, five months after discharge from the hospital. Only those persons aged 18-64 years with a clinical diagnosis of schizophrenia and prescribed an antipsychotic depot injection, at the time of discharge from the hospital, were included in the study. Medication adherence rates were calculated individually by the degree of attendance to receive the depot medication during the follow-up period.

The conceptual model of quality of life (QoL) adopted in this study was based on the needs satisfaction and life satisfaction models. These models are based on the level of QoL achieved by an individual based on a common set of values defining one's needs, wants and desires. However, individuals can vary and therefore, including an assessment of the importance of areas of life to the individual is also important. These models were operationalised in this study using adapted questions from the Schedule for the Evaluation of Individual Quality of Life (SEIQoL) (O'Boyle, 1994) and the Lancashire Quality of Life Profile (Oliver, 1991). A model of broader QoL, rather than the more limited health-related QoL was used because mental illness can affect the whole spectrum of people's lives.

Quality of life (QoL) was only measured at the follow-up interview in the community for two reasons. First, defining and measuring QoL across different settings is difficult. For example, the Lancashire Quality of Life Profile includes items about visiting friends, travelling on public transport and living independently that would be inappropriate for application in a hospital setting. Second, medication adherence was measured in the community only because in the hospitals, respondents were not responsible for their own medication-taking behaviour. An objective of the study was to investigate associations between medication adherence and QoL, and therefore it was appropriate that the QoL measure was also only administered in the community.

Criticisms of previous studies of the mentally ill suggest that patients are carefully selected,

the research milieu is atypical to usual conditions for the average patient in the community and often research designs can substantially increase staff-patient contact time confounding the results of the research (Johnson, 1984; Barnes, 1991). However, the study reported in this thesis offers three advantages to previous research. First, this study was naturalistic in its enquiry, describing life for people with schizophrenia living in the community. Second, this study researched beyond the identification of the adverse effects of antipsychotic medication by including an assessment of the perceived consequences of adhering to medication from the patient's perspective. Third, little QoL and medication-taking behaviour research has been published on the 'revolving door' patient. In this study, the respondents were invited to participate from consecutive admissions to the acute psychiatry admission wards. Respondents were only excluded from this study if they had English language difficulties (n=7), were self-discharged from the hospital against medical advice (n=3) or if community mental health staff had identified them as unsuitable for the interview (n=2). However, it is still unknown how generalisable these findings are outside the study districts and with other groups in different cultural settings. Before discussing the results of the study, the methodological difficulties experienced during the study (Section 11.1) and the limitations of the study (Section 11.2) are discussed. These sections will be followed by a discussion of quality of life measurement for people with schizophrenia (Section 11.3), the perceived effects of antipsychotic medication in relation to quality of life (Section 11.4) and the implications of the findings for the community care of people with schizophrenia (Section 11.5).

11.1 Methodological difficulties experienced during the study

From the pilot work, it was assumed that consecutive admissions to acute psychiatry admission wards in hospitals would provide a complete sampling frame from which to invite potential respondents to participate. In turn, this would facilitate a more robust interpretation of the results since it would be an exact sample. However, many practical difficulties complicated the recruitment of all eligible patients.

- i. Recruitment, in the first instance, relied on medical staff enthrusting patients to want to discuss the study with the researcher (ethics committees' recommendation, see Section 5.2). Therefore, the ethics of the research compromised the recruitment

process; staff were sometimes too busy to approach patients and some staff appeared more adept at gaining patients' agreements than others.

- ii. All hospital wards participating in this study were acute admission wards. Therefore, there was only a short period between which respondents had regained their mental well-being sufficiently to be interviewed and before they were discharged.
- iii. The study hospitals were all teaching hospitals and therefore, the researcher competed with medical students to interview patients.
- iv. All wards were 'open' wards and as such patients were permitted to leave the ward at their convenience and therefore, 'catching' patients was difficult.
- v. Many activities were organised for patients as part of their rehabilitation and so time available during the day for a recruitment interview was limited.

Twenty potential respondents refused and 30 were 'missed' during the recruitment phase, i.e. identified as fulfilling the study criteria but were discharged before they were interviewed. Reasons for missing patients may fall in to those discussed above but also because they were unexpectedly discharged. 'Hot-bedding' was a problem for these wards. This occurred when patients were put on extended leave (living in the community but remaining on the hospital's books) due to a worse case requiring admission. Crude bed occupancy rates (where the numerator is all patients on the unit list including patients on leave and the denominator is the bed number of the unit) for the study hospitals were 96-115%. In 1991, the Royal College of Psychiatrists suggested 88% as an ideal bed occupancy. Socio-demographic characteristics, psychiatric histories, confirmation of diagnoses and prescriptions at discharge could not be ascertained for the refused and missed samples since access to medical records was not permitted without written consent from the participant.

This study wanted to maximise the opportunity of including individuals who may display varying rates of medication adherence in the community. Therefore, following up in-patients after discharge was decided as the best research strategy since at the point of discharge, all respondents would be uniform in terms of being in contact with secondary services and receiving regular medication. After discharge from the hospital, it was expected that the responsibility for medication would shift from the hospital services to the individual. However, in practice, type of community accommodation (some hostels stipulated that

medication adherence was a prerequisite for staying there) and contact with community outreach services, compromised independent medication-taking behaviour. Also, some respondents were lost to follow-up due to readmission to the hospital, moving out of the study district, return of their psychotic symptoms, untraceable due to no fixed abode and there was one suicide.

Reliability of respondents' reporting was explored using triangulation (multiple data collection methods), i.e. medical notes, staff reported information and postal questionnaires with significant others. However, the congruency between the different data sets varied and little can be concluded on which data set was superior (see Chapters 6, 7 and 9). Triangulation also increased the time required to collect the data. The availability of medical notes on hospital wards and in the medical records' departments was often poor, and required repeated visits to the appropriate wards/departments. Also, medical and nursing staff were not always available to act as external validators for the DSM-III-R diagnoses of patients and for using the Global Assessment of Functioning Scale (American Psychiatric Association, 1987). Similarly, the final response rate from significant others' postal questionnaires (60%) was achieved only after three 2-weekly reminder letters and telephone calls.

11.2 The limitations of the study

It is unknown how closely the study sample approximates to a random sample of the population due to the difficulties of calculating a response rate for the recruitment phase (outlined in Section 6.1). The study recruited a sample of 79 in-patients from consecutive admissions to the acute admission wards of four hospitals. However, 20 potential respondents refused participation and a further 30 potential respondents were identified as eligible but 'missed' during the recruitment process.

Respondents were followed-up in the community, on average, five-months after discharge from the hospitals. Out of the 79 in-patients recruited to the study, only 70 were eligible for follow-up because 8 had not been discharged during the data collection period and one had been discharged outside the study districts. Of the remaining 70 recruited respondents, 12 were unavailable for the follow-up interview because 9 had been readmitted to hospital, two

had moved out of the study district and one respondent had committed suicide. Consequently, there were 58 eligible respondents available for the follow-up interview. Forty-one respondents completed and two respondents part-completed both the recruitment and follow-up interviews (response rate=74%; n=58) (see Figure 6.1).

The socio-demographic characteristics and psychiatric histories of the respondents did not differ significantly between those who completed the recruitment questionnaire only (n=36) and those who also completed the community questionnaire (n=43). Also, the range of characteristics of the sample suggested that the group studied was a reasonable cross-section of people with schizophrenia (aged 18-64 years and prescribed depot formulations of antipsychotic medication). Although it is acknowledged that there can be considerable heterogeneity in behaviour and symptoms within the diagnostic category. While caution has to be applied to the quantitative analysis of the community data due to the sample size of 41 and the limited variation in medication adherence, useful inductive work relevant to the objectives of this study has been presented.

It may have been useful to co-administer a standardised instrument for measuring the adverse effects of antipsychotic medication. The objective ratings could have been compared with the patients' self-report. However, many adverse effect rating scales require administration by a clinician and therefore were inappropriate for inclusion in this study. Further, it was decided that the interview instrument was of sufficient length and should not be extended.

The qualitative analysis of the comments relating to medication issues was inductive. Pilot work suggested that patients would have had difficulty responding to an unstructured interview. However, many respondents made additional comments to open questions that illustrated how they interacted with, and perceived, their medication. Caution must be applied to the results because the comments were in response to the semi-structured questions and therefore, the information reported was not respondent-led. Given more resources, it would have been preferable for a second coder to code the qualitative notes and an estimate of inter-coder reliability calculated to ensure consistent interpretation by the researcher.

In spite of the limitations of the study discussed above, people with schizophrenia are a

difficult population to recruit for research studies and therefore, it is felt that the data presented in this thesis can valuably contribute to the field of quality of life (QoL) and pharmacy practice research in schizophrenia.

11.3 Quality of life measurement in schizophrenia research

This study adopted two approaches to measuring the quality of life (QoL) of people with schizophrenia living in the community:

- a respondent-led method adapted from the Schedule for the Evaluation of Individual Quality of Life (SEIQoL) (O'Boyle, 1994) (inductive approach)
- a disease-specific instrument, Lancashire Quality of Life Profile (LQoLP) (Oliver, 1991) (deductive approach)

The objectives of this part of the study were (i) to describe the areas of life, people with a diagnosis of schizophrenia, felt were important for their QoL and (ii) to analyse whether the Lancashire Quality of Life Profile measured all those areas of life important to people with schizophrenia (n=41).

Both the respondent-led approach to quality of life (QoL) assessment and the disease-specific instrument provided interesting data concerning the quality of life of people with schizophrenia living in the community. Progress in the measurement of QoL is reliant upon researchers administering and assessing QoL in a range of settings and populations. This study contributes to the body of literature on the respondent-led methods of QoL assessment and the Lancashire Quality of Life Profile. First, this section will discuss the respondent-led approach to QoL measurement. This will be followed by a discussion of the application of the Lancashire Quality of Life Profile with this sample and then, both approaches will be compared.

Respondent-led assessment of quality of life (QoL) in the mentally ill may be regarded with some scepticism due to the nature of the illness (e.g. distorted perceptions, lack of insight) that may question the reliability of respondent reporting. However, in order to achieve an assessment of individual QoL, by the very nature of the concept only an individual can

respond. As this study illustrates, also it is difficult to access a suitable 'significant other' who can respond on behalf of the respondents with schizophrenia, who will know the features of an individual's life well-enough to be able to comment and rate them. By the very nature of the illness, respondents may not have family or any close friends with whom they have a close relationship. In this study, 20 out of the 25 respondents who named someone who knew them well, named care staff. Even so one can only expect a significant other to comment on objective and not the subjective components of QoL. Objective reports by others cannot substitute an individual's report. Phenomenological approaches, such as the Schedule for the Evaluation of Individual Quality of Life (SEIQoL), require an individual to assess their quality of life according to their terms of reference (O'Boyle, 1994). The SEIQOL approach was developed in response to the criticism of the relevance of an external value system being imposed on respondents by standardised instruments (O'Boyle, 1994). It also acknowledges that QoL is a fluid concept that varies between respondents and for individuals over time or throughout the course of an illness (O'Boyle, 1994).

The SEIQoL approach has been used with a range of populations from healthy young and older adults to people with physical health problems such as orthopaedic patients, gastroenterology outpatients, HIV positive/AIDS patients and with elderly carers for Alzheimer's disease patients. However, this approach has not been used to date with a sample of people diagnosed with schizophrenia. The SEIQoL approach was adapted to make it simpler in this study (with permission) due to the unknown cognitive abilities of the respondents. Respondents were asked to elicit, and rank in order of priority, the five areas of life that contributed to their quality of life. They were not asked to make ratings of each area using a bar chart (importance rating) nor to weight the areas using the disc weighting procedure (O'Boyle *et al.* 1993). However, they were asked to rate their satisfaction with their QoL (from the worst life imaginable to the best life imaginable, through very good, good, all right, bad, very bad) in relation to each of these areas of life using the 'Delighted-Terrible Faces' Scale' (Andrews and Withey, 1976). Finally, they were asked to rate their overall QoL in relation to these five areas of life using the faces' scale.

Out of the 42 respondents, two respondents withdrew their consent for the study and two were able to name five areas of life ("cues") but were unable to prioritise them. The

remaining 38 respondents named at least one important area of life. Thirty-six respondents were able to name their three areas of life and 25 respondents named five areas of life. This data suggests that the people with schizophrenia in this sample could respond to the open approach of quality of life assessment using the adapted SEIQoL questions. Although, occasionally respondents had difficulty in providing sufficient context with the area of life nominated to ensure appropriate coding.

The variation in the respondent-led areas of life nominated illustrated the range of areas of life that were important to respondent's quality of life. The data also highlighted that while some areas of life were the first most important to some individuals, they did not appear in the five most important areas of life for others. It is recognised that no standardised instrument could reflect the range of areas of life and their relative degree of importance appropriate for all respondents at an item specific level. This is the advantage of the respondent-led approach to the measurement of quality of life.

Asking respondents to prioritise the areas of life mentioned using the SEIQoL approach and then rate their satisfaction with each area named, provided the respondents an opportunity to indicate those areas of life that were most important to them and their level of satisfaction/dissatisfaction with each. The prioritisation of areas of life may be used to indicate those areas which should take precedence in rehabilitation programmes. Hickey *et al.* (1996) reported that an area of life that is going badly for an individual but is of less importance has less impact than an area that is going badly but is of greater importance.

In this study, quality of life (QoL) as defined by the respondent-led approach measured more than the health status of this sample with schizophrenia and more than the areas of life affected by their illness. Health was rated as one of the five most important areas of life for some people, but for others it was not mentioned. Respondents named areas of life that were more than health-related issues, even though the study itself was completed by people with mental health problems and much of the data was collected in a medical setting.

Hunt (1997) called for more information in the field of quality of life (QoL) research concerning the best way to elicit people's views, concerns and values concerning their

medical treatment. Barry *et al.* (1993) acknowledged that QoL improvements are dependent on an individual's perspective. Similarly, Hunt (1997) reported that individuals have different coping abilities and will make different adjustments in life according to various health states. The study reported here contributes to this debate. The majority of people with schizophrenia in this study were able to respond to this open method of assessment of QoL.

While a few respondents (n=4) were unable to name and prioritise their areas of life (cues), the majority did not experience difficulty. Thirty-six respondents (88%) named and prioritised at least three areas of life. Future collaborative work on the use of the Schedule of the Evaluation of Individual Quality of Life (SEIQoL) using the importance ratings and the direct weighting procedure with people with schizophrenia should be explored taking into account the cognitive deficits experienced by this patient group.

Standardised instruments such as the Lancashire Quality of Life Profile do not examine the preferences of the respondents, but assume equal weighting amongst items. Häyry (1991) suggests that it is contrary to common sense to suppose that all items in a given scale have equal importance and equally unrealistic to assume that all individuals would have the same preferences and priorities. The needs-approach to QoL has been criticised for deriving single scores from respondents' values and then a single mean score for groups of patients, since it loses any aspect of an individual's preferences and values (Rosenberg, 1995; Hunt, 1997). O'Boyle (1994) suggested that this is the advantage of the weighting procedure of the SEIQoL over standardised instruments.

Even though the Lancashire Quality of Life Profile assumes equal weighting for all items included in the scale, it is a profile measure and, as such, does not collapse the scores to an average rating or summary score. It permits identification of domains of life based on community roles and values where respondents are satisfied or dissatisfied. Currently, the LQoLP has been piloted in the U.K. and U.S.A. and tested on patients of community mental health centres in both the U.K. (n=24) and the U.S.A. (n=68), physically disabled people in the U.K. (n=27), controls from a general health centre in the U.S.A. (n=15) and chronic mental health 'cases' of a social services department in the U.K. (n=390). Further work is being undertaken by its authors to determine the range of questionnaire features and in

producing norms relating to a U.K. population (Oliver *et al.* 1996). In this study, it was tested with 41 people with schizophrenia living in the community approximately five months after discharge from hospital. This study contributes to the body of evidence concerning the administration of the Lancashire Quality of Life Profile with the severely mentally ill.

The LQoLP has both strengths and weaknesses. The authors must be credited on their extensive developmental and testing phases of the instrument. The LQoLP was easily administered with most respondents in this study appearing to enjoy completing the interview. As with all structured instruments, the advantages are in the data produced relating to the main areas of life which may be statistically explored for relationships and compared with other population data. However, from the experience of this study, weaknesses lie in the psychometric properties of the instrument. Overall, the reliability and validity data of the Lancashire Quality of Life Profile were weak for this data set, but mainly acceptable.

The reliability of some of the scale scores caused concern. Perceived quality of life (composed of the domain subscales) had poor reliability. This finding may not be surprising given the variation of the items included throughout the nine life domains (work/education, leisure/participation, religion, finances, living situation, legal/safety, family relations, social relations and health). However, when the domain subscales were considered independently of one another, three of the eight subscales tested (the ninth subscale was work with only one item) had a Cronbach's $\alpha < 0.5$ (leisure/participation, religion and social relations) which questions the reliability of these subscales with this data set. Also, the negative affect subscale of the Affect-Balance Scale had the lowest internal reliability score compared with the other measures of subjective well being (Cronbach's $\alpha < 0.5$). The negative affect subscale also achieved the lowest internal reliability values with Oliver *et al.* (Cronbach's $\alpha = 0.67$) (1996:70). Previously, Lehman (1983) suggested that measures of psychological well-being such as the Self-Esteem Scale (Rosenberg, 1965) and the Affect-Balance Scale (Bradburn, 1969) can present problems in this client group. Items included in the negative affect subscale such as loneliness and boredom have been associated with response inaccuracy (Oliver *et al.* 1996:80). Although, the authors did not detail how this was measured. Also, during pilot work, Oliver *et al.* (1996) found that respondents had difficulty

responding to the Affect-Balance Scale in its original form and re-ordered the items into positive and negative affect response sets to simplify reporting. However, this may have affected the properties of the scale. Data from the literature and the findings reported here from this study, query the reliability of some of the subscales in the Lancashire Quality of Life Profile and suggest that further work is required to develop and re-test the scales.

This study also addressed the content validity of the Lancashire Quality of Life Profile (LQoLP) with a sample of people with a diagnosis of schizophrenia. At a domain specific level, the content validity of the LQoLP was endorsed. However at an item-specific level, 44% of respondent-led areas of life that were reported with the SEIQoL to be important to their quality of life were not included in the scale (e.g. intimate relationships, self-care, contact with mental health services/staff, medication issues, conversation/communication and pets). It is acknowledged that one instrument cannot hope to include all items of importance to all respondents. However, instruments should measure items that are important to people in their everyday lives to enhance both the relevance of health outcome measurement and the response rates.

At an item-specific level, some of the questions included in the Lancashire Quality of Life Profile appeared awkward and the meaning of the data collected was not always clear. Interestingly, the main problems were with the objective indicators as outlined below.

- Domain of work/education

“How satisfied are you with:
your job? (Sheltered employment, occupation or industrial therapy; studies).
the amount of money that you make?
being unemployed or retired?”

The final item of this domain is mutually exclusive to the other two. If the respondent is a student, then only the first item is relevant. This makes analysis difficult for checking the reliability of this subscale with only one item relevant.

- Domain of leisure/participation

The first item asks respondents if they have ‘been out to play or watch a sport’, in the last two weeks. In this study, only five respondents had. Therefore, the relevance of this item must

be questioned. Also, a yes/no answer may have different meanings to different people. One respondent in this study replied 'No' but added that it was because she could not afford to go. So putting this item in context may reveal that it is measuring financial inhibitors rather than leisure/participation.

Leisure items were identified as an important area of life for many respondents during the respondent-led quality of life questions and by putting a free-response item in for a hobby or past-time may be beneficial and improve the content validity of the scale.

- Domain of finances

Respondents are asked for their total weekly income. Interviewers are instructed to enter the figure before deductions or payment of expenses. However, respondents who lived at home or in hostels did not always know the original figure and only knew what they received to spend each week. This compromised the researcher's ability to compare between individuals.

- Domain of family relations

Respondents were given a fixed set of response choices for the frequency of contact that they had with their family: daily, weekly, monthly, annually, less than annually, not appropriate. However, these responses appeared very crude when respondents who saw family every couple of months were forced into the annual category.

- Domain of social relations

Respondents were asked about a close friend, a friend to whom they could turn for help if needed and if they had visited a friend. For some respondents this was the same person and on occasions this was a family member or sometimes a member of the community mental health team. These items did not aim to discriminate between the identity of different friendships and provided little description about the quality and social roles of the friends. It also did not allow respondents to differentiate intimate relationships or relationships between members of the same or different sexes which was of particular importance to some respondents.

More detail on respondents' social networks was explored independently of the LQoLP. Respondents had a mean number of 5.5 total contacts, 4.1 contacts when distant professionals were excluded, 3.5 when regular contacts were counted (seen at least monthly) and 2.9 when regular contacts were counted but people who shared accommodation were excluded. This provided a greater understanding of the social network of respondents, an important aspect of social health, which is an essential component of QoL (Bowling, 1991:8). Equally important are the quality of the contacts and the social roles the contacts have in the community. A greater number of contacts was significantly more likely with a younger age, with less severe illness and with greater improvement in symptoms since taking medication (respondent-defined). Respondents with the greater number of regular contacts were more likely to be dissatisfied with the amount of money they had to spend on enjoyment (Spearman's $\rho=0.452$; $p=0.005$; $n=37$), suggesting that people with friends were more likely to engage in a social life and more integrated into the community.

- Domain of religion

The inclusion of the domain of religion for all respondents must be questioned. In this study, it was only relevant for half the respondents. However, for the remaining half who followed a religion, it must be acknowledged that religion was reported by them to be an important area of their lives. Oliver *et al.* (1996) also found religion to be the most problematic when determining construct validity for the construct 'perceived QoL'. Kemmler *et al.* (1997) excluded the domain of religion from their study. Rather than the 'experts' deciding whether to include religion in population tools, the respondent-led approach to QoL assessment, by definition, has the advantage of avoiding that decision (although the method is generally limited to asking respondents to name only five areas of life) .

- Domain of health

It is recognised that the Lancashire Quality of Life Profile was developed as a measure of health and welfare of mental health clients. However, the health domain lacks depth about respondents' objective and subjective responses to multiprofessional assistance (e.g. community psychiatric nurse, key worker, social worker, occupational therapist) and their subjective experiences of their medication, which are necessary components of community care for most people with severe mental illness.

Further analysis tested the construct validity of perceived quality of life (composed of the nine life-domain sub-scales) against global well-being. Four out of the nine sub-scales had significant Spearman correlations with global well-being. However, the average score for all life domains was not associated with global well-being. This data suggests that perceived quality of life is not measuring the same construct as global well-being. These findings were endorsed by Kemmler *et al.* (1997) who also demonstrated poor evidence of construct validity for perceived quality of life. In conclusion, this evidence questions the existence of the construct 'perceived quality of life' as represented by the life-domains model of the Lancashire Quality of Life Profile.

Some authors have suggested a prescriptive approach to identifying the life domains necessary for inclusion. Instead of asking patients, Franklin *et al.* (1986) suggested including those domains that are most likely to be influenced by the care, treatment or service provided to patients. Perhaps, as Oliver *et al.* (1996:83) suggested "the construction of the 'perfect instrument' is illusory". However, we must be wary of the application of naive quality of life instruments in health care environments where policy makers are keen to use outcome measures for decisions concerning resource allocation. More research is required to contribute to the theory of measurement of quality of life with people with mental health problems, before current instruments are used inappropriately.

In conclusion, this study compared the respondent-led approach to quality of life assessment (adapted questions from the Schedule for the Evaluation of Individual Quality of Life (O'Boyle, 1994), with a disease-specific instrument, the Lancashire Quality of Life Profile (Oliver, 1991). Both approaches have strengths and weaknesses. The respondent-led approach has its strength in its validity by including the values and preferences of the individual, and in its importance rating. However, a maximum of just five areas of life are elicited and difficulties may arise in adopting the measure in longitudinal studies where respondents may nominate different areas of life which can make comparisons difficult. Although, this may be easily overcome at the follow-up interview by asking the respondents about the original five domains nominated at baseline. Alternatively, the Lancashire Quality of Life Profile does not identify the individuals' frames of reference, and these can differ substantially between individuals; and it assumes that all items have equal weighting with

the respondents. However, it does cover the main areas of life and comparisons over time may be more easily analysed. This study contributes to this theoretical debate by comparing the value of using a qualitative respondent-led approach with a structured life-domain instrument.

Quality of life (QoL) derived using the respondent-led approach was compared to QoL as measured by the Lancashire Quality of Life Profile at a global level. 'Life as a whole' rated using the faces' scale with the respondent-led areas of life was compared with the global well-being measure of life satisfaction from the Lancashire Quality of Life Profile. Spearman's correlation was positive and significant in the expected direction (Spearman's $\rho=0.43$; $p\leq 0.01$; $n=39$). Positive and significant correlations were also obtained with the Happiness Scale (Gurin et al. 1960) (Spearman's $\rho=0.41$; $p\leq 0.05$; $n=35$), the Self-Esteem Scale (Rosenberg, 1965) (Spearman's $\rho=0.57$; $p\leq 0.001$; $n=37$) and the Affect-Balance Scale (Bradburn, 1969) (Spearman's $\rho=0.36$; $p\leq 0.05$; $n=39$). These data provide evidence of construct validity of global quality of life as measured by the respondent-led areas of life and the faces' scale.

Compared to the Lancashire Quality of Life Profile, the respondent-led approach to quality of life assessment has the advantages of including individual values and preferences. However, work is needed to gain more data on the reliability and validity of the respondent-led approach to quality of life assessment with people with schizophrenia. Also, research is required to consider how respondents may modify their responses in relation to their mental ill health. Are their aspirations and expectations modified according to environmental influences (e.g. social deprivation) as well as distorted perceptions and impaired insight, which could affect the importance ratings of their preferences and values?

A number of the respondent-led areas of life were also represented by the Lancashire Quality of Life Profile suggesting that at a domain-level the Lancashire Quality of Life Profile had content validity. Oliver *et al.* (1996:80) reported that they were satisfied with the validity properties of the scale. However, more concern should be focused at the item-specific level. For the sample involved in this study, 44% of items important to their quality of life were not included (e.g. girlfriend/boyfriend, pets, playing the piano - for a complete list see Appendix

Twelve). Some of the additional items were nominated by a number of the respondents (e.g. intimate relationships) while other areas of life were unique to a few respondents (e.g. pets). The respondent-led approach offers the advantage of being content-specific to the respondent on each occasion of administration. Measuring the quality of life of respondents in relation to their most important areas of life provides valuable information for the health care professionals about individuals' levels of functioning in those areas.

Due to the methodological difficulties of researching people with schizophrenia where sample attrition can result in small sample sizes, the added advantage of the respondent-led approach is its increased sensitivity (Chambers, 1993). Cross-sectional data for the respondent-led approach varies between individuals but longitudinal data collection and analysis may monitor changes of quality of life over time (Guyatt *et al.* 1987). Some studies have established greater sensitivity in establishing changes over time using open methods compared with standardised tools (Tugwell *et al.* 1990). Future studies may also want to focus on the relationships of quality of life with symptoms of mental illness. Oliver *et al.* (1996:80) showed that specific mental symptomology such as loneliness or boredom can lead to inaccuracy of response. 'Practically, accuracy is dependent upon things such as perception, interpretation and expression, all factors difficult to control for in such situations.'

Ultimately, this study has shown that the potential benefit of using both approaches in tandem is the assurance of reliable and comparable measurement but also with validity and relevance to the individual. However, further work is required to advance the psychometric properties of the Lancashire Quality of Life Profile and to assess whether the SEIQoL disc weighting procedure can be used with people with varying degrees of mental illness.

11.4 How is antipsychotic medication related to the quality of life of people with schizophrenia?

The specific medication-related objectives of this study included investigating respondents' views and experiences about antipsychotic medication in hospital and after discharge in the community; to detect any changes in views between settings; and to observe any associations

between particular views and experiences of medication and medication adherence.

Qualitative accounts by respondents illustrated a mistrust of medication, the hospital and health professionals (both working in the hospital and the community). Some aspects of the mistrust in medication were due to the experience of unexpected unwanted effects. A perceived lack of communication and respect for the patient by the health professionals also seemed to contribute to feelings of mistrust. It would be simpler to suggest that the negative feelings were more likely linked to the paranoid aspects of the illness. However, it may be presumptuous to blindly label all negative comments and behaviour as a manifestation of the mental illness as Rosenhan's assumed behaviour experiments illustrated (Rosenhan, 1973). During the community interview, one respondent recounted her negative experience in hospital.

“They had no respect for patients. What’s happened to the hospitals? They never used to be like that. The other patients, they ask your business. They want to know how much you pay for things. It was terrible. The patients wouldn’t clean the bath. They’d leave their knickers on the floor. It wasn’t nice having to look at them. The males used to be in their own dormitories and women in theirs, now they’ve mixed them all up. It’s disrespectful it is. [Staff member] said I was always moaning. I wasn’t moaning. A white male nurse there, he said I was childish. I wasn’t childish, he was the one who was childish. He used to watch football all day. [Football World Cup 1994 was being televised during her admission].”

(Case 49)

The majority of patients who stop their medication, experience repeated admissions to hospital resulting in a poorer prognosis or are a danger to themselves and others (Turner, 1997). However, being discharged from hospital to live in the community suggests that people are able to be responsible for their own behaviour and subsequently, for the choice of taking their own medication. Depot medication does not necessarily help those individuals who do not want to take their medication because they will not present at clinic for the injection or will not be at home when health professionals visit.

In the recent document, ‘From compliance to concordance’ (Royal Pharmaceutical Society of Great Britain and Merck Sharp and Dohme, 1997) calls were made to move away from the ‘superior’ prescriber (doctor) and passive patient to a more equal therapeutic partnership. This partnership requires negotiation between the prescriber and patient on an equal level including the possible outcome of agreeing to differ on a therapeutic decision. Key features

of the prescriber-patient relationship are respect for the patient's agenda and an open relationship to avoid mistrust, misunderstanding and concealment. While laudable by its intentions, the unique nature of schizophrenia may muddy the strategy. Does mental illness conflict with partnerships of trust between health care professionals and patients? The findings of this study suggest that there are existing needs for information about the illness, its treatment and the associated adverse effects, as well as a need to correct misconceptions and misinformation. Knowledge about the adverse effects of medication can help people to rationalise their experiences and reassure them that their ill health is not worsening. Respondents reported that the fear of side-effects was one reason for wanting to stop their medication. Some health professionals are concerned that too much information about the adverse effects of medication can scare respondents and cause them to stop their medication. However, information is freely available from libraries and one respondent in hospital brought a copy of the Association of the British Pharmaceutical Industry Compendium of Drug Data Sheets to the interview as his reference source for learning about his medication. Information about medication should be made available to those patients who want it and the role of health professionals is to facilitate a patient's understanding of that information.

Respondents also identified a lack of autonomy and involvement in decisions about their medication as a problem for them. Although the literature recognises that individuals are the best judges of the risks and benefits of treatment and that only they can best determine the level of acceptable risk (Fayers, 1992). Refusing antipsychotic drug therapy is acknowledged as a main factor associated with readmission to hospital. Any strategies that may be employed to increase adherence to therapy would subsequently have beneficial effects for the patients and the National Health Service by reducing the number of inpatient admissions and avoiding drug wastage. However, more research is required to determine if the health professionals in mental health care are ready for a more open therapeutic alliance with their patients.

Some participants in this research wanted more information about their illness and their medication. As there are individual prescriptions for individual clients, there should also be individual strategies for providing information, improving adherence and measuring the impact of treatment on quality of life, with the aim of enhancing quality of life.

Oliver *et al.* (1996:143) piloted the Lancashire Quality of Life Profile with a sample of social services department clients (n=422) and analysis considered those who were and were not in receipt of medication. Neither diagnosis, symptoms nor type of medication were detailed. Receipt of medication was not related to any measures of subjective well-being, including mental health. Significant associations existed between receipt of medication and younger age, shorter duration of illness, seeing a doctor and being recently hospitalised for their nerves. However, receipt of medication was self-reported and as such, caution should be applied to the associations found due to the possibility of response bias. Approximately one-quarter of respondents reported not taking any medication.

The data from the study reported here, were explored to generate hypotheses about the relationships between QoL and medication adherence. **Qualitatively**, respondents discussed both the positive and negative effects of medication in terms of managing symptoms and causing unwanted effects that had a negative impact on an individual's quality of life (QoL). It was unclear if the unwanted effects of medication were solely due to the medication or combined with the consequences of the illness. **Quantitative** analyses were less clear about the relationship between medication adherence and QoL.

In this study, regular attenders for medication were significantly ($p \leq 0.05$) less likely to be able to name all their prescribed drugs while they were in hospital and were more likely to be severely ill in hospital. Irregular attenders were significantly ($p \leq 0.05$) more likely to want to stop their medication.

Respondents who had greater levels of medication adherence in general were more likely to score lower on the Affect-Balance scale (worse psychological well-being), to report a lower weekly income and were more likely to be more compromised in their social, occupational and psychological functioning when in hospital as measured by the Global Assessment of Functioning Scale (American Psychiatric Association, 1987). The total variance of general medication adherence explained by a stepwise multiple regression model was 54.7%. The co-variables were severity of illness which explained 23.6%, Affect-Balance explained a further 23% and income explained the remaining 8.1%. Caution must be applied to these result due to the small sample size and the negative skew of the adherence data. However,

hypotheses may be generated about medication non-adherence. From this model, it appears that the respondents (people with schizophrenia living in the community) were more susceptible to medication non-adherence if they were less compromised in psychological, social and occupational functioning when in hospital (less severe illness measured by GAF Scale), if they had better psychological functioning (measured by the Affect-Balance Scale) and if they lived independently (income was higher for those who lived in independent accommodation). The relationship between medication adherence and severity of illness may support the concept of 'intelligent adherence', i.e. people who are more ill are more likely to take their medication. Further work is required to test these hypotheses and model. However, in conclusion, these data do not support a quantitative relationship between medication adherence and QoL.

Respondents who had greater levels of medication adherence on the expected day according to their prescription, had a lower level of educational and technical qualifications, were able to name all their medication in hospital (suggesting an interest or involvement with their medication in hospital), reported no other problems in the community making their illness worse and identified themselves as 'white' rather than 'black'. The total variance of medication adherence on the expected day according to the prescription explained by the model was 53.3%. Ability to name all medication in hospital explained 13.1% of the variance, level of educational and technical qualifications explained a further 18.6%, having a problem in the community making illness worse a further 13.3% (accommodation was the most common problem reported) and ethnic group explained the remaining 9.3%. Again, caution must be applied to these results due to the small sample size and the negative skew of the adherence data. However, hypotheses may be generated to explain medication non-adherence. From this model, it appears that the respondents were more susceptible to medication non-adherence on the expected day according to their prescription, if they were unable to name all their medication in hospital, if they had a higher level of educational and technical qualifications, if they reported having problems in the community that were making their illness worse, and if they identified themselves as 'black'. Further work is required to test this hypothesis. Also, it would be interesting to test if ability to name all medication represents a level active involvement in medication. Further work may explore medication-taking behaviour type, e.g. active participation, passive acceptance (see Section 7.4) in

association with ability to name medication. Warner (1994:170) postulated that outcome of schizophrenia is worse among the better educated because of the greater labour market stresses that affect the educated. Is education a confounder in medication adherence? A study by Tunnicliffe *et al.* (1992) completed a retrospective analysis through nursing records to determine the effects of ethnicity on 'dropping out' from depot medication within one year. They found that respondents of an Afro-Caribbean origin were significantly more likely to drop out than non Afro-Caribbean respondents. However the contribution of ethnicity to non-compliant behaviour was modest compared to the other variables. Overall, the data presented from this study do not support a quantitative relationship between medication adherence and QoL.

Associations between the medication data and the average global well-being item from the LQoLP were tested. Global well-being and medication adherence were not significantly associated. The only significant relationship showed that the mean global well-being was significantly lower for those respondents who reported that their medication or symptoms affected their days in the community (Mann Whitney z statistic=-2.355; p=0.019).

The lack of a **quantitative** relationship between global well-being and medication adherence when the **qualitative** data suggest that medication (or symptoms) affected QoL, may question the sensitivity of the Lancashire Quality of Life Profile. However, limitations were evident with the negative skew of the adherence data and so quantitative analyses could only be exploratory. Also, QoL factors were related to the subjective experiences of medication and did not necessarily translate to adherent or non-adherent behaviour. Further work could focus on the subjective evaluation of medication and its relationship with QoL.

As discussed in Chapter 2, few quality of life (QoL) measures for people with schizophrenia have incorporated ratings of subjective response to medication and its unwanted effects. The impact of medication on respondents' QoL is often seen of marginal significance when compared with the remittance of positive symptoms. However, the qualitative results presented in this thesis, suggest that more attention should be paid to the unwanted effects of medication in future studies of quality of life in schizophrenia, and the development of instruments for quality of life assessment. Adopting respondent-led approaches allows

respondents to include the items such as unwanted effects of medication and make them a significant component should they wish. In chronic long term illnesses such as schizophrenia, medication plays an important part in the management and rehabilitation of patients. Therefore, measuring the value of that medication in terms of its effectiveness, adverse effects (and their consequences), subjective experiences and quality of life also appears to be a crucial aspect of community care. It is not suggested that QoL assessment takes the place of the assessment of symptom response when evaluating antipsychotic drug therapy but that QoL assessment is an additional measure. As this study has shown, medication adherence is about more than symptom response. The patient perspective cannot be ignored in a society where people can express their own medication-taking behaviour. If the U.K. Government introduces compulsory community treatment orders where some individuals do not have a free choice in taking their medication, then ethical decisions must be made on the evidence concerning the positive and negative impact of medication on symptoms and QoL.

In order to gain knowledge of the impact of medication on QoL, this study has shown that qualitatively, respondents describe both the positive and negative impacts of taking medication. However, quantitatively, measures of subjective well-being (e.g. perceived quality of life based on the nine life domains of work/education, leisure/participation, religion, finances, living situation, legal/safety, family relations, social relations and health, global well-being, Cantril's Ladder) did not predict medication adherence rate. Although psychological well-being (e.g. Affect-Balance Scale) part-predicted medication adherence. This research does not prove that there is no relationship between medication and QoL but may suggest that current tools are not sensitive enough to demonstrate an effect. Longitudinal studies are required that measure QoL with individuals demonstrating a range of medication-taking behaviour. However, before these studies may take place, more work is required in developing sensitive instruments. The community care of people with schizophrenia, in most of cases, will involve antipsychotic drug therapy. Yet few measures overtly measure objective and subjective data on the consequences of taking such medication. It is proposed that items should be included in scales to represent the subjective experience of medication and its effects. This is more than measuring the presence of medication adverse effects and measuring symptom response. Measurement should focus on the

consequences of adverse effects and the consequences of residual symptoms. In support of these findings and recommendations, Diamond (1985) published case studies of patients with schizophrenia illustrating how individual patient's priorities and preferences affected their attitudes to medication, their tolerance of adverse effects and their acceptance or rejection of treatment.

One aim of quality of life (QoL) assessment in the mentally ill is to provide evidence to determine the contribution of therapeutic interventions and programmes of care to life satisfaction, or overall happiness (Baker and Intagliata, 1982). As quality of life is only one aspect of health outcome assessment it is often suggested that symptom scales and other objective data can be collected at the same time. However, symptom and side-effect rating scales are measures of prevalence of the symptoms themselves and not a measure of the **impact** of symptoms, or unwanted medication effects, on functioning or QoL. Eight QoL instruments were reviewed in this thesis for the measurement of QoL for people with schizophrenia living in the community, and only one instrument attempts to measure the impact of, and patient's satisfaction with medication (Quality of Life Interview for Mental Health - Becker *et al.* 1993). However, all who work in the field recognise the importance of medication in controlling symptoms for people with schizophrenia. Only now with the advent of the new atypical medication (e.g. clozapine) has QoL measurement begun to be actively measured in clinical trials (Meltzer *et al.* 1990; Meltzer *et al.* 1993).

A recommendation from the study reported here is the development of a domain measure of medication that may be added to the Lancashire Quality of Life Profile within perceived quality of life. Objective indicators could ask about the type, number and regimen of medication and its effectiveness in symptom management. Subjective components could focus on satisfaction with medication in terms of subjective well-being (e.g. the ability to complete activities of importance to the individuals) and the satisfaction of respondents with the amount of involvement that they have in managing their medication (autonomy). Further work is required to determine appropriate items for scale measurement. From the qualitative aspects of the study reported here, there is no doubt that medication is an important area of life for some respondents. The opportunity to have an additional scale to supplement the Lancashire Quality of Life Profile may be an attractive future development. Often the

outcome of treatment in terms of symptoms alleviation and assessment of adverse effects is clinician-led. However, there have been successful attempts in including patients in these assessments (e.g. the Liverpool University Side-Effect Rating Scale by Day *et al.* 1995). It is often assumed that patients' reports on the wider impacts of treatment on well-being should be dismissed due to assumptions about poor reliability and validity of patient report (Hunt and McKenna, 1993; Awad *et al.* 1997b). Attempts were made in this study to guard against any distorted reporting by using reports from significant others and medical notes to corroborate objective information and the use of open questions which were office coded. However, lack of concordance between these sources cannot be assumed to be the responsibility of the patient. Published studies provide evidence that people with psychoses can reliably and consistently report information about their satisfaction and feelings (Davidhizar, 1985; Brewin, 1992; Hogan and Awad, 1992). Lehman (1988) illustrated that while life satisfaction was negatively correlated with symptoms of anxiety and depression, it was not associated with thought disorder.

This study was cross-sectional and highlighted qualitative data about the effects of antipsychotic medication and quality of life. For future studies, causality of any relationships should be explored and a controlled study design should be applied. Therefore, this study provides information for the development of hypotheses about medication-taking behaviour; quality of life measurement and the relationship between the two for a sample of people with schizophrenia. Some analyses explored relationships with small subsets of the sample and therefore, analyses need to be replicated on larger samples to increase the confidence in the results. It would be of further interest to know if the quality of life satisfaction ratings are stable over time with variation in rates of medication adherence; a longitudinal study would be important to realise any changes and the direction of these changes. However, Oliver *et al.* (1997) warned that adopting the Lancashire Quality of Life Profile to show change over time requires a potent intervention if only small sample sizes are available. For less effective interventions, immense sample sizes may be required to produce statistically significant changes.

11.5 Implications for the community care of people with schizophrenia

During the exploration of the data, relationships between formal/informal admissions and medication or quality of life (QoL) variables were discovered. Coid (1993) identified the lack of QoL research that included people who had experienced a compulsory detainment in hospital, with the assumption that such people would have negative attitudes that would affect their subjective perceptions of QoL. Paradoxically, one of the ethical committees involved in this study wanted to exclude detained patients from recruitment (see Section 5.2). However, as discussed earlier, the current U.K. government is reviewing the possibility of introducing compulsory treatment orders for the care of people with severe mental illness. Therefore, it is of particular importance to explore relationships between quality of life and voluntary/involuntary care.

Further analyses identified relationships between compulsory detainment while in-patients and medication or QoL variables from the community interview. Respondents who had experienced a compulsory detainment in hospital were significantly more likely to ($p \leq 0.05$):

- be taking a lower number of drugs (both in hospital and the community)
- report medication as having more negative effects on well-being (in hospital)
- report positive overall QoL using the faces' scale in the respondent-led items (community)
- have monthly or less contact with relatives (Lancashire Quality of Life Profile (LQoLP)) (community)
- be older on first admission to a psychiatric hospital/ward (LQoLP) (community)
- be more satisfied with the domain of work (unemployment status) (LQoLP) (community)
- be more satisfied with the domain of social relations (LQoLP) (community)
- be more satisfied with the domain of health (LQoLP) (community)
- score lower on negative affect (less depressed) (LQoLP) (community)
- have higher positive self-esteem, lower negative self-esteem and higher self-esteem total (LQoLP) (community)

and significantly less likely to:

- report that their medication or symptoms affected their days in the community

These relationships drive the hypothesis that those people who were compulsorily detained in hospital were more likely to be more satisfied with their QoL in the community, both respondent-defined and in the areas of unemployment status, social relations, health and psychological well-being. In hospital, they were prescribed fewer medication than those admitted voluntary and were more likely to report negative effects on their well-being.

In the community also, they were prescribed fewer medication. However, they were less likely to report that their medication or symptoms affect their days in the community. They had less contact with relatives and were significantly older on their first admission (may be due to a reluctance to engage with health and social services). However, the data do not inform why this subgroup of the sample report higher satisfaction with aspects of QoL in the community compared with those respondents who had experienced a voluntary admission to hospital. It may be because simply they are no longer compulsory detained in the hospital, therefore a predictive factor (i.e. lack of autonomy) of poor QoL has been removed, or it may be because their symptoms have been treated effectively (which would be positive support for community treatment orders). However, there was no relationship between informal/formal status and functioning according to the Global Assessment of Functioning (GAF) Scale (American Psychiatric Association, 1987).

Further work on larger samples is required to corroborate the relationship between QoL variables and compulsory detainment in hospitals that may help to inform the introduction of community treatment orders. Analysis with symptom rating scales may help to establish whether the relationship was due to improved symptomology.

In recent conference proceedings, Bindman *et al.* (1998) highlighted the concept of 'perceived coercion'. Their research showed that coercion was perceived by patients who experienced an involuntary admission to hospital, and also by others who reported a lack of control and involvement during their admission to hospital, even though they were admitted voluntary. The results reported in this thesis also may be interpreted in relation to 'perceived coercion'. From the analysis of the qualitative data concerning medication, both in the hospital and in the community, a range of medication taking-behaviours were identified: passive acceptance, active participation, ignored participation, reluctant participation and

conditional acceptance. These behaviour-types were not independent of each other, with some individuals moving between behaviour types within the same interview. Subsequent to identification, the behaviour types were compared with the literature which showed similar classification systems, providing evidence of validity (Szasz and Hollender, 1956; Diamond, 1985). Some of these behaviour types such as ignored participation and reluctant acceptance, suggested a degree of 'perceived coercion' by the respondents. Future work could explore the concept of perceived coercion and its association with medication-taking behaviour and quality of life. Data such as this would be of paramount importance in informing future community care policies such as compulsory treatment orders. Even if treatment orders are justified in their use for the care of the patient and those around them, methods of administration may be optimised so that individuals can feel involved in the process and feel less coerced.

The Schedule for the Evaluation of Individual Quality of Life represents a human 'wants-approach' to quality of life measurement which focuses on the aspects of life that are important to an individual. While an individual approach does not suit comparisons between individuals, groups or societies, it does permit a valid assessment that may allow a measure of improvement for the individual (Cribb, 1985) and overall scores (on the full SEIQoL) can be used as outcome indicators in clinical trials. In today's health policy for the mentally ill living in the community, care packages are formulated on an individual basis and people are measured against themselves for improvement. In this environment, an individual approach to quality of life measurement may be the best strategy. Alternatively, the Lancashire Quality of Life Profile (Oliver, 1991) is a population tool that may permit comparisons between different groups and different care approaches. Combining the use of both tools, while time consuming, may provide health care practitioners with the best information for decision-making on an individual and population basis. It also addresses Hunt's (1997) criticism of using tools that may discriminate against an individual should their preferences be excluded from population measures that are used in the process of resource allocation.

REFERENCES

References

- American Psychiatric Association. (1987) *Diagnostic and Statistical Manual for Mental Disorders (3rd edn, revised) (DSM-III-R)*. Washington, DC:APA.
- Andrews, F.M. and Crandall, R. (1976) The validity of measures of self-reported well-being. *Social Indicators Research* **3**, 1-19.
- Andrews, F.M. and Robinson, J.P. (1991) Measures of subjective well-being. In: Robinson, J.P., Shaver, P.R. and Wrightsman, L.S. (Eds.) *Measures of Personality and Social Psychological Attitudes*, pp. 61-114. London: Academic Press Limited.
- Andrews, F.M. and Withey, S.B. (1976) *Social Indicators of Well-Being. Americans' Perceptions of Life Quality*, Ann Arbor, Michigan: Plenum Press.
- Appelbaum, P.S. and Gutheil, T.G. (1980a) Drug refusal: a study of psychiatric inpatients. *American Journal of Psychiatry* **137(3)**, 340-346.
- Appelbaum, P.S. and Gutheil, T.G. (1980b) The Boston state hospital case: "Involuntary mind control," the constitution and the "right to rot". *American Journal of Psychiatry* **137(6)**, 720-723.
- Awad, A.G. (1989) Drug therapy in schizophrenia - variability of outcome and prediction of response. *Canadian Journal of Psychiatry* **34(7)**, 711-720.
- Awad, A.G. (1992) Quality of life of schizophrenic patients on medications and implications for new drug trials. *Hospital and Community Psychiatry* **43 (3)**, 262-265.
- Awad, A.G. and Hogan, T.P. (1994) Subjective response to neuroleptics and the quality of life: implications for treatment outcome. *Acta Psychiatrica Scandinavica* **89(Suppl. 380)**, 27-32.
- Awad, A.G., Voruganti, L.N.P. and Heslegrave, R.J. (1997a) Measuring quality of life in patients with schizophrenia. *Pharmacoeconomics* **1**, 32-47.
- Awad, A.G., Voruganti, L.N.P. and Heslegrave, R.J. (1997b) A conceptual model of quality of life in schizophrenia: description and preliminary clinical validation. *Quality of Life Research* **6**, 21-26.
- Babiker, I.E. (1986) Noncompliance in schizophrenia. *Psychiatric Developments* **4**, 329-337.

- Babiker, I.E. and Thorne, P. (1993) Do psychiatric patients know what is good for them? *Journal of the Royal Society of Medicine* **86**, 28-30.
- Baker, F. and Intagliata, J. (1982) Quality of life in the evaluation of community support systems. *Evaluation Programme and Planning* **5**, 69-79.
- Barham, P. and Hayward, R. (1991) *From the mental patient to the person*, New York: Routledge.
- Barnes, T.R.E. (1991) Depot antipsychotic drugs and prevention of psychotic relapse. *Clinical Neuropharmacology* **14**(Suppl.2), S1-S6.
- Barnes, T.R.E. (1992) Clinical assessment of the extrapyramidal side effects of antipsychotic drugs. *Journal of Psychopharmacology* **6**(2), 214-221.
- Barry, M.M., Crosby, C. and Bogg, J. (1993) Methodological issues in evaluating the quality of life of long-stay psychiatric patients. *Journal of Mental Health* **2**, 43-56.
- Bartkó, G., Herczeg, I. and Zador, G. (1988) Clinical symptomology and drug compliance in schizophrenic patients. *Acta Psychiatrica Scandinavica* **77**, 74-76.
- Bebbington, P. and Kuipers, L. (1994) The clinical utility of expressed emotion in schizophrenia. *Acta Psychiatrica Scandinavica* **89**, 46-53.
- Becker, M., Diamond, R. and Sainfort, F. (1993) A new patient focused index for measuring quality of life in persons with severe and persistent mental illness. *Quality of Life Research* **2**, 239-251.
- Bentham, J. (1834/1983). *Deontology*, Oxford: Clarendon Press.
- Bhugra, D., Hilwig, M., Hossein, B., Marceau, H., Neehall, J., Leff, J., Mallett, R. and Der, G. (1996) First-contact incidence rates of schizophrenia in Trinidad and one-year follow-up. *British Journal of Psychiatry* **169**, 587-592.
- Bigelow, D.A., Brodsky, G., Stewart, L. and Olson, M. (1982) The concept and measurement of quality of life as a dependent variable in evaluation of mental health services. In: Tash, W. and Stahler, G. (Eds.) *Innovative approaches to mental health evaluation*, pp. 345-366. New York: Academic Press.
- Bigelow, D.A., Gareau, M.J. and Young, D.J. (1990) A quality of life interview.

Psychosocial Rehabilitation Journal **14**, 94-98.

Bigelow, D.A., McFarland, B.H. and Olson, M. (1991) Quality of life of community mental health programme clients: validating a measure. *Community Mental Health Journal* **27**, 43-55.

Bigelow, D.A. and Young, D.J. (1991) Effectiveness of a case management program. *Community Mental Health Journal* **27(2)**, 115-123.

Bindman, J., Reid, Y., Thornicroft, G., Szmukler, G. and Tiller, J. (1998) Patients' experiences of coercion during hospital admission. *Proceedings of the Association of European Psychiatrists, Section Committee, Psychiatric Epidemiology and Social Psychiatry* 16-18 April, 11. (Abstract).

Blascovich, J. and Tomaka, J. (1991) Measures of self-esteem. In: Robinson, J.P., Shaver, P.R. and Wrightsman, L.S. (Eds.) *Measures of Personality and Social Psychological Attitudes*, pp. 115-160. London: Academic Press Limited.

Bleuler, E. (1913) *Dementia praecox or the group of schizophrenias*, New York: Translated into English, 1950. International Universities Press.

Bluglass, R. (1984) *A guide to the Mental Health Act 1983*. London: Churchill Livingstone.

Boczkowski, J.A., Zeichner, A. and DeSanto, N. (1985) Neuroleptic compliance among chronic schizophrenic outpatients: an intervention outcome report. *Journal of Clinical Psychology* **53**, 666-671.

Bowling, A. (1991) *Measuring health: a review of quality of life measurement*, Buckingham: Open University Press.

Bowling, A. (1995) *Measuring disease: a review of disease-specific quality of life measurement scales*, Buckingham: Open University Press.

Bowling, A. (1996) The effects of illness on quality of life: findings from a survey of households in Great Britain. *Journal of Epidemiology and Community Health* **50**, 149-155.

Bradburn, N.M. (1969) *The Structure of Psychological Well-Being*, Chicago: Aldine Publishing Company.

Brewin, C.R. (1992) Believing what patients tell us. *Journal of Mental Health* **1**, 83-84.

- British Medical Association and Royal Pharmaceutical Society of Great Britain (1997) Drugs used in psychoses and related disorders. In: *British National Formulary*, 34th edn. pp. 161-171. London: BMA.
- Brown, G.W. (1959) Experiences of discharged chronic schizophrenic mental hospital patients in various types of living group. *Millbank Memorial Fund Quarterly* **37**, 105-131.
- Brown, G.W., Carstairs, G.M. and Topping, G.C. (1958) The post hospital adjustment of chronic mental patients. *The Lancet* **ii**, 685-689.
- Browne, J.P., O'Boyle, C.A., McGee, H.M., McDonald, N.J. and Joyce, C.R.B. (1997) Development of a direct weighting procedure for quality of life domains. *Quality of Life Research* **6**, 301-309.
- Bryman, A. and Cramer, D. (1997) *Quantitative data analysis with SPSS for windows. A guide for social scientists*, London, New York: Routledge.
- Buchanan, A. (1992) A two-year prospective study of treatment compliance in patients with schizophrenia. *Psychological Medicine* **22**, 787-797.
- Bullinger, M. (1995) German translation and psychometric testing of the SF-36 health survey: preliminary results from the IQOLA project. *Social Science and Medicine* **41**(10), 1359-1366.
- Bulpitt, C.J. (1992) Untitled contribution to the discussion on Cox D. et al. Quality-of-life assessment: can we keep it simple? *Journal of the Royal Statistical Society* **155**, 378.
- Burnett, P.L., Galletly, C.A., Moyle, R.J. and Clark, C.R. (1993) Low-dose depot medication in schizophrenia. *Schizophrenia Bulletin* **19**(1), 155-164.
- Burnett, S. (1994) A new lease on life. *Nursing Times* **90**(31), 57-59.
- Cairns, J. (1996) Measuring health outcomes. Condition specific and patient specific measures are of limited use when allocating resources. *British Medical Journal* **313**, 6.
- Caldicott, F. (1994) Progress in psychiatry. *Medical Education* **28**(Suppl.2), 39-41.
- Calman, K.C. (1984) Quality of life in cancer patients - an hypothesis. *Journal of Medical Ethics* **10** 124-127.

- Campbell, A., Converse, P.E. and Rodgers, W.L. (1976) *The Quality of American Life: Perceptions, Evaluations and Satisfaction*, New York: Russell Sage Foundation.
- Cantril, H. (1965) *The pattern of human concerns*, New Brunswick, New Jersey: Rutgers University Press.
- Central Statistical Office. (1995) *Social Trends 25*. London: HMSO.
- Chambers, L.W. (1993) The McMaster Health Index Questionnaire: an update. In: Walker, S.R. and Rosser, R. (Eds.) *Quality of life assessment: key issues in the 1990s*, pp. 131-149. London: Kluwer Academic Publishers.
- Cherlin, A. and Reeder, L.G. (1975) The dimensions of psychological well-being: a critical view. *Sociological Methods and Research* **4**, 189-214.
- Clark, P. and Bowling, A. (1989) Observational study of quality of life in NHS nursing homes and a long-stay ward for the elderly. *Ageing and Society* **9**, 123-148.
- Clinical Standards Advisory Group (1995) *Schizophrenia. Vols. 1 and 2*, London: HMSO.
- Clozapine Study Group (1993) The safety and efficacy of clozapine in severe treatment-resistant schizophrenic patients in the UK. *British Journal of Psychiatry* **163**, 150-154.
- Cohen, C.I. and Sokolovsky, J. (1978) Schizophrenia and social networks: ex-patients in the inner city. *Schizophrenia Bulletin* **4**, 546-560.
- Cohen, J. (1968) Weighted kappa: Nominal scale agreement with provision for scaled disagreement or partial credit. *Psychological Bulletin* **70**, 213-220.
- Cohen, N.L. (1993) Stigmatization and the "noncompliant" recidivist. *Hospital and Community Psychiatry* **44**(11), 1029.
- Coid, J. (1993) Quality of life for patients detained in hospital. *British Journal of Psychiatry* **162**, 611-620.
- Collins, E.J., Hogan, T.P. and Desai, H. (1991) Measurement of therapeutic response in schizophrenia. A critical survey. *Schizophrenia Research* **5**, 249-253.
- Cooper, J.E. (1991) Schizophrenia and allied conditions. *Medicine International* **94**,

3917-3922.

Cowen, P.J. (1991) Drug treatment in psychiatry. *Medicine International* **94**, 3932-3936.

Cresswell, C.M., Kuipers, L. and Power, M.J. (1992) Social networks and support in long-term psychiatric patients. *Psychological Medicine* **22**, 1019-1026.

Cribb, A. (1985) Quality of life-a response to K C Calman. *Journal of Medical Ethics* **11**, 142-145.

Cronbach, L.J. (1951) Coefficient alpha and the internal structure of tests. *Psychometrika* **22**, 293-296.

Croog, S.H., Levine, S., Testa, M.A., Brown, B., Bulpitt, C.J. (1986) The effects of antihypertensive therapy on the quality of life. *New England Journal of Medicine* **314**: 1657-1664.

David, A.S. (1990) Insight and psychosis. *British Journal of Psychiatry* **156**, 798-808.

David, A.S. (1992) Illness and insight. *British Journal of Hospital Medicine* **48(10)**, 652-654.

Davidhizar, E.R. (1985) Can clients with schizophrenia describe feelings and beliefs about taking medications? *Journal of Advanced Nursing* **10**, 469-473.

Davies, L.M. and Drummond, M.E. (1994) Economics and schizophrenia: the real cost. *British Journal of Psychiatry* **165(Suppl.25)**, 18-21.

Davies, S., Thornicroft, G., Leese, M., Higgibotham, A. and Phelan, M. (1996) Ethnic differences in risk of compulsory admission among representative cases of psychosis in London. *British Medical Journal* **312**, 533-537.

Davies, T. (1997) ABC of mental health: Mental health assessment. *British Medical Journal* **314**, 1536-1539.

Davis, J.M. (1975) Overview: Maintenance therapy in psychiatry: I. Schizophrenia. *American Journal of Psychiatry* **132(12)**, 1237-1245.

Davis, J.M. (1976) Recent developments in the drug treatment of schizophrenia. *American Journal of Psychiatry* **133**, 208-214.

- Davis, J.M., Schaffer, C.B., Killian, G.A., Kinard, C. and Chan, C. (1980) Important issues in the drug treatment of schizophrenia. *Schizophrenia Bulletin* **6**(1), 70-87.
- Dawson, H. (1972) Reasons for compulsory admission. In: Wing, J.K. and Hailey, A.M. (Eds.) *Evaluating a community psychiatric service. The Camberwell Register 1964-71*, pp. 221-229. London: Oxford University Press.
- Day, J.C., Wood, G., Dewey, M., Bentall, R.P. (1995) A self-rating scale for measuring neuroleptic side-effects. Validation in a group of schizophrenic patients. *British Journal of Psychiatry* **166**, 650-653.
- Dencker, S.J. (1992) The value of quality of life rating in psychiatry. *Nordisk Journal of Psychiatry* **46**, 91-93.
- Department of Health (1989) *Caring for People. Community care in the next decade and beyond*. London: HMSO.
- Department of Health (1990) *The Care Programme Approach for People with a Mental Illness referred to Specialist Psychiatric services*. Joint Health/Social Services Circular HC(90)23/LASSL(90)11. London: HMSO.
- Department of Health (1992) *The Health of the Nation. A strategy for health in England*. London: HMSO.
- Department of Health (1994) *Introduction of supervision registers for mentally ill people from 1 April 1994*. HSG(94)5, London: HMSO.
- Diamond, R.J. (1983) Enhancing medication use in schizophrenic patients. *Journal of Clinical Psychiatry* **44**, 7-14.
- Diamond, R. (1985) Drugs and the quality of life: the patient's point of view. *Journal of Clinical Psychiatry* **46**, 29-35.
- Dworkin, R.J. (1992) *Researching persons with mental illness*, Newbury Park, CA: Sage Publications Inc.
- Endicott, J., Nee, J., Harrison, W. and Blumenthal, R. (1993) Quality of life enjoyment and satisfaction questionnaire: a new measure. *Psychopharmacology Bulletin* **29**(2), 321-326.
- Endicott, J., Spitzer, R.L., Fleiss, J.L. and Cohen, J. (1976) The Global Assessment Scale.

- A procedure for measuring overall severity of psychiatric disturbance. *Archives of General Psychiatry* **33**, 766-771.
- Fabrega, H. (1990) Psychiatric stigma in the classical and medieval period: a review of the literature. *Comprehensive Psychiatry* **31**(4), 289-306.
- Falloon, I., Watt, D.C. and Shepherd, M. (1978) A comparative controlled trial of pimozide and fluphenazine decanoate in the continuation therapy of schizophrenia. *Psychological Medicine* **8**, 59-70.
- Farquhar, M. (1995) Elderly people's definitions of quality of life. *Social Science and Medicine* **41**(10), 1439-1446.
- Fayers, P. (1992) Untitled contribution to the discussion on Cox D. et al. Quality-of-life assessment: can we keep it simple? *Journal of the Royal Statistical Society* **155**, 382.
- Fenton, W.S. and McGlashan, T.H. (1991) Natural history of schizophrenia subtypes, II: positive and negative symptoms and long-term course. *Archives of General Psychiatry* **48**, 978-986.
- Finn, S.E., Bailey, J.M., Schultz, R.T. and Faber, R. (1990) Subjective utility ratings of neuroleptics in treating schizophrenia. *Psychological Medicine* **20**, 843-848.
- Fitzpatrick, R., Fletcher, A., Gore, S., Jones, D., Spiegelhalter, D. and Cox, D. (1992) Quality of life measures in health care. I: Applications and issues in assessment. *British Medical Journal* **305**, 1074-1077.
- Flannagan, J.C. (1978) A research approach to improving our quality of life. *American Psychologist* **33**, 138-147.
- Fleischhacker, W.W., Meise, U., Gunther, V. and Kurz, M. (1994a) Compliance with antipsychotic drug treatment: influence of side effects. *Acta Psychiatrica Scandinavica* **89**, 11-15.
- Fleischhacker, W.W. and Whitworth, A.B. (1994b) Adverse effects of antipsychotic drugs. *Current Opinion in Psychiatry* **7**, 71-75.
- Fletcher, A., Gore, S., Jones, D., Fitzpatrick, R., Spiegelhalter, D. and Cox, D. (1992) Quality of life measures in health care. II: Design, analysis and interpretation. *British Medical Journal* **305**, 1145-1148.

- Franklin, J.F., Simmons, J., Solovitz, B., Clemons, J.R. and Miller, G.E. (1986) Assessing quality of life of the mentally ill. A three-dimensional model. *Evaluation and the Health Professions* **9** (3), 376-388.
- Freeman, C. and Tyrer, P. (Eds.) (1992) *Research methods in psychiatry. A beginner's guide* (2nd edn). London: Gaskell.
- Freeman, H.L. and Alpert, M. (1986) Prevalence of schizophrenia in an urban population. *British Journal of Psychiatry* **149**, 603-611.
- Gerlach, J. (1994) Oral versus depot administration of neuroleptics in relapse prevention. *Acta Psychiatrica Scandinavica* **89**, 28-32.
- Gerlach, J. and Casey, D.E. (1994) Drug treatment of schizophrenia: myths and realities. *Current Opinion in Psychiatry* **7**, 65-70.
- Gill, T.M. and Feinstein, A.R. (1994) A critical appraisal of the quality of quality-of-life measurements. *Journal of the American Medical Association* **272** (8), 619-626.
- Goffman, E. (1963) *Stigma. Notes on the management of spoiled identity*, Englewood Cliffs, New Jersey: Prentice-Hall Inc.
- Goldberg, T.E., Greenberg, R.D., Griffin, S.J., Gold, J.M., Kleinman, J.E., Pickar, D., Schulz, S.C. and Weinberger, D.R. (1993) The effect of clozapine on cognition and psychiatric symptoms in patients with schizophrenia. *British Journal of Psychiatry* **162**, 43-48.
- Goldie, N. (1988) "I hated it there but I miss the people": a study of what happened to a group of ex-long stay patients from Claybury Hospital. [Research Paper 1]. Health & Social Services Research Unit, Department of Social Services, South Bank Polytechnic London.
- Goldstein, M.J. and Kern, S.R. (1994) Psychological factors in schizophrenia. *Current Opinion in Psychiatry* **7**, 61-64.
- Goodare, H.M. (1992) Untitled contribution to the discussion on Cox, D. et al. Quality-of-life assessment: can we keep it simple? *Journal of the Royal Statistical Society* **155**, 378.
- Gurin, G., Veroff, J. and Feld, S. (1960) *Americans view their mental health*, New York: Basic Books.

- Guyatt, G., Walter, S. and Norman, G. (1987) Measuring change over time: assessing the usefulness of evaluative instruments. *Journal of Chronic Disease* **40** 171-178.
- Hale, A. (1993) Will the new antipsychotics improve the treatment of schizophrenia? Depot preparations still hold the key to compliance. *British Medical Journal* **307**, 749-750.
- Harrison, G., Owens, D., Holton, A. Neilson, D. and Boot, D. (1988) A prospective study of severe mental disorder in Afro-Caribbean patients. *Psychological Medicine* **18**, 643-657.
- Häyry, M. (1991) Measuring the quality of life: why, how and what? *Theoretical Medicine* **12**, 97-116.
- Hays, R.D., Vickery, B.G. and Engel, J. (1993) Postscript. Epilepsy Surgery Outcome Assessment. In: Engel, J. (Ed.) *Surgical treatment of the Epilepsies*, 2nd edn. pp. 685-688. New York: Raven Press.
- Heinrichs, D.W., Cohen, B.P. and Carpenter, W.T. (1985) Early insight and the management of schizophrenic decompensation. *The Journal of Nervous and Mental Disease* **173**(3), 133-138.
- Heinrichs, D.W., Hanion, T.E. and Carpenter, W.T. (1984) The quality of life scale: an instrument for rating the schizophrenic deficit syndrome. *Schizophrenia Bulletin* **10**, 388-398.
- Hickey, A.M., Bury, G., O'Boyle, C.A., Bradley, F., O'Kelly, F.D. and Shannon, W. (1996) A new short form individual quality of life measure (SEIQoL-DW): application in a cohort of individuals with HIV/AIDS. *British Medical Journal* **313**, 29-33.
- Hirsch, S. (1991) Maintenance medication for schizophrenia: changing perspectives on use and evaluation. In: Bebbington, P.E. (Ed.) *Social Psychiatry. Theory, Methodology and Practice*, pp. 389-399. New Brunswick: Transaction Publishers.
- Hirsch, S. (1993) Pharmacological and psychosocial long-term treatment of schizophrenia. In: Brunello, N., Mendlewicz, J. and Racagni, G. (Eds.) *New generation of antipsychotic drugs: novel mechanisms of action. Volume 4*, pp. 77-90. Karger: International Academic Biomedical Drug Research Basel.
- Hirsch, S.R., Gajnd, R., Rohde, P.D., Stevens, B.C. and Wing, J.K. (1973) Outpatient maintenance of chronic schizophrenic patients with long-acting fluphenazine: double-blind placebo trial. *British Medical Journal* **1**, 633-637.

- Hogan, T.P. and Awad, A.G. (1992) Subjective response to neuroleptics and outcome in schizophrenia: a re-examination comparing two measures. *Psychological Medicine* **22**, 347-352.
- Hogan, T.P., Awad, A.G. and Eastwood, M.R. (1983) A self-report scale predictive of drug compliance in schizophrenics: reliability and discriminative ability. *Psychological Medicine* **13**, 177-183.
- Hogan, T.P., Awad, A.G. and Eastwood, M.R. (1985) Early subjective response and prediction of outcome to neuroleptic drug therapy in schizophrenia. *Canadian Journal of Psychiatry* **30**(4), 246-248.
- Hogarty, E., Goldberg, S.C., Schooler, N.R. (1974) Drug and sociotherapy in the after care of schizophrenic patients: II. Two-year relapse rates. *Archives of General Psychiatry* **34**, 603-608.
- Hogarty, G. (1984) Depot neuroleptics: the relevance of psychosocial factors-a United States perspective. *Journal of Clinical Psychiatry* **45**(5,Sec.2), 36-42.
- Hogarty, G.E., Schooler, N.R., Ulrich, R., Mussare, F., Ferro, P. and Herron, E. (1979) Fluphenazine and social therapy in the aftercare of schizophrenic patients. Relapse analyses of a two-year controlled study of fluphenazine decanoate and fluphenazine hydrochloride. *Archives of General Psychiatry* **36**, 1283-1294.
- House of Commons (1990) National Health Service and Community Care Act. London: HMSO.
- Hunt, S.M. (1997) The problem of quality of life. *Quality of Life Research* **6**, 205-212.
- Hunt, S.M. and McKenna, S.P. (1993) Measuring quality of life in psychiatry. In: Walker SR and Rosser RM, (Eds.) *Quality of life Assessment. Key issues in the 1990s*, Dordrecht, London, Boston: Kluwer Academic Press.
- Huxley, P. and Warner, R. (1992) Case management, quality of life and satisfaction with services of long-term psychiatric patients. *Hospital and Community Psychiatry* **43** (8), 799-802.
- Hyland, M.E. (1992) Selection of items and avoidance of bias in quality of life scales. *Pharmacoeconomics* **1**(3), 182-190.

- Hyman, M.D. (1971) The stigma of stroke. *Geriatrics* **May**, 132-141.
- Jablensky, A., Sartorius, N., Ernberg, G., Anker, M., Korten, A., Cooper, J.E., Day, R. and Bertelsen, A. (1992) Schizophrenia: Manifestations, incidence and course in different cultures. A World Health Organisation ten country study. *Psychological Medicine* (**Suppl. 20**), 1-97.
- Jachuk, S.J., Brierley, H., Jachuk, S. and Willcox, P.M. (1982) The effect of hypotensive drugs on the quality of life. *Journal of the Royal College of General Practitioners* **32** 103-105.
- Jernigan, T.L. (1992) Neuroanatomical factors in schizophrenia. In: Kavanagh, D.J. (Ed.) *Schizophrenia. An overview and practical handbook*, pp. 97-106. London: Chapman and Hall.
- Johnson, D.A.W. (1984) Observations on the use of long-acting depot neuroleptic injections in the maintenance therapy of schizophrenia. *Journal of Clinical Psychiatry* **5**(Sec.2), 13-21.
- Johnstone, E. (1993) Schizophrenia: problems in clinical practice. *The Lancet* **341**, 536-538.
- Johnstone, E.C. (1994) *Searching for the causes of schizophrenia*, Oxford: Oxford University Press.
- Johnstone, E.C. and Geddes, J. (1994) How high is the relapse rate in schizophrenia? *Acta Psychiatrica Scandinavica* **89**, 6-10.
- Johnstone, E.C. and Lang, F.H. (1994) Onset, course and outcome of schizophrenia. *Current Opinion in Psychiatry* **7**, 56-60.
- Jones, K., Robinson, M. and Golightly, M. (1986) Long-term psychiatric patients in the community. *British Journal of Psychiatry* **149**, 537-540.
- Joyce, C.R.B. (1994) Requirements for the assessment of individual quality of life. In: McGee, H.M. and Bradley, C. (Eds.) *Quality of life following renal failure. Psychosocial challenges accompanying high technology medicine*, pp. 43-54. Switzerland: Harwood Academic Publishers.
- Kane, J.M. (1987a) Treatment of schizophrenia. *Schizophrenia Bulletin* **13**(1), 133-156.
- Kane, J. (1987b) Low-dose and intermittent neuroleptic treatment strategies for

schizophrenia. *Psychiatric Annals* **17**(2), 125-130.

Kane, J.M. (1990) Treatment programme and long-term outcome in chronic schizophrenia. *Acta Psychiatrica Scandinavica* **82**(Suppl.358), 151-157.

Kane, J.M., Cooper, T.B., Sachar, E.J. (1981) Clozapine: plasma levels and prolactin response. *Psychopharmacology* **73**, 184-187.

Kane, J.M. and McGlashan, T.H. (1995) Treatment of schizophrenia. *The Lancet* **346**, 820-825.

Kaplan, R.M. and Bush, J.W. (1982) Health related quality of life measurement for evaluative research and policy analysis. *Health Psychology* **1** 61-80.

Karlsson, G. (1992) The health economist's point of view concerning quality of life. *Nordisk Journal of Psychiatry* **46**, 95-99.

Kelly, G.R., Mamon, J.A. and Scott, J.E. (1987) Utility of the health belief model in examining medication compliance among psychiatric outpatients. *Social Science and Medicine* **25**(11), 1205-1211.

Kemmler, G., Holzner, B., Neudorfer, C., Meise, U. and Hinterhuber, H. (1997) General life satisfaction and domain-specific quality of life in chronic schizophrenic patients. *Quality of Life Research* **6**, 265-273.

Kemp, R., Haywood, P., Applewhaite, G., Everitt, B. and David, A. (1996) Compliance therapy in psychotic patients: randomised controlled trial. *British Medical Journal* **312**, 345-349.

Kennedy, J.L. (1994) Prediction of neuroleptic response: genetic strategies. In: Gaebel, W. and Awad, A.G. (Eds.) *Prediction of neuroleptic treatment outcome in schizophrenia. Concepts and methods*, pp. 147-154. Wien: Springer-Verlag.

Kind, P., Rosser, R. and Williams, A. (1982) Valuation of quality of life; some econometric evidence. In: Jones-Lee, M.W. (Ed.) *The value of life and safety*, pp. 159-170. Amsterdam: Elsevier/North Holland.

King, M., Coker, E., Leavey, G., Hoare, A. and Johnson-Sabine, E. (1994) Incidence of psychotic illness in London, comparison of ethnic groups. *British Medical Journal* **304**, 1115-1119.

- Kissling, W. (1994) Compliance, quality assurance and standards for relapse prevention in schizophrenia. *Acta Psychiatrica Scandinavica* **89**, 16-24.
- Kmietowicz, Z. (1997) What does schizophrenia cost? *Costs & Options in Schizophrenia* **12**, 4.
- Kraepelin, E. (1896) Dementia praecox. Translated into English, 1987. In: Cutting, J. and Shepherd, M. (Eds.) *The clinical roots of the schizophrenia concept*, Cambridge: Cambridge University Press.
- Launer, M. (1996) Selected side-effects: 17. Dopamine-receptor antagonists and movement disorders. *Prescribers' Journal* **36(1)**, 37-41.
- Leach, A. and Scherer, S. (1992) The epidemiology of schizophrenia. *Current Opinion in Psychiatry* **5**, 20-24.
- Lecrubier, Y. and Meltzer, H.Y. (1993) The treatment of schizophrenia: cost- and risk-benefit issues. In: Brunello, N., Mendlewicz, J. and Racagni, G. (Eds.) *New Generation of Antipsychotic Drugs: novel mechanisms of action*, 4th edn. pp. 143-145. Karger: International Academic Biomedical Drug Research Basel.
- Leff, J. (1986) Recent research on relatives' expressed emotion. In: Kerr, A. and Snaith, P. (Eds.) *Contemporary issues in schizophrenia*, pp. 339-345. London: Gaskell.
- Leff, J.(Ed.). (1993) The TAPS project: Evaluating community placement of long stay psychiatric patients. *British Journal of Psychiatry* **162(Suppl. 19)**, 1-56.
- Leff, J.P. and Wing, J.K. (1971) Trial of maintenance therapy in schizophrenia. *British Medical Journal* **3**, 559-604.
- Lehman, A. (1983) The well-being of chronic mental patients. *Archives of General Psychiatry* **40**, 369-373.
- Lehman, A. (1988) A quality of life interview for the chronically mentally ill. *Evaluation Programme and Planning* **11**, 51-62.
- Lehman, A.F. (1995) Measures of quality of life among persons with severe and persistent mental disorders. *Social Psychiatry and Psychiatric Epidemiology* **29**, 1-11.
- Lehman, A.F., Possidente, S. and Hawker, F. (1986) The quality of life of chronic patients

in a state hospital and in community residences. *Hospital and Community Psychiatry* **37**(9), 901-907.

Lehman, A.F., Ward, N.C. and Linn, L.S. (1982) Chronic mental patients: the quality of life issue. *American Journal of Psychiatry* **139**(10), 1271-1276.

Lelliott, P., Audini, B., Johnson, S. and Guite, H. (1997) London in the context of mental health policy. In: Johnson, S., Ramsay, R., Thornicroft, G., Brooks, L., Lelliott, P., Peck, E., Smith, H., Chisholm, D., Audini, B., Knapp, M. and Goldberg, D. (Eds.) *London's Mental Health. The report for the King's Fund London Commission*, pp. 33-44. London: King's Fund.

Lewis, A.J. (1934) The psychopathology of insight. *British Journal of Medical Psychology* **14**, 332-348.

Lewis, G., Croft-Jeffreys, C. and David, A. (1990) Are British psychiatrists racist? *British Journal of Psychiatry* **157**, 410-415.

Liang, M.H. (1989) Compliance and quality of life: confessions of a difficult patient. *Arthritis Care and Research* **2**(3), S71-S74. (Abstract).

Lin, F.I.H., Spiga, R. and Fortsch, W. (1979) Insight and adherence to medication in chronic schizophrenics. *Journal of Clinical Psychiatry* **40**, 430-432.

Lipton, F.R., Cohen, C.I., Fischer, E. and Katz, S.E. (1981) Schizophrenia: a network crisis. *Schizophrenia Bulletin* **7**, 144-151.

Littlewood, R. (1992) Psychiatric diagnosis and racial bias. An empirical and interpretative approach. *Social Science and Medicine* **34**, 141-149.

Littlewood, R. and Lipsedge, M. (1981) Acute psychotic reactions in Caribbean-born patients. *Psychological Medicine* **11**, 303-318.

Littlewood, R. and Lipsedge, M. (1989) *Aliens and alienists. Ethnic minorities and psychiatry*, 2nd edn. Harmondsworth: Penguin.

Lydiard, R.B. and Laird, L.K. (1988) Prediction of response to antipsychotics. *Journal of Clinical Psychopharmacology* **8**(1), 3-13.

Macmillan, J.F., Crow, T.J., Johnson, A.L. and Johnstone, E.C. (1986a) The Northwick Park

study of first episodes of schizophrenia. III. Short-term outcome in trial entrants and trial eligible patients. *British Journal of Psychiatry* **148**, 128-133.

Macmillan, J.F., Gold, A., Crow, T.J., Johnson, A.L. and Johnstone, E.C. (1986b) The Northwick Park study of first episodes of schizophrenia. IV. Expressed emotion and relapse. *British Journal of Psychiatry* **148**, 133-143.

Malm, U., May, P.R.A. and Dencker, S.J. (1981) Evaluation of the Quality of Life of the Schizophrenic Outpatient: A Checklist. *Schizophrenia Bulletin* **7**, 477-487.

Malmberg, A.K. and Wessely, S. (1994) Diagnosis and phenomenology of schizophrenia and schizoaffective disorder. *Current Opinion in Psychiatry* **7**, 51-55.

Marder, S.R. (1996) Treatment of schizophrenia with typical antipsychotic drugs. *Journal of Clinical Psychiatry Monograph* **14**, 3-5.

Marder, S.R. (1996) Adverse effects of clozapine. *Journal of Clinical Psychiatry Monograph* **14**, 11-12.

Marder, S.R., Hubbard, J.W., Van Putten, T., Hawes, E.M., McKay, G., Mintz, J., May, P.R.A. and Midha, K.K. (1986) Plasma fluphenazine levels in patients receiving two doses of fluphenazine decanoate. *Psychopharmacology Bulletin* **22**(1), 264-266.

Marder, S.R. and May, P.R.A. (1986) Benefits and limitations to neuroleptics-and other forms of treatment-in schizophrenia. *American Journal of Psychotherapy* **XL**(3), 357-369.

Marder, S.R., Mebane, A., Chien, C., Winslade, W.J., Swann, E. and Van Putten, T. (1983) A comparison of patients who refuse and consent to neuroleptic treatment. *American Journal of Psychiatry* **140**(4), 470-472.

Marder, S.R., Van Putten, T., Mintz, J., McKenzie, J., Lebell, M., Faltico, G. and May, P.R.A. (1984) Costs and benefits of two doses of fluphenazine. *Archives of General Psychiatry* **41**, 1025-1029.

Marková, I.S. and Berrios, G.E. (1992) The meaning of insight in clinical psychiatry. *British Journal of Psychiatry* **160**, 850-860.

Marks, I.M. (1992) Innovations in mental health care delivery. *British Journal of Psychiatry* **160**, 589-597.

- Maslow, A.H. (1970) *Motivation and personality*, 2nd edn. New York, Evanston, London: Harper & Row.
- McCall, S. (1975) Quality of life. *Social Indicators Research* **2**, 229-248.
- McDowell, I. and Newell, C. (1987) *Measuring Health: A Guide to Rating Scales and Questionnaires*, New York: Oxford University Press.
- McEvoy, J.P., Freter, S., Everett, G., Geller, J., Appelbaum, P., Apperson, J. and Roth, L. (1989a) Insight and the clinical outcome of schizophrenic patients. *The Journal of Nervous and Mental Disease* **177**(1), 48-51.
- McEvoy, J.P., Apperson, L.J., Appelbaum, P.S., Ortlip, P., Brecosky, J., Hammill, K., Geller, J.L. and Roth, L. (1989b) Insight in schizophrenia. Its relationship to acute psychopathology. *The Journal of Nervous and Mental Disease* **177**(1), 43-47.
- McGlynn, E.A., Norquist, G.S., Wells, K.B., Sullivan, G. and Liberman, R.P. (1988) Quality-of-care research in mental health: responding to the challenge. *Inquiry* **25**, 157-170.
- McGovern, D., Hemmings, P., Cope, R. and Lowerson, A. (1994) Long-term follow-up of young Afro-Caribbean Britons and white Britons with a first admission diagnosis of schizophrenia. *Social Psychiatry and Psychiatric Epidemiology* **29**(1), 8-19.
- McHorney, C.A., Ware Jr, J.E., Lu, R. and et al. (1994) The MOS 36-item Short-Form health survey (SF-36):III. Tests of data quality, scaling assumptions, and reliability across diverse patient groups. *Medical Care* **32**, 40-66.
- McIntyre, K., Farrell, M. and David, A.S. (1989) What do psychiatric inpatients really want? *British Medical Journal* **298**, 159-160.
- Medical Outcomes Trust. (1996) Source Pages. A resource directory for the health outcomes field. Boston, MA: Medical Outcomes Trust.
- Medical Outcomes Trust. (1997) Source Pages. A resource directory for the health outcomes field. Boston, MA: Medical Outcomes Trust.
- Meeberg, G.A. (1993) Quality of life: a concept analysis. *Journal of Advanced Nursing* **18**, 32-38.
- Meltzer, H. (1992) Dimensions of outcome with clozapine. *British Journal of Psychiatry*

160, 46-53.

Meltzer, H.Y. (1996) Untitled contribution to the discussion on Marder (1996): Treatment of schizophrenia with typical antipsychotic drugs. *Journal of Clinical Psychiatry Monograph* **14**, 5.

Meltzer, H.Y., Burnett, S., Bastani, B. and Ramirez, L.F. (1990) Effects of six months of Clozapine treatment on the quality of life of chronic schizophrenic patients. *Hospital and Community Psychiatry* **41(8)**, 892-897.

Meltzer, H.Y., Cola, P., Way, L., Thompson, P.A., Bastani, B., Davies, M.A. and Snitz, B. (1993) Cost effectiveness of clozapine in neuroleptic-resistant schizophrenia. *American Journal of Psychiatry* **150**, 1630-1638.

Meltzer, H.Y. and Okayli, G. (1995) Reduction of suicidality during clozapine treatment of neuroleptic-resistant schizophrenia: impact on risk-benefit assessment. *American Journal of Psychiatry* **152**, 183-190.

Michaels, R.A. and Mumford, K. (1989) Identifying akinesia and akathisia: the relationship between patient's self-report and nurse's assessment. *Archives of Psychiatric Nursing* **III(2)**, 97-101.

Michalos, A.C. (1974) Strategies for reducing information overload in social reports. *Social Indicators Research* **1**, 124.

Milburn, H.J. and Cochrane, G.M. (1997) Treating the patient as a decision maker is not always appropriate. [Letter]. *British Medical Journal* **314**, 1906.

Moodley, P. and Thornicroft, G. (1988) Ethnic group and the compulsory admission of psychiatric patients. *Medicine, Science and the Law* **28**, 324-328.

Morrison, D.T. (1996) Management of therapy-resistant schizophrenia. *British Journal of Psychiatry* **169(Supp1.1)**, 15-20.

Naber, D., Walther, A., Kircher, T., Hayek, D. and Holzbach, R. (1994) Subjective effects of neuroleptics predict compliance. In: Gaebel, W. and Awad, A.G. (Eds.) *Prediction of neuroleptic outcome in schizophrenia*, pp. 85-98. Wien: Springer-Verlag.

Naber, D. (1995) A self-rating to measure subjective effects of neuroleptic drugs, relationships to objective psychopathology, quality of life, compliance and other clinical

- variables. *International Clinical Psychopharmacology* **10** (Suppl. 3), 133-138.
- Najman, J.M. and Levine, S. (1981) Evaluating the impact of medical care and technologies on the quality of life: a review and critique. *Social Science and Medicine* **15F**, 107-115.
- Neeleman, J. and Power, M.J. (1994) Social support and depression in three groups of psychiatric patients and a group of medical controls. *Social Psychiatry and Psychiatric Epidemiology* **29**(1), 46-51.
- NHS Executive (1994) Guidance on the discharge of mentally disordered people and their continuing care in the community. HSG(94)27, London: HMSO.
- Nunnally, J.C. (1978) *Psychometric theory*, 2nd edn. New York: McGraw-Hill.
- O'Boyle, C. (1995) Making subjectivity scientific. *The Lancet* **345**, 602.
- O'Boyle, C.A. (1994) The Schedule for the Evaluation of Individual Quality of Life (SEIQoL). *International Journal of Mental Health* **23** (3), 3-23.
- O'Boyle, C.A., McGee, H., Hickey, A., Joyce, C.R.B. and O'Malley, K. (1993) The Schedule for the Evaluation of Individual Quality of Life (SEIQoL). Administration Manual. Department of Psychology, Medical School, Royal College of Surgeons in Ireland.
- O'Boyle, C.A., McGee, H., Hickey, A., O'Malley, K. and Joyce, C.R.B. (1992) Individual quality of life in patients undergoing hip replacement. *The Lancet* **339**, 1088-1091.
- O'Boyle, C.A., McGee, H. and Joyce, C.R.B. (1994) Quality of life: Assessing the individual. In: Albrecht, G.L. and Fitzpatrick, R. (Eds.) *Quality of life in health care*, Greenwich, CT: JAI Press.
- Office of Population Censuses and Surveys. (1980) Classification of occupations and coding index. London: HMSO.
- Office of Population Censuses and Surveys. (1991) Census Country Report for Inner London. Vol.1 (Part 1), pp 101-110. London: HMSO.
- Office of Population Censuses and Surveys. (1995) General Household Survey 1993. London: HMSO.
- Okin, R.L. and Pearsall, D. (1993) Patients' perceptions of their quality of life 11 years after

- discharge from a state hospital. *Hospital and Community Psychiatry* **44**(3), 236-240.
- Oliver, J., Huxley, P., Bridges, K. and Mohamad, H. (1996) *Quality of life and mental health services*, London; New York: Routledge.
- Oliver, J.P.J. (1991) The social care directive: development of a quality of life profile for use in community services for the mentally ill. *Social Work & Social Sciences Review* **3** (1), 5-45.
- Oliver, J.P.J., Huxley, P.J., Priebe, S. and Kaiser, W. (1997) Measuring the quality of life of severely mentally ill people using the Lancashire Quality of Life Profile. *Social Psychiatry and Psychiatric Epidemiology* **32**, 76-83.
- Oppenheim, A.N. (1992) Questionnaire design, interviewing and attitudinal measurement. London; New York: Pinter Publishers.
- Orth-Gomer, K., Britton, M. and Rehnqvist, N. (1979) Quality of care in an out-patient department: the patient's view. *Social Science and Medicine* **13A** 347-351.
- Overall, J.E. and Gorham, D.R. (1962) The Brief Psychiatric Rating Scale. *Psychological Reports* **10**, 799-812.
- Owen, F. and Cross, A.J. (1992) Biochemistry of schizophrenia. In: Kavanagh, D.J. (Ed.) *Schizophrenia. An overview and practical handbook*, pp. 79-96. London: Chapman and Hall.
- Pan, P.C. and Tantum, D. (1989) Clinical characteristics, health beliefs and compliance with maintenance treatment: a comparison between regular and irregular attenders at a depot clinic. *Acta Psychiatrica Scandinavica* **79**, 564-570.
- Parkerson, G.R., Broadhead, W.E. and Tse, C. (1992) Quality of life and functional health of primary care patients. *Journal of Clinical Epidemiology* **45** (11), 1303-1313.
- Pathare, S.R. and Paton, C. (1997) ABC of mental health: Psychotropic drug treatment. *British Medical Journal* **315**, 661-664.
- Patrick, D.L. and Erickson, P. (1993) *Health Status and Health Policy. Quality of Life in Health Care Evaluation and Resource Allocation*, New York: Oxford University Press.
- Pattison, E.M. and Pattison, M.L. (1981) Analysis of a schizophrenic psychosocial network. *Schizophrenia Bulletin* **7**, 135-143.

- Perkins, R.E. and Moodley, P. (1993) Perceptions and problems in psychiatric inpatients: denial, race and service usage. *Social Psychiatry and Psychiatric Epidemiology* **28**, 189-193.
- Pickar, D. (1995) Prospects for pharmacotherapy of schizophrenia. *The Lancet* **345**, 557-562.
- Pickar, D., Owen, R.R., Litman, R.E., Konicki, P.E., Guttierrez, R. and Rapaport, M.H. (1992) Clinical and biological response to clozapine in patients with schizophrenia. *Archives of General Psychiatry* **49**, 345-353.
- Pocock, S. (1983) Clinical trials: a practical approach. Chichester: John Wiley.
- Pratt, J.P. and Dunnett, N.G.M. (1985) A rehabilitation project for psychiatric patients. *The Pharmaceutical Journal* **234**, 172-173.
- Ramsay, R. and Fahy, T. (1995) Psychiatry. *British Medical Journal* **311**, 167-170.
- Read, T., Potter, M. and Gurling, H.M.D. (1992) The genetics of schizophrenia. In: Kavanagh, D.J. (Ed.) *Schizophrenia. An overview and practical handbook*, pp. 107-125. London: Chapman and Hall.
- Reynolds, G.P. (1992) Developments in the drug treatment of schizophrenia. *Trends in Pharmacology Science* **13**, 116-121.
- Ritchie, J.H., Dick, D. and Lingham, R. (1994) The Report of the Inquiry into the Care and Treatment of Christopher Clunis. London: HMSO.
- Rosen, B.M., Hadzi-Pavlovic, D. and Parker, G. (1989) The life skills profile: a measure assessing function and disability in schizophrenia. *Schizophrenia Bulletin* **15**, 325-337.
- Rosenberg, M. (1965) *Society and the adolescent self-image*, Princeton, NJ: Princeton University Press.
- Rosenberg, R. (1992) Quality of life, ethics and philosophy of science. *Nordisk Journal of Psychiatry* **46**, 75-77.
- Rosenberg, R. (1995) Health-related quality of life between naturalism and hermeneutics. *Social Science and Medicine* **41**(10), 1411-1415.
- Rosenhan, D.L. (1973) On being sane in insane places. *Science* **179**, 250-258.

- Rosser, R., Allison, R., Butler, C., Cottee, M., Rabin, R. and Selai, C. (1993) The Index of Health-related Quality of Life (IHQL): a new tool for audit and cost-per-QALY analysis. In: Walker, S.R. and Rosser, R. (Eds.) *Quality of Life Assessment: key issues in the 1990s*, pp. 179-184. London: Kluwer Academic Publishers.
- Rosser, R., Cottee, M., Rabin, R. and Selai, C. (1992) Index of health-related quality of life. In: Hopkins, A. (Ed.) *Measures of the quality of life and the uses to which such measures may be put*, pp. 81-90. London: Royal College of Physicians of London.
- Rothwell, P.M., McDowell, Z., Wong, C.K. and Dorman, P.J. (1997) Doctors and patients don't agree: cross sectional study of patients' and doctors' perceptions and assessments of disability in multiple sclerosis. *British Medical Journal* **314**, 1580-1583.
- Royal Pharmaceutical Society of Great Britain and Merck Sharp and Dohme (1997) *From compliance to concordance. Achieving shared goals in medicine taking*. London: RPSGB and MSD.
- Sauer, W.J. and Warland, R. (1982) Morale and life satisfaction. In: Mangen, D.J. and Peterson, W.A. (Eds.) *Research Instruments in Social Gerontology. Volume 1. Clinical and Social Psychology*, pp. 195-240. Minneapolis: University of Minnesota Press.
- Scambler, G. (1984) Perceiving and coping with stigmatizing illness. In: Fitzpatrick, R., Hinton, J., Newman, S., Scambler, G. and Thompson, J. (Eds.) *The experience of illness*, pp. 203-226. London: Tavistock Publications.
- Schneider, K. (1959) *Clinical Psychopathology*, New York: Translated by M.W. Hamilton, Grune and Stratton.
- Schuessler, K.F. and Fisher, G.A. (1985) Quality of life research and sociology. *Annual Review of Sociology* **11**, 129-149.
- Sellwood, W. and Tarrier, N. (1994) Demographic factors associated with extreme noncompliance in schizophrenia. *Social Psychiatry and Psychiatric Epidemiology* **29**, 172-177.
- Shalev, A., Hermesh, H., Rothberg, J. and Munitz, H. (1993) Poor neuroleptic response in acutely exacerbated schizophrenic patients. *Acta Psychiatrica Scandinavica* **87**, 86-91.
- Shur, E. (1988) The epidemiology of schizophrenia. *British Journal of Hospital Medicine* **40**, 38-45.

- Simmons, S. (1994) Quality of life in community mental health care - a review. *International Journal of Nursing Studies* **31** (2), 183-193.
- Simpson, C.J., Hyde, S.E. and Faragher, E.B. (1989) The chronically mentally ill in community facilities. *British Journal of Psychiatry* **154**, 77-82.
- Skantze, K., Malm, U., Dencker, S.J. and May, P.R.A. (1990) Quality of life in schizophrenia. *Nordisk Journal of Psychiatry* **40**, 71-75.
- Slevin, M.L., Plant, H., Lynch, D., Drinkwater, J. and Gregory, W.M. (1988) Who should measure the quality of life, the doctor or the patient? *British Journal of Cancer* **57**, 109-112.
- Soni, S.D., Gaskell, K. and Reed, P. (1994) Factors affecting rehospitalisation rates of chronic schizophrenic patients living in the community. *Schizophrenia Research* **12**, 169-177.
- Spitzer, R.L., Endicott, J. and Robins, E. (1975) Research Diagnostic Criteria (RDC). *Psychopharmacology Bulletin* **11**, 22-24.
- Spitzer, W.O., Dobson, A.J., Hall, J. (1981) Measuring quality of life of cancer patients: A concise QL-index for use by physicians. *Journal of Chronic Diseases* **34**, 585-597.
- Statistical Package for the Social Sciences. (1990) SPSS/PC + Statistics 4.0. Chicago: SPSS, Inc.
- Strauss, J.S. and Carpenter, W.T. (1972) The prediction of outcome in schizophrenia. I. Characteristics of outcome. *Archives of General Psychiatry* **27**, 739-746.
- Strauss, J.S. and Carpenter, W.T. (1974) The prediction of outcome in schizophrenia: II. Relationships between predictor and outcome variables. A report from the WHO International Pilot Study of Schizophrenia. *Archives of General Psychiatry* **31**, 37-42.
- Strauss, J.S., Carpenter, W.T. and Nasrallah, A.T. (1978) How reliable is the psychiatric history? *Comprehensive Psychiatry* **19**, 213-219.
- Streiner, D.L. and Norman, G.R. (1989) *Health Measurement Scales: A Practical Guide to their Development and Use*, Oxford: Oxford University Press.
- Sullivan, M. (1992) Quality of life assessment in medicine. Concepts, definitions, purposes and basic tools. *Nordisk Journal of Psychiatry* **46**, 79-83.

- Szabadi, E. (1996) Problems for prescribing for psychiatric patients. *Prescribers' Journal* **36**(4), 184-191.
- Szasz, T.S. and Hollender (1956) A contribution to the philosophy of medicine. The basic models of the doctor-patient relationship. *Archives of Internal Medicine* **97**, 585-592.
- Tantum, D. (1988) Quality of life and the chronically mentally ill. *The International Journal of Social Psychiatry* **34** (4), 243-247.
- Tarrier, N. and Barrowclough, C. (1990) Family interventions for schizophrenia. *Behavior Modification* **1990**, 408-440.
- Tarrier, N., Beckett, R., Harwood, S., Bajer, A., Yusupoff, L. and Ugarteburu, I. (1993) A trial of two cognitive-behavioural methods of treating drug resistant residual psychotic symptoms in schizophrenic patients: I Outcome. *British Journal of Psychiatry* **162**, 524-532.
- Teeling-Smith, G. (1988) *Measuring Health: A Practical Approach*, Chichester: John Wiley.
- Torrance, G.W. (1987) Utility approach to measuring health-related quality of life. *Journal of Clinical Disease* **40** (6), 593-600.
- Tugwell, P., Bombardier, C., Buchanan, W., Goldsmith, C., Grace, E., Bennett, K.J. (1990) Methotrexate in rheumatoid arthritis: impact on quality of life assessed by traditional standard item and individualised patient preference health status questionnaires. *Archives of Internal Medicine* **150** 59-62.
- Tunncliffe, S., Harrison, G. and Standen, P.J. (1992) Factors affecting compliance with depot injection treatment in the community. *Social Psychiatry and Psychiatric Epidemiology* **27**, 230-233.
- Tuninger, E. and Levander, S. (1996) Large variations of plasma levels during maintenance treatment with depot neuroleptics. *British Journal of Psychiatry* **169**, 618-621.
- Turner, T. (1997) ABC of mental health: Schizophrenia. *British Medical Journal* **315**, 108-111.
- Turner, T.H., Lovett, A. and Ness, M. (1990) What should community mental health workers do? *Psychiatric Bulletin* **14**, 661-663.
- United Kingdom Clinical Pharmacy Association (1996) *Pharmaceutical Journal* **256**, 345.

- Van Putten, T. (1974) Why do schizophrenic patients refuse to take their drugs? *Archives of General Psychiatry* **31**, 67-72.
- Van Putten, T., May, P.R.A. and Marder, S.R. (1980) Subjective response to thiothixene and chlorpromazine. *Psychopharmacology Bulletin* **16**, 36-38.
- Van Putten, T., May, P.R.A. and Marder, S.R. (1984) Response to antipsychotic medication: the doctor's and the consumer's view. *American Journal of Psychiatry* **141**(1), 16-19.
- Vickery, B.G., Hays, R.D., Hermann, B.P., Bladin, P.F. and Batzel, L.W. (1993) Outcomes with respect to quality of life. In: Engel, J. (Ed.) *Surgical Treatment of the Epilepsies*, 2nd edn. pp. 623-636. New York: Raven Press.
- Wahl, O.F. and Harman, C.R. (1989) Family views of stigma. *Schizophrenia Bulletin* **15**(1), 131-139.
- Ware, J.E., Brook, R.H., Davies, A.R. and Lohr, K.N. (1981) Choosing measures of health status for individuals in general populations. *American Journal of Public Health* **71**: 620-625.
- Ware, J.E. (1995) The status of health assessment 1994. *Annual Review of Public Health* **16**, 327-354.
- Warner, R. (1994) *Recovery from schizophrenia. Psychiatry and political economy*, 2nd edn. London and New York: Routledge.
- Weiden, P.J. and Olsson, M. (1995) Cost of relapse in schizophrenia. *Schizophrenia Bulletin* **21**, 419-429.
- Weinstein, M.C. and Stason, W.B. (1976) *Hypertension: A Policy Perspective*, Cambridge, MA: Harvard University Press.
- Wessely, S., Castle, D., Der, G. and Murray, R. (1991) Schizophrenia and Afro-Caribbeans. A case-control study. *British Journal of Psychiatry* **159**, 795-801.
- White, K., Roy, D. and Hamilton, I. (1997) ABC of mental health: Community mental health services. *British Medical Journal* **314**, 1817-1820.
- WHOQOL Group (1993) Measuring Quality of Life: The Development of the World Health Organization Quality of Life Instrument (WHOQOL). Geneva: WHO.

- Willcox, D.R.C., Gillan, R. and Hare, E.H. (1965) Do psychiatric outpatients take their drugs? *British Medical Journal* **2**, 790-792.
- Williams, A. (1985) The value of QALYs. *Health and Social Services Journal* **95** 3-5.
- Wing, J.K. (1975) Epidemiology of schizophrenia. *British Journal of Psychiatry* **9** 25-31.
- Wing, J.K. (1978) Social influences on the course of schizophrenia. In: Wynne, L.C., Cromwell, R.L. and Matthys, S. (Eds.) *The nature of schizophrenia: new approaches to research and treatment*, pp. 599-616. New York: John Wiley.
- Wing, J.K., Cooper, J.E. and Sartorius, N. (1974) Measurement and classification of psychiatric symptoms: an instruction manual for the PSE and Catego Program. London: Cambridge University Press.
- Wing, J.K., Curtis, R.H. and Beevor, A.S. (1996a) HoNOS: Health of the Nation Outcome Scales. Report on Research and Development July 1993-December 1995. London: Royal College of Psychiatrists.
- Wing, J.K., Curtis, R.H. and Beevor, A.S. (1996b) HoNOS: Health of the Nation Outcome Scales. Trainers' Guide. London: College Research Unit (CRU).
- Wing, J.K., Curtis, R.H. and Beevor, A.S. (1996c) HoNOS: Health of the Nation Outcome Scales. Raters' Pack. London: College Research Unit (CRU).
- World Health Organisation. (1948) Official Records of the World Health Organization, No. 2, p.100. Geneva: WHO.
- World Health Organisation (1990) *International Classification of Diseases*, 10th edn. Geneva: WHO.
- Young, J.L., Zonana, H.V. and Shepler, L. (1986) Medication noncompliance in schizophrenia: codification and update. *Bulletin of the American Academy of Psychiatry and Law* **14**(2), 105-122.
- Zautra, A. and Goodhart, D. (1979) Quality of life indicators: a review of the literature. *Community Mental Health Review* **4** (1), 1-10.

APPENDICES

APPENDIX ONE

Popular quality of life (QoL) measures used in outcome studies of schizophrenia

1. Quality of Life Checklist (QoLC) (Malm *et al.* 1981)

Malm *et al.* (1981) vaguely conceptualised QoL as ‘a wide range of factors in the material and social environment, together with subjective experience’. The authors suggested that the outcome criterion be ‘the patient’s existential situation’ which involved the patient and four overlapping systems: the health care system, the rehabilitation system, the family system, and the community humanitarian system. However, the authors do not offer any theoretical underpinnings to their model. They developed the scale to identify the needs of people attending a Swedish outpatient clinic.

Content

The QoLC comprises nine sections incorporating 92 items: housing and household; knowledge and education; relationships; dependency; inner experience; mental health; leisure; employment; religion. There is no evidence to support the specific items/domains included in the scale but there is the option to omit irrelevant or add supplementary items, if appropriate. The authors developed the checklist for use with out-patients to assist therapeutic planning but recommend that it may be used with in-patients. They provided no information to support use with this group.

Administration and scoring

The semi-structured instrument takes 5-10 minutes to complete after a 1-hour semi-structured interview. Some clients may be able to self-complete. Clients or interviewers rate each item as *satisfactory* or *unsatisfactory*, in relation to the previous month. An *unsatisfactory* judgement may indicate an unmet need or equally an unsatisfactory level of involvement by the client. This could lead to difficulties in the interpretation of the results. They offer a 0-10 numerical scale for satisfaction ratings if more details are required. Authors suggest existing rating scales that may be used in appropriate sections to increase the reliability of the ratings, if required. The scores are not aggregated in any way, nor is a global QoL rating included. Item ratings are intended to inform specific rehabilitation or community programmes of care for the individual. Discrepancies between client and professional ratings are discussed and the authors recommend that the final judgement lies with the rater. However, the authors do not validate this advice in any way.

Reliability and validity testing

The instrument was piloted with 40 outpatients with the presence of schizophrenic signs and symptoms (Malm *et al.* 1981). However, no psychometric analyses of the scale were published. The authors claimed that the instrument could be used ‘as a guide for treatment’ and on these grounds, dismiss the requirements for reliability testing. However, they also suggested that it may be employed to measure outcome. In this instance, operational definitions were borrowed from existing rating scales and were refined according to local standards. Pilot testing claimed that the instrument provided valuable information highlighting areas of need for the individual. Heinrichs *et al.* (1984) described the QoLC as a reminder ‘of the full range of illness related dysfunction that should be considered in assessing schizophrenic patients.’ However, criticised the scale for not providing the

methodology for that assessment.

2. Satisfaction with Life Domain Scale (SLDS) (Baker and Intagliata, 1982)

Baker and Intagliata (1982) developed the Satisfaction with Life Domains Scale (SLDS) to evaluate community support programmes for chronically mentally ill patients, including those with schizophrenia, in New York state. The authors presented a conceptual model of QoL that represents relationships between external environments, individual experiences/perceptions, individual health status and QoL responses.

Content

The SLDS is a measure of respondent satisfaction with 15 life areas: their house/apartment/place of residence; the food they ate; their neighbourhood as a place to live; the clothing they wear; the people they lived with; their relationships with their family; how they get on with other people; their job/workday programming; the way they spend their spare time; their economic situation; what they did in the community for fun; their friends; the services and facilities in their area; their health; the place they live in currently compared with the state hospital.

Administration and scoring

The SLDS is a self-report instrument, administered by a trained interviewer, that takes 10-15 minutes to complete. The respondent determines satisfaction with each life area using an adapted “faces” response scale (Andrews and Withey, 1976). This consists of 7 faces ranging from a “delighted” face (a large upturned smile: score 7) to a “terrible” face (a large down turned mouth: score 1). Respondents were asked to use the faces’ scale to rate their satisfaction with each life area. Analysis may consider the items independently or the items may be summed and the total score used.

Reliability and validity testing

The instrument was piloted with 118 people receiving community support services for the chronic mentally ill in NY state. Over half were classified as ‘schizophrenic’. Each client’s case manager measured their clients’ mental health statuses using the Global Assessment Scale (GAS) (Endicott *et al.* 1976). GAS ratings were weakly positively related to clients’ self-reported life qualities using the SLDS ($r=0.29$; $p<0.001$) and the Affect-Balance total score ($r=0.17$; $p<0.05$). Cherlin and Reeder (1975) questioned the utility of the Affect-Balance total score and suggested that the individual subscale scores may be more appropriate.

Total satisfaction scores on the life domains exhibited a positive relationship with the Affect-Balance Scale ($r=0.64$, $p<0.001$). This provided some evidence that each instrument taps common dimensions of life satisfaction. Open-ended interviews with a sub-sample of 20 respondents produced consistent results with the SLDS. However, the range of data to support this statement was small. The frequencies and mean item scores may be compared with Andrews and Withey’s (1976) data from a national sample.

One problem identified with the scale is the positive response bias resulting from using the Andrews and Withey (1976) Delighted-Terrible Faces’ Scale. This is a well-known finding in the satisfaction literature. Despite the positive skew of the data, variation was found in scores for individual domains. The SLDS requires further psychometric testing.

3. Quality of Life Scale (QLS) (Heinrichs *et al.* 1984)

Heinrichs *et al.* (1984) designed the Quality of Life Scale (QLS) to standardise and quantify the judgements about deficit symptoms typically made by clinicians treating schizophrenic patients. Deficit symptomatology represents functional impairment. The authors presented a theoretical rationale for the scale items based on four categories: intrapsychic foundations, interpersonal relations, instrumental role, common objectives and activities. Defects in the first category of items are expected to reflect impairments in the other three categories. The QLS is intended as a measure of outcome and a measure of change. It is recommended that the instrument be used with measures of other dimensions of pathology. The QLS was developed in the USA.

Content

The QLS is a 21-item scale providing information on symptoms and functioning during the preceding four weeks: household, friends, acquaintances, social activity, social network, social initiative, withdrawal, sociosexual, occupational role, work functioning, work level, work satisfaction, sense of purpose, motivation, curiosity, anhedonia, aimless inactivity, commonplace objects, commonplace activities, empathy and emotional interaction.

Administration and scoring

A trained clinician administers the QLS as a semi-structured interview that requires 45 minutes to complete. The trained clinician makes ratings using a fixed interval 7-point scale (low score=severe impairment; high score=unimpaired functioning). Each item has 3 components: a brief descriptive statement to focus the rater; a set of suggested probes; and a 7-point scale with descriptive anchors. The probes are to encourage the rater to establish a complete picture before making a judgement using the scale, including asking questions beyond the probes so that judgements are tailor-made to the individual. Raters are expected to take into account other causes for dysfunction, other than the deficit symptomatology of schizophrenia. The instrument was designed for use outside institutions. However, the authors suggest that it may be used to establish pre-admission deficit symptoms and functioning of the individual. The instrument has only thus been developed for use with patients with schizophrenia who inform the raters' responses.

Reliability and validity testing

The model was tested with 111 cases recently discharged from inpatient care (93% were diagnosed with chronic schizophrenia or schizoaffective disorder, according to the Research Diagnostic Criteria (Spitzer *et al.* 1975)). The authors suggested that the scale could be used with patients of other diagnostic categories (e.g. chronic affective or personality disorders). However, they do not provide any information to support this view. A principal component factor analysis produced data consistent with the model (73% of the variance was explained). The factor structure was examined separately for males and females. Similar factor loadings in both patterns and magnitude were evident. Inter-rater reliabilities were examined for three raters and 24 independent ratings. Resulting intraclass correlations for the four categories ranged between 0.91 and 0.97. The intraclass correlation coefficient for the total score (average of all items) was 0.94. Per cent exact agreement for the three raters for all items ranged from 0.25 to 0.83. Information was also tested for five trainee raters with 10 patients. Intraclass correlation for the four categories ranged from 0.84 to 0.94. The total score intra class correlation was 0.88. The QLS is a detailed scale including many of the important domains of QoL. However, further work is required to fully test its psychometric properties.

4. The Oregon Quality of Life Questionnaire (OQLQ) (Bigelow *et al.* 1982; Bigelow *et al.* 1990; Bigelow *et al.* 1991)

The Oregon Quality of Life Questionnaire (OQLQ) was developed to assess mental health programme performance. It is based on a conceptual model of need and role. The authors described the QoL concept using both objective (e.g. aspects of community functioning) and subjective (e.g. life satisfaction) indicators. Two versions are available: a structured self-report questionnaire (Bigelow *et al.* 1991) and a semi-structured interviewer administered instrument where information is obtained from the respondent during an interview (Bigelow *et al.* 1990). The interviewer's own observations, clinical judgement and information from significant others also influence ratings (e.g. family, clinicians, landlords). The latter version was developed for use where respondents were having difficulty answering structured questions. The authors have reported that the semi-structured version is easier to administer.

Content

The OQLQ (structured self-report questionnaire) has 14 domains or separate scales composed of 263 items: psychological distress; well-being; tolerate and cope with stress; basic need satisfaction; independence; interpersonal interaction; spouse role; social support; work at home; work on the job; employability; meaningful use of leisure time; negative consequences of alcohol; negative consequences of drug use.

The OQLQ (semi-structured interview) is composed of 141 items. The domains covered are housing, self-maintenance, home-maintenance, finances, employment, psychiatric medications, physical health, meaningful use of time, psychological distress, psychological well-being, interpersonal functioning. Within the domains, satisfaction of need and performance are assessed. Service evaluation is measured by including service items concerning the domains.

Administration and scoring

Administration of the structured self-report questionnaire requires 30-40 minutes by a trained interviewer (not necessarily a clinician). Administration of the semi-structured interview also requires a trained interviewer (clinician or an individual with significant experience with the target population) and takes approximately 45 minutes to complete. Scoring is the same for both versions. Most items are scored using 4-point ordinal response choices. Item scores within each scale are added and are then transformed to within a range of 0-100 (high scores always reflect a better quality of life; occasionally this requires the reversal of some item scores). The raw scale scores may be further transformed into a standardised distribution if required. For further details of interviewer training, administration and scoring, see Olson *et al.* 1981; Bigelow *et al.* 1990.

Reliability and validity testing: structured self-report questionnaire

Trained interviewers tested the structured self-report questionnaire over a three year period throughout the state of Oregon. More than 2,000 interviews were conducted with a pre-treatment and post-treatment cohort of clients from 24 community mental health programmes. One hundred and ninety community residents were also tested.

The authors tested interviewer reliability during training which yielded 98% correct responses. Evidence of internal consistency of the structured self-report questionnaire was demonstrated with 8 of the 14 scales, producing Cronbach alpha ratings ≥ 0.823 . More scale

development is required with the remaining scales. Test-retest reliability ranged from 0.37 to 0.64. However, they do not specify the interval between administrations.

Clinical staff from three different states indicated a high degree of face validity for the structured self-report questionnaire. The structured self-report questionnaire provided evidence of predictive validity between different communities. On 9 scales, significantly different scores were illustrated between community residents from an economically depressed county (n=30) compared with the other community residents (n=160). Different scores were also yielded when they compared patients from four different mental health programmes: a community support programme for the chronically mentally ill (CSP (n=152)); a drug programme (n=71); an alcohol programme (n=297) and a general psychiatric programme (n=204).

Treatment effects were shown in 9 of the 14 scales from the structured self-report questionnaire. However, the questionnaire was unable to detect dose-effects (i.e. number of visits to the programme). Client satisfaction with treatment did not correlate with improvement due to treatment. The authors suggested three reasons for this outcome: satisfaction scores may be independent of treatment efficacy; improvement may not yield an increased satisfaction with treatment; ceiling effects, i.e. generally high level of satisfaction with treatment.

Improvement (pre- and post-treatment) in the OQLQ (structured self-report version) was correlated with respondents' own retrospective impressions of improvement. Respondents' retrospective assessments of improvement were found to be a successful predictor variable for 9 scales. Since client satisfaction did not correlate with improvement, client judgements about improvement are specific to treatment and not a global attitude. Clients' retrospective reports did not yield high correlations on all scales suggesting that pre- and post-treatment measures make unique contributions on several scales.

A disadvantage of structured self-report questionnaire is the rigorous training and monitoring required to preserve the collection of quality data.

Reliability and validity testing of the semi-structured interview

The semi-structured interview version of the OQLQ was tested on 6 patients with 6 raters, resulting in 36 scores for each item. The raters' agreements ranged from 58-100%, with more than half of the items achieving > 90% agreement. Cronbach alpha ratings for evidence of internal consistency ranged from 0.32 to > 0.80, with more than half of the scales > 0.80.

The semi-structured interview was tested in a study of discharged patients and was found sensitive to differences in service provision (Bigelow and Young, 1991). The interview-rating version has been reported to have high face validity (i.e. credibility and acceptance) among experienced practitioners.

Advantages of the semi-structured interview version are that it permits interviewer discretion; additional information can be collected from significant others and professionals; and it is easier to administer than the self-report version. Respondents reported difficulty answering the questions in the highly structured version, perhaps due to problems with understanding reality, abstract thinking and making choices (Simmons, 1994).

Both versions of the OQLQ are quite comprehensive and measure the important domains of QoL. However, both instruments require further psychometric testing.

5. The Quality of Life Interview (QLI) (Lehman, 1983; Lehman *et al.* 1986; Lehman, 1988)

Lehman (1983) originally developed the Quality of Life Interview (QLI) for a study of chronically mentally disabled people living in board-and-care homes in Los Angeles, USA (n=278; 63% schizophrenia). The conceptual model has three components: personal characteristics, objective life conditions and satisfaction with life domains.

Content

The QLI comprises 9 life domains with 143 items: living situation, family relations, social relations, leisure activities, work, finances, personal safety, health and religion (a late addition based upon open-ended responses by clients). The authors explained that they derived the domains from previous studies on psychiatric patients, measures of resources and functioning, conceptual reviews on QoL and surveys in general populations (see Lehman *et al.* 1982 and Lehman, 1988 for the relevant references). This literature dated from 1963-1980.

Administration and scoring

Administration of the self-report interview takes approximately 45 minutes. The interview is highly structured to ensure consistency, minimise interviewer effects and allow use by non-clinicians. Non-clinicians require some brief training. Lehman (1988) stated that with some practice and occasional advice from an experienced clinician, interviewers with associate or bachelor level degrees have little trouble using the instrument. Each domain has an objective component and then respondents rate their level of satisfaction with that domain using a fixed interval 7-point scale represented as a visual analogue scale (Andrews and Withey, 1976; Campbell *et al.* 1976). Satisfaction with general life is also assessed using the same rating scale. Demographic information is collected first followed by a rating of general life satisfaction. Subsequently, pairs of objective information or levels of functioning and satisfaction ratings in each of the 9 life domains are presented. Finally, the general life satisfaction rating is repeated, followed by some open ended probes.

Reliability and validity testing

The instrument has been tested with three chronically mentally ill populations, aged 18-65 years, including people with schizophrenia. These different populations were from board-and-care homes in Los Angeles (n=278), an inpatient sample from New York (n=99) and a supervised out-patient sample in New York (n=92). The same life domains were used for all 3 settings.

Internal consistency reliability coefficients ranged from 0.35-0.87 (Los Angeles sample) and 0.44-0.88 in (New York Sample - both inpatient and outpatient information was analysed together). In two later studies, Lehman (1995) reported that the internal consistency reliabilities ranged from 0.79-0.88 for the life satisfaction scales and 0.44-0.82 for the objective QoL scales.

One-week test-retest reliabilities ranged from 0.41-0.95 for the life satisfaction scales and 0.29-0.98 for the objective QoL scales (sub-sample of New York Group (n=45)).

Content validity was defended through the development of the instrument from previous literature and measures. Lehman (1988) reported that factor analyses supported a central factor for each scale (e.g. scale measuring satisfaction with social relations (8 items) measured one overall factor ($\alpha=0.70$)).

Principal component factor analysis confirmed construct validity of the domain-specific scales indicating that people differentiated their feelings between various life areas, emphasising the psychological aspects of the QoL experience (Lehman *et al.* 1982). Construct validity was also tested by considering the intercorrelations of the objective and subjective measures within each life domain which were quoted as 'modest' (Lehman, 1988). The strongest correlation with general life satisfaction was gained from the subjective indicators, followed by the objective measures and the demographic variables had the least strong correlation. General life satisfaction scores significantly correlated with measures of depression ($r=-0.17$ to -0.56) and measures of anxiety ($r=-0.25$ to -0.33). There was no correlation between life satisfaction and thought disorder.

The performance of the multivariate QoL model was tested. A four-stage stepwise multivariate regression of general life satisfaction was based on the earlier model using 4 sets of predictor variables: demographics, diagnoses, objective domain-specific indicators and subjective domain-specific indicators. At each successive stage, significant predictor variables were forced into the model from the preceding stage and then additional significant predictors were added from the next set of variables. The predicted variance (r^2) ranged from 0.40 (for the New York in-patients, $n=99$) to 0.49 (for the New York outpatients, $n=92$) to 0.57 (for the Los Angeles board-and-care residents, $n=278$). These values compared favourably with values gained for the general population ($r^2=0.42-0.61$) (Andrews and Withey, 1976; Campbell *et al.* 1976).

Studies have shown the QLI to differentiate between hospital patients and supervised community residential programmes in the USA and UK (Lehman *et al.* 1986; Simpson *et al.* 1989). The predominant diagnosis in all studies was schizophrenia (57%-76% of patients).

6. The quality of life self-report (QLS-100) (Skantze *et al.* 1990)

This Swedish instrument was developed from the earlier pilot work of the Quality of Life Checklist (Malm *et al.* 1981). The authors modelled QoL as a subjective feeling affected by personal characteristics and welfare which in turn are affected by objective indicators of standard of living. Standard of living does not directly predict QoL.

Content

The QLS-100 comprises 100 items in 14 sections based on factors that most people consider influence their satisfaction with their life: Housing; physical environment; household and personal care; public service; knowledge and education; contacts; dependence; finances; inner experiences; religion; mental health; physical health; work; leisure. The authors attributed the derivation of the content of this scale from previous studies. However, they do not cite any references.

Administration and scoring

This is a self-report instrument completed in 15 minutes. Items that are deemed *unsatisfactory* are circled by the client. Unsatisfactory items score 1 point. Total scores are

presented. The authors suggested an alternative way of presenting scores as the ratio of the number of unsatisfactory items in relation to the total number of items in each section.

Reliability and validity testing

The instrument was tested on an outpatient sample with a DSM-III diagnosis of schizophrenia and receiving maintenance treatment with depot neuroleptics at the outpatient clinic (n=61). One-hour semistructured interviews with the respondents found that patients were able to use the instrument. No psychometric data were presented.

7. The Lancashire Quality of Life Profile (LQoLP) (Oliver, 1991)

The Lancashire Quality of Life Profile (LQoLP) was developed in the UK by Oliver and colleagues at the University of Manchester (Oliver, 1991). Its development was stimulated by changes in the provision of services to the chronically mentally ill instigated by Governmental papers such as the National Health Service and Community Care Act, 1990 (House of Commons, 1990). The LQoLP takes its perspective from the combination of health and social care which supports the ethos of a 'community care' package to meet the needs of clients (beyond those just concerning health care) (see Chapter 1). It is based on the Lehman Quality of Life Interview (Lehman, 1988) (see instrument 5 above). However, Oliver introduced some modifications: cultural adaptations for a UK audience, and operational refinements, for the instrument to evaluate multidisciplinary community services (rather than as a research tool). The authors have been developing the LQoLP since 1988 and document their pilot and field testing of the instrument since that time (Oliver *et al.* 1996).

Content

The LQoLP comprises 100 items, focusing on social and economic dimensions, in 9 life domains: work/education, leisure/participation, religion, finances, living situation, legal/safety, family relations, social relations and health. Each domain comprises objective indicators and satisfaction ratings. The ratings are made using a Life Satisfaction Scale (LSS) which is a 7-point Likert type scale which is an adapted version of the delighted-terrible scale (Andrews and Withey, 1976). The instrument begins with questions relating to the respondent's personal characteristics. Next, the first of two items asking for the respondent's rating of their global well-being (GWB) using the LSS is presented. Paired objective items and subjective ratings using the LSS for each domain follow. Perceived QoL is operationalised as the series of respondents' satisfaction ratings to the domain measures. Included in the interview, are two scales of psychological well-being (PWB): the Affect-Balance Scale (Bradburn, 1969) and the Self-Esteem Scale (Rosenberg, 1965). However, the items in these scales were rearranged into response sets of their subscales of positive and negative aspects, due to respondent difficulties. Finally, GWB is again assessed using three different approaches: Cantril's ladder (Cantril, 1965), 3-point Happiness scale (Gurin *et al.* 1960) and the second item using the LSS to operationalise the rating. Cantril's ladder (Cantril, 1965) was altered from a 9-point categorical scale to a continuous analog-type scale. The Happiness Scale (Gurin *et al.* 1960) is considered to be related to satisfaction and mental health but not identical to them.

The interviewers are asked to make a judgement on the reliability of reporting using a 4-point response scale ranging from 'very reliable' to 'very unreliable'. Interviewers are also asked to make a global rating of the respondent's QoL using the Spitzer Quality of Life Uniscale (Spitzer *et al.* 1981).

Administration and scoring

The LQoLP is a structured self-report instrument for administration by non-clinicians in community settings. Administration requires approximately 45 minutes - 1 hour. The objective information per domain is categorical or continuous data. The satisfaction ratings are completed using a 7-point Likert scale (LSS). The data generates a profile that represents the subscales of the questionnaire.

Reliability and validity testing

Psychometric properties of the LQoLP were tested in a series of pilot studies (Phase IV and V) both in the UK and Colorado, USA (Oliver, 1991). Phase IV involved patients of community mental health centres in both the UK (n=24) (CMHCUK) and the USA (n=68) (CMHCUSA), physically disabled people in the UK (n=27) (PD) and controls from a general health centre in the USA (n=15) (GHC). The phase V study involved chronic mental health 'cases' of a social services department in the UK (n=390) (SSD).

● Reliability

Test-retest reliabilities of life satisfaction scores ranged from 0.49-0.78. Oliver (1991) defined his test-retest reliability statistic as the degree of association between the two items of GWB; one at the start of the instrument and one at the end. Measurements were therefore taken the same day, approximately 45 minutes apart and a 'repeat-effect' may have taken place where the respondent's first answer affected the way in which respondents replied on the second occasion. Typically, this data was reported as stable. Mean scores were tested and no significant differences were detected for four out of the five trials. However, the SSD sample ratings were the least correlated (Pearson $r=0.49$) and the mean scores were significantly different ($p=0.002$).

Reliability of reporting, as judged by the interviewers, provided little explanation to the significant differences in the GWB ratings of the SSD sample. Oliver (1991) reports that a factor analysis will be performed at a later stage to explore indicators of susceptibility to test instability. One explanation offered by Oliver (1991) is that the respondents having completed a review of their 'QoL' by specific life domains have become sensitised to the negative aspects of their lives and therefore the second GWB rating is inevitably lower. Inter-rater reliabilities were tested with two social workers making judgements on 17 respondents well known to both interviewers. The QoL Uniscale scores were moderately correlated ($r=0.44$, $p<0.05$). However, mean ratings of the interviewers were significantly different ($p=0.004$).

Reliability of the scale was tested using three multiitem scales: perceived quality of life (Andrews and Withey, 1976), the Affect-Balance Scale (ABS) (Bradburn, 1969) and the Self-Esteem Scale (SES) (Rosenberg, 1965). The test statistics (inter-item mean correlation, standardised item alpha and Guttman split-half correlation) were employed with the Phase IV and Phase V data respectively. For perceived quality of life, the mean inter-item correlations were low (0.19 and 0.16), internal consistency reliabilities (Cronbach's alpha) were 0.86 and 0.84 and the Guttman split-half correlations were 0.82 and 0.73. The ABS was analysed by its separate components of positive affect and negative affect. Positive affect demonstrated the greater reliability: mean inter-item correlations were 0.37 and 0.33; internal consistency reliabilities (Cronbach's alpha) were 0.75 and 0.71; split half coefficients were 0.70 and 0.61. Negative affect ratings were 0.29 and 0.32 for the mean inter-item correlations, 0.68 and 0.70 for internal consistency reliabilities (Cronbach's alpha) and 0.57

and 0.64 for the split half coefficients. The SES was analysed by its separate components of positive self-esteem and negative self-esteem. Positive self-esteem demonstrated the greater variability: mean inter-item correlations were 0.53 and 0.38; internal consistency reliabilities (Cronbach's alpha) were 0.85 and 0.75; split half coefficients were 0.85 and 0.67. Negative self-esteem ratings were 0.45 and 0.39 for the mean inter-item correlations, 0.80 and 0.76 for internal consistency reliabilities (Cronbach's alpha) and 0.76 and 0.73 for the split half coefficients.

- **Validity**

The author argues that the LQoLP has, at least, face validity due to the inclusion of previously developed questionnaires and measures of related concepts. However, content validity needs to be established through empirical validation.

Construct validity was tested through correlating the measures of GWB and PWB (Cantril's Ladder, the LSS average score for the items at the start and end of the instrument and the Happiness Scale, the ABS and the SES) for Phase IV and Phase V data. All scales were positively ($0.24 \leq r \leq 0.63$) and significantly correlated ($p=0.001$). Perceived quality of life domain scores also correlated with measures of GWB (Cantril's Ladder and the LSS average score). Much variation was observed across groups and between the UK and the USA. Most consistent findings were demonstrated with the UK, SSD sample ($n=390$). Uneven results were most prominent on the smaller samples, questioning analyses with small samples and the stability of measures between settings and cultures. Construct validity was generally supported by a pattern of significant positive bivariate correlations between the perceived quality of life domain subscores for just over half of the domain scales. These were largest with the Phase V study. However, the weakest domain was religion which did not correlated with 5 out of the remaining 8 domain scores.

Criterion validity was supported by repeating Lehman's (1988) multiple regression analysis with the Phase IV and Phase V data. The LSS average score was used as the dependent variable. The dependent variable was regressed against personal characteristics alone, then personal characteristics and objective indicators and finally, against personal characteristics, objective indicators and subjective well-being. The total amount of variance (r^2) accounted for by the Phase IV studies was 69% and in the Phase V study was 62%; compared with Lehman (1988) who explained 40-57%.

8. Quality of Life Index for Mental Health (QLI-MH) (Becker *et al.* 1993)

The Quality of Life Index for Mental Health (QLI-MH) (Becker *et al.* 1993) was developed to evaluate patients' behaviour in a range of discrete domains. Originally, this was used in a drug trial of people with treatment-resistant schizophrenia. The QLI-MH comprises a combination of previously developed, well-tested scales with additional questions.

Content

The QLI-MH comprises 9 domains (113 items): symptom severity (36 items) (including the Brief Psychiatric Rating Scale, Overall and Gorham, 1962), activities of daily living skills (24 items) (including the Life Skills Profile, Rosen *et al.* 1989; Spitzer *et al.* (1981) Quality of Life Index), psychological well-being (12 items) (including the Affect-Balance Scale, Bradburn, 1969), physical health (12 items), satisfaction levels for different objective quality of life indicators (10 items), occupational activities (6 items), goal attainment (6 items),

social relations (5 items) (International Pilot Study of Schizophrenia Scale, Strauss and Carpenter, 1974) and economics (2 items). Andrews and Withey's (1976) life satisfaction items were used to inform the satisfaction items included in the QLI-MH: client's satisfaction with living environment, housing, amount of fun, food, clothing and mental health services. A global item that asks about life as a whole is also included. The symptom severity domain includes an item on the side-effects of antipsychotic medication.

Two other versions exist: clinician and family. Both of which cover similar or adapted items of the client's version. The clinician version includes the Life Skills Profile (Rosen *et al.* 1989) and the Spitzer *et al.* (1981) Quality of Life Index. The family version includes items relating to the amount of assistance clients require and how family members feel about providing that amount of help.

Administration and scoring

The QLI-MH is self-administered and takes 20-30 minutes to complete. Although, authors have found that some patients require assistance. An ordinal 7-point scale is presented for respondents to rate their satisfaction with each item. The scale ranges from 'very dissatisfied' to 'very satisfied'. Items are weighted according to their relative importance to the individual. Importance is rated on a 5-point scale ranging from 'not at all important' to 'extremely important'. The global item is rated on a 7-point scale ranging from 1 ('very unhappy') to 7 ('very happy'). Alternative clinician (10-20 minutes to complete) and family versions (no information provided on completion times) are also available to supplement patient reports and to highlight any discrepancies.

For those original scales included in the instrument, the original scoring method is retained. For the total score, items are required to be rescaled on a common scale using a linear transformation. The total score is an aggregation of the transformed subscale scores. However, Bowling (1995a:100) commented that the transformation '... is based on the incorrect assumption that each of the subscales is an interval scale'.

Reliability and validity testing

The QLI-MH is a very comprehensive instrument and is one of the few instruments that permits respondents' to weight items according to their preferences. The instrument is currently undergoing reliability validation testing and further work is required to establish the psychometric properties.

Initial testing was carried out with a sample of 40 outpatients with a DSM-III-R diagnosis of schizophrenia and their clinicians. Three respondents were unable to reliably complete the instrument. Inter-item correlations for domain scores ranged from 0.02 to 0.64 (patient version) and 0.16-0.73 (clinician version). Refinement of the scale is required for those scales whose properties are weak. Test-retest reliabilities were tested with 10 people with a diagnosis of schizophrenia and their clinicians at a 3-10 day interval. Agreement ranged from 84-87%. Content validity was justified by the inclusion of a number of well-tested HRQoL scales. Patients, their families, mental health professionals and university review groups reviewed the items included in the scale. A correlation of 0.68 was reported between the QLI-MH and the global QoL uniscale item. Correlations between respondent and clinician ratings were 0.57 for the total score and 0.50 for the global QoL uniscale item. The authors relied on the pre-reported reliability and validity testing for the existing measures included in the scale. No psychometric testing was reported for the family questionnaire.

APPENDIX TWO

Requirements of a quality of life instrument

The Medical Outcomes Trust Scientific Advisory Committee (1997) recommended eight attributes by which to evaluate an instrument's strengths and weaknesses. The relative importance of each criterion depends on the instrument's intended use and application. For example, if the instrument is intended for discriminative or evaluative purposes between individuals or populations (see Guyatt *et al.* 1992); or if the instrument is intended for research or clinical practice settings, criteria should be assessed accordingly. It is warned that the properties of an instrument depend on its context of use and therefore, one should have evidence about an instrument for each of its intended applications. A clear description of the sample size, characteristics of the sample, testing conditions and study design methods should be detailed for any work undertaken to test or adapt a new instrument (Medical Outcomes Trust, 1997:6). Bowling (1995a:295-296) also listed a review of the important criteria to consider when generally selecting and administering a scale.

The eight instrument attributes are listed below (for detailed definitions and review criteria see Medical Outcome Trust, 1997:6-9).

- **Conceptual and Measurement Model**

A conceptual model is the justification for and description of the concept(s) that the instrument claims to assess and the relationship between those concepts. A measurement model represents the structure and scoring methods of the instrument's scale and sub-scales. The scale should also demonstrate adequate variability in domain scores relative to its intended use (avoidance of floor or ceiling effects). The level of measurement e.g. ordinal, interval or ratio scales and the rationale for the chosen scoring methods (e.g. use of raw scores, standardisation or weighting) should be stated.

- **Reliability**

Test reliability of an instrument is a measure of the degree of freedom from random error. Internal consistency is an estimate of the reliability based on all possible correlations between two sets of items within the test. The most frequently used statistic for estimating internal consistency is Cronbach's alpha (Cronbach, 1951).

For instruments used over time, a test-retest reliability (reproducibility) attribute is tested. This represents 'the extent to which similar results are obtained when an instrument is administered on repeated occasions to stable subjects.' (Guyatt *et al.* 1992). However, this definition does not inform the researcher about acceptable levels of variation. Repeat-effect, i.e. when the influence of the first administration affects the responses for the second administration, can cause reliability to be overestimated. Conversely, an underestimation of reliability can occur with true variations in respondent characteristics. Careful consideration should be given to the time permitted between measurements and the nature of the underlying concept concerning its propensity to true change in given circumstances.

A third measure of reliability (inter-rater reproducibility) is required when more than one interviewer or rater is involved in administering the instrument. If the instrument is tested on subsequent occasions, one may want to test intra-rater reliability and inter-rater reliability. For categorical responses (dichotomous), Cohen's (1968) kappa test of concordance may be

applied.

Acceptable levels of reliability differ according to whether comparisons are being made between groups (0.70) or between individuals where the standard is much higher (0.90 or above) (Nunally, 1978). Other authors accept values >0.50 as an indicator of good internal consistency, as well as test-retest reliability (Cronbach, 1951).

- **Validity**

The validity of an instrument is concerned with degree to which an instrument measures the underlying attribute. Content validity is a measure of the standard of clarity, comprehensiveness, and redundancy of items and scales of an instrument relative to its intended use and name. A definition or conceptual framework is required as a standard against which content validity may be evaluated. All items should be relevant to the content areas of the instrument. Items should be reviewed for their relevance to the instrument's objectives, and similarly, the instrument's objectives should be reviewed for comprehensiveness. The number of items per domain should reflect the relative importance of that domain to the instrument construct (Bowling, 1991:14). Content validity is a subjective judgement, rather than a statistical test. It has been claimed that a group of experts may inspect whether a scale reflects the concept it purports to represent (Ware *et al.* 1981). However, when clinician and patient ratings of QoL have been empirically compared, poor correlations result (Rothwell *et al.* 1997; Slevin *et al.* 1988; Jachuk *et al.* 1982; Orth-Gomer *et al.* 1979). Lay groups have also been used for determining the content validity of an instrument.

Face validity is an informal assessment of whether the items included in the scale could reasonably measure the underlying attribute of the instrument. Face validity is an estimate of the meaning and relevance of the items. (Bowling, 1991:14).

Construct validity is concerned with hypothetical instrument attributes that cannot be directly measured. Testing of the instrument involves developing theories about the relationship between the instrument attribute and other measures. Testing is undertaken to confirm or dispel these theories. Problems arise when the hypothesis is disproved. It is not clear whether the problem is with the instrument or with the hypothesised theory (Bowling, 1991:15). Construct validity may be dichotomised into convergent and discriminant validity. Assessment of the relationships between the new instrument and other variables and also other constructs to which it should be related are tested. Correlations provide evidence of the extent of these relationships. If the correlation coefficient is too high, the new instrument may be measuring the same concept. Convergent validity requires the new instrument to correlate moderately with measures of the same construct. Discriminant validity requires the instrument to have no associations with dissimilar variables (Bowling, 1991:15). It has been suggested that a low or zero-correlation is more informative, since it clearly states that instruments are measuring different concepts (Joyce, 1994:50).

Evidence showing correlations between the instrument scores and criterion measures represent criterion validity, i.e. reflect the accuracy of measurement. Criterion measures are widely accepted validated measures of the construct under test. In health status assessment, criterion validity is rarely tested due to the lack of criterion or 'gold standard' measure of health and its related concepts such as QoL (Bowling, 1991:15). Criterion validity may be dichotomised into concurrent and predictive validity. Concurrent validity involves

administering the new instrument and the criterion instrument simultaneously to establish if the new measure may be a suitable substitute for the criterion measure. Predictive validity considers the ability of the new instrument to predict future differences. For this test, the criterion is available at a future endpoint (Bowling, 1991:15).

- **Responsiveness**

Responsiveness (i.e. the extent to which scores change when subjects improve or deteriorate) is a particularly important criterion for longitudinal studies. The people with the health condition under study, their significant others or their providers of health care, best define minimal important change. Sufficient sample sizes and variability of scores are required to detect a real change (Vickrey *et al.* 1993).

- **Interpretability**

Interpretability represents the degree to which qualitative meaning may be assigned to the quantitative scores of an instrument.

- **Burden**

Burden may be due to administration of the instrument (demands placed on those who conduct the study) or participation in studies using the instrument (demands placed on respondents, e.g. time, energy). The abilities of the target population are an important consideration for the feasibility of QoL measurement (Vickrey *et al.* 1993). Missing data and refusal rates should be made explicit as measures of acceptability of the instrument.

- **Alternative forms**

Information on alternative forms other than the original source instrument should be listed (e.g. telephone-administered, interviewer-administered, self-administered, observer-rated, proxy reports etc.). All instrument criteria and information relating to its use must be demonstrated with the alternative form instrument.

- **Cultural and language adaptations**

Reliability and validity properties of QoL instruments developed in a particular language or culture must be reassessed when translated into a different language or adopted for use in a new culture (Vickrey *et al.* 1993). Before each adapted instrument is evaluated for its own instrument criteria, it has to achieve conceptual equivalence (relevance and meaning of concepts in different languages and cultures) and linguistic equivalence (question wording and meaning in items, response choices, all aspects of the instrument and its applications). The use of American measures in the UK and other European settings must be considered in terms of cultural differences/translation.

APPENDIX THREE

Letter of invitation for pilot work with attenders of community psychiatric nurse clinics

Date

Dear Client,

My name is Sally-Anne Francis. I am a research pharmacist at the Medical College of St. Bartholomew's Hospital.

My project is looking at what people think about their medication so to find out what the good and the bad things are about the medication. With your permission, I would like to ask you about your views and opinions of the medication you are receiving. I will not be recording your name and all information will be treated as strictly confidential. I would like to assure you that I have no links with the health centre or your doctor and therefore the interview will be completely private.

I would be extremely grateful for any help you could give me with my project.

Yours sincerely,

Sally-Anne Francis

APPENDIX FOUR

Semi-structured interview schedule for pilot work with attenders of community psychiatric nurse clinics

1. Are you taking any medication at the moment, including any injections?
2. Do you know what they are called?
3. Do you think that medication is important? Why?
4. How do you find your medication?
Helpful
Unhelpful
Indifferent
5. Have you ever felt like not taking your medication?
6. When was your medication last reviewed?
7. Do you feel able to influence the type of medication you receive?
8. Is there anything that you would like to change about your medication?
9. Do you have any problems with unwanted effects?
10. If you do not feel well or have a problem with your medication, is there someone that you can go and see to talk with?
11. How would you describe your quality of life? Why do you say that?
12. What are the good things about life?
13. What are the bad things about life?
14. Do you feel that your medication affects these in a good or bad way?

OTHER INFORMATION COLLECTED:

- * Marital status
- * Accommodation
- * Number of people living with
- * Date of last admission
- * Any family?
- * How long on current therapy?

APPENDIX FIVE

Patient consent form for main research study

STUDY OF QUALITY OF LIFE AND MEDICATION ADHERENCE

INFORMATION FOR PATIENTS

Although we know about the immediate benefits of using depot neuroleptic medication for treating the symptoms of your illness, we would like to increase our knowledge of the long term benefits. In particular we would like to know more about the way people's general health and lifestyle are affected. To do this we are carrying out a study of people prescribed this particular medication and would like you to take part.

This study would require you to be interviewed by us before you are discharged and again three months later. The questionnaires will include questions about your health and lifestyle (such as everyday activities) and also your views and opinions about the medication you receive. Further, we would like to be able to refer to your medical notes and to ask your carer some questions concerning your general health.

All the information we collect, both from you and your carer, will be treated as strictly confidential and will not be revealed to anyone. We hope you are willing to help us with this study. Agreeing to take part will not affect the way you are treated in hospital. Similarly, if you do not wish to take part or wish to withdraw during the course of the study, this will not affect your treatment in anyway.

If you are willing to take part in this study, could you please sign the form below.

CONSENT FORM

I, ...

of

.....hereby consent to take part in the study of quality of life and medication adherence.

Signed

Dated

APPENDIX SIX

Patient information leaflet for main research study



Contact: Sally-Anne Francis

Department of General Practice
Medical College of St. Bartholomew's
Hospital
Charterhouse Square
London EC1M 6BQ

Tel: 071 982 6000 ext. 5021



*The Medical Colleges of Saint Bartholomew's
and the Royal London Hospitals*

University of London

Joint Academic Department of General Practice and Primary Care

QUALITY OF LIFE STUDY

.

THANK YOU FOR TAKING PART



What is it about?

Although we know about the immediate benefits of using medicine giving by injection for treating the symptoms of your illness, we would like to increase our knowledge of the long term effects. In particular, we would like to know more about the way people's general health and lifestyle are affected.

Why have we come to you?

We are asking everybody on your type of medication who are staying in hospital to take part.

Is the study confidential?

Yes. The information we collect will not be presented in any form which can be associated with the names and addresses of those who have taken part.

Do you have to take part?

We hope you are willing to help us with this study. Agreeing to take part will not affect the way you are treated in hospital. Also, if you do not wish to take part or wish to drop out during the course of the study, this will not affect your treatment in any way.

What do you have to do?

PART ONE

This study will require you to be interviewed by us before you are discharged from hospital. The questionnaires will include questions about your health and lifestyle (such as everyday activities) and also your views and opinions about the medication you receive. We would also like to be able to refer to your medical notes and to ask your carer or relative some questions concerning your general health.

We have finished the first part of the study by having the interview today

.....

PART TWO

The next part of the study is about three months after you have left hospital. This will be sometime in

.....

It is very important that I see you again. I will write to you to remind you when to meet. If you wish to speak to me, you can contact me at the address or telephone number on the back.

Thank-you for all your help.

APPENDIX SEVEN

Information collected in the recruitment questionnaire

- **Medication views and experiences**

Questions 1 and 2 - Knowledge of the medication they are taking

These questions were based on those used in the pilot semi-structured interviews (Section 3.2). They were simply used to focus the patient on their medication and to introduce this section of the questionnaire. It was clarified with the patient that it did not matter if they did not know the answer to these questions.

Question 3 - Opinions about the effects of the medication on symptoms of illness

This question was developed from 'Do you think that medication is important? Why?' used in the pilot semi-structured interviews (Section 3.2). It is a more specific question intended to stimulate the respondent to think about their medication in terms of their illness.

Questions 4 - 7 - Unwanted effects of medication and their effect on daily activities

These questions focussed on the unwanted effects ('side-effects') of medication and the implication of these effects on activities of daily living.

Questions 8 - 10 - Experiences of non-adherence to medication

These questions explored experiences of stopping medication or feelings of wanting to stop medication. They also asked the respondent about the perceived outcome of stopping their medication.

Questions 11 - 13 - Intentions of taking medication after discharge

These questions explored the respondents' intentions and feelings about taking medication after discharge from hospital.

- **Insight**

Question 14 - 16 - Insight

A respondent's insight into their illness and their perceived need for treatment may affect their views and experiences of medication. There is no valid tool for measuring insight that may be used in this instance (see Chapter One). The questions used here (question 14) were taken from the Present State Examination (PSE 9) (Wing *et al.* 1974). This was experimental since they had not been used in isolation from the rest of the PSE before (personal communication, Professor J Wing). Question 15 and 16 explored the perceived need for treatment, having focussed the patient on their illness symptoms and their need for admission. It was also included as a measure of internal consistency to compare with responses to question three.

- **Admission/current symptoms and problems** (Questions 17-23 taken from Bowling and Parkman, 1993)

Question 17 and 18

These questions were used to change the focus of the questionnaire to the respondents' current admission. It was stressed to the respondents that it did not matter if they could not remember the date on which they were admitted.

Question 19 - Reason for admission

The response to this question provided additional information to their insight of their illness and their perceived need for hospital admission and medication.

Question 20 and 21 - Admission and current symptoms

These questions encouraged the respondent to think of their illness episode, from the time they were admitted to the current time of interview. The symptoms on admission were analysed with the information about reason for admission. The respondents' perceived importance of their symptoms, in terms of needing admission, were explored. It also investigated the notion of whether people felt that they had benefited from admission, in terms of a decrease in their symptoms.

Question 22 and 23 - Admission and current problems

These questions looked for stressful events or 'unmet needs' which may have contributed to the admission or delayed discharge.

Question 24 and 25 - Medication and illness effects on daily activities

This question examined the impact of the illness and medication on daily activities. Whether the effects were because of the illness or medication, the patient did not have to specify. It also gave the respondents the opportunity of reporting the benefits of medication in terms of daily living.

Question 26 - Other health problems

This was a closing question to the section focussing on symptoms and problems. It is well known from the literature that people with mental health problems suffer greater morbidity. This question was used briefly to illustrate the scope of physical health problems described by the respondents.

● **Personal information**

Question 27 - Age and date of birth

The age reported was checked using the date of birth and in turn, the date of birth was validated against that reported in the medical notes. A deviance of +/- two years was accepted (taken from Bowling and Parkman, 1993).

Question 28 - Marital Status

Marital status was explored and checked in accordance with the medical records.

Questions 29 - 32 - Ethnicity

This series of questions was asked to establish the cultural background of the respondent and their perceived ethnicity (taken from Bowling and Parkman, 1993).

Questions 33 - 36 - Home circumstances

These questions established the respondents' living situations before admission and accommodation needs for discharge (taken from Bowling and Parkman, 1993).

Question 37 - Support from relatives

These questions checked if there was any familial support after discharge from hospital and importantly, if the respondent was happy with any arrangements.

Question 38 - 46 - Employment

These questions examined employment status before admission and the respondents' intentions of seeking work after discharge. The questions taken from the General Household Survey (Office of Population Censuses and Surveys, 1995) provided a crude measure of social class according to the Registrar General's Classification of Occupations (Office of Population Censuses and Surveys, 1980).

Questions 47 - 52 - Education

These questions confirmed the age left school and attendance at further education classes. The highest qualification gained was documented. These questions were taken from the General Household Survey (Office of Population Censuses and Surveys, 1995).

● **Permission to contact others**

Question 56 - Contacting the General Practitioner (GP)

This question asked the respondents if they had a General Practitioner (GP). Respondents were asked for their permission for the researcher to contact the GP. The GP was only contacted on those occasions either when the respondent had dropped out of contact with the community mental health services or when the GP was responsible for administering the depot medication.

Question 57 - Contacting 'a significant other'

The respondent was asked to name a 'significant other' whom the researcher could contact. These were sent a postal questionnaire, after the respondents had completed a successful community interview, to validate the objective information reported.

● **Further information recorded by the researcher during the recruitment phase**

The researcher recorded the length of the interview (in minutes), places of the interview, gender of patient, and any other observations.

Diagnosis

DSM-III-R diagnostic criteria (American Psychiatric Association, 1987) were used by the researcher and diagnosis determined using medical notes retrospectively. There were no resources to validate this, however, where possible, the presence of a DSM-III-R diagnosis of schizophrenia was confirmed by junior medical staff.

Severity of illness

Severity of illness was assessed by the researcher using the Global Assessment of Functioning Scale (American Psychiatric Association, 1987) and where possible, patients were also assessed by hospital ward/community staff. The scale allows the observer to judge a person's "psychological, social and occupational functioning" as a single score estimate. It represents Axis V of the DSM-III-R diagnostic criteria and is based on the widely used Global Assessment Scale (GAS) (Endicott et al, 1976).

**QUALITY OF LIFE AND MEDICATION
ADHERENCE STUDY****RECRUITMENT QUESTIONNAIRE**

DATE OF INTERVIEW

START TIME

FINISH TIME

Although we know about the immediate benefits of using medicine given by injection for treating the symptoms of your illness, we would like to increase our knowledge of the long term effects. In particular, we would like to know about the way people's general health and lifestyle are affected. To do this we are carrying out a study of people on your medication and would like you to take part. All replies will be treated in the strictest confidence; no individuals will be identified in the final report.

I would like to ask you about your views and opinions of the medication you receive. The answers you give are treated as confidential. Please answer as openly as possible.

1. Do you know what medication you are taking, including any injections?

Yes 1 - Go to Qu. 2

No 2 - Go to Qu. 3

2. Can you name them?

Injection:

Others:

3. In your opinion, what difference has the medication, including your injection, made to the symptoms of your illness?

4. Do you have any problems with your medication or your injection, for example, side-effects?

Yes 1 - Go to Qu. 5
No 2 - Go to Qu. 8

5. Can you tell me about them? (PROBE / PROMPT)

6. Do you feel that these side-effects you have just told me about, (**mention the side-effects reported by the client**) affect anything you do or anything that you would like to do?

Yes 1 - Go to Qu. 7
No 2 - Go to Qu. 8

7. Would you like to tell me in what way?

8. Have you ever felt like NOT taking your medication or NOT having your injection?

Yes 1 - Go to Qu. 9
No 2 - Go to Qu. 11

9. Would you like to tell me why?

10. What happened when you didn't take your medication or didn't go for your injection?

11. Will you be taking medication or having an injection after you have been discharged?

Yes	1	- Go to Qu. 12
No	2	- Go to Qu. 13
DK	3	- Go to Qu. 14

12. How do you feel about that?

13. Would you like to tell me why?

Now I would like to ask you some questions about what you think about your illness. I would like to know your opinions and views. There are no right or wrong answers.

14. Do you think there is anything the matter with you?

(What do you think it is?)

(Could it be a nervous condition?)

(What do you think the cause is?)

(Why did you need to come to hospital?)

(Do you think (*specific delusions or hallucinations*) were part of a nervous condition?)

15. In your opinion, do you feel that medication helps the symptoms of your illness?

Yes	1	- Go to Qu. 16
No	2	- Go to Qu. 17
DK	3	- Go to Qu. 17

16. Would you like to tell me in what ways?

HEALTH

I would like to ask you some questions about your health.

17. Can you remember the date you were admitted to hospital this time?

Day ____ Month ____ Year ____

18. So, how long do you feel you have been here this time, how many weeks or months, would you say?

Less than one week	1
One week but less than two weeks	2
Two weeks but less than four weeks	3
Four weeks but less than two months	
Two months but less than three months	
Three months but less than six months	
Six months but less than one year	7
One year or more (please specify)	8

19. People are admitted to hospital for all different kinds of reasons.
Why do you think you were admitted to hospital this time?

20. Some people remember experiencing certain symptoms of their illness when they were first admitted to hospital. Do you remember experiencing any particular symptoms of your illness when you were first admitted?
21. Are you experiencing any symptoms of your illness now? (These may be the same as when you were first admitted, or these may be new symptoms).
22. Some people become ill because they have problems (eg work problems, family problems, housing problems). Did you have any particular problems when you first became ill?
23. Are you experiencing any kind of problems now?
24. Do you feel that your medication or the symptoms you are experiencing affects the way you spend your day, for example, your hobbies, your leisure time?
- | | | |
|---------------|---|----------------|
| Yes | 1 | - Go to Qu. 25 |
| No | 2 | - Go to Qu. 26 |

25. Can you tell me in what ways?

26. Have you any other health problems, any physical health problems?

May I go on to ask you some questions about yourself and your background? I would like to remind you that all the information you give will be treated confidentially.

PERSONAL DETAILS

27a. May I ask how old you are? . . . years

27b. And your date of birth: Day.....Month.....Year.....

28.	Are you:	Single (never married)	1
		Married / Cohabiting	2
		Separated	3
		Divorced	4
		Widowed	5

29.a) In what country were you born:

England	1
N. Ireland	2
Scotland	3
Wales	4

Outside UK, please specify 5 - Go to (b)

29.b) If born outside the UK, in what year did you first arrive in the UK?

30. Do you know what country was your mother born:

England 1
N. Ireland 2
Scotland 3
Wales 4

Outside UK, please specify 5

31. Do you know what country was your father born:

England 1
N. Ireland 2
Scotland 3
Wales 4

Outside UK, please specify 5

32. To which of the groups listed below do you consider yourself to belong?

Asian	Bangladeshi	01
	Chinese . . .	02
	Indian	03
	Pakistani . .	04
	Vietnamese	05

Black	African . . .	06
	Caribbean .	07
	U.K./British	08

White	English . . .	09
	Irish	10
	Jewish	11
	Kurdish . . .	12
	Scottish . . .	13
	Turkish . . .	14
	Welsh	15

Other European 16

Other, please specify 17

HOME CIRCUMSTANCES

33. Can you tell me what type of accommodation you were living in before this admission to hospital?

Rented from Local Authority	01
Privately rented	02
Board and Lodging	03
Bed and Breakfast	04
Housing Association	05
Owner occupier or living in same household as owner occupier	06
No Fixed Abode	07
Staffed Group Home	08
Unstaffed Group Home	09
Hostel (please specify)	10
Other (please specify)	11

34. If own or rented accommodation:
Did you share this accommodation with anyone else?

Alone	1
Family	2
Friends	3
Family and friends	4
Others	5

35. Will this accommodation be still available to you, after you are discharged?

Yes	1	- Go to Qu. 37
No	2	- Go to Qu. 36
Don't know	3	- Go to Qu. 37

36. Do you know what type of accommodation you will have when you are discharged?

Rented from Local Authority	01
Privately rented	02
Board and Lodging	03
Bed and Breakfast	04
Housing Association	05
Owner occupier or living in same household as owner occupier	06
No Fixed Abode	07
Staffed Group Home	08
Unstaffed Group Home	09
Hostel (please specify)	10
Other (please specify)	11
Don't know	12

37.

a) Is there a relative who will support you when you are discharged?

Yes, living with me	1	- Go to Qu. (d)
Yes, visiting regularly . . .	2	- Go to Qu. (d)
No	3	- Go to Qu. (b)
Not sure	4	- Go to Qu. (b)

b) Would you want someone to visit you regularly after you are discharged?

Yes	1
No	2
Don't know	3

c) Would you want someone to live with you after you are discharged?

Yes	1	]
No	2	] Go to Qu. 38
DK	3	]

d) Are you happy with this arrangement?

Yes	1	
No	2	- Go to (e)
DK	3	- Go to (e)

e) Would you like to tell me why you say that?

EMPLOYMENT

38. There are many reasons why people don't or can't seek work so may I just check, before this admission to hospital, were you in paid employment?

Yes	1	- Go to Qu. 42
No	2	- Go to Qu. 39

39. Were you...

Unemployed waiting to take up a job	1	- Go to Qu. 41
Unemployed looking for work . .	2	- Go to Qu. 41
Unemployed but not looking for work	3	- Go to Qu. 40

40. There are many reasons why people don't or can't seek work so may I just check, what was the main reason you were not looking for work?

Student	1
Long term sick or disabled	2
Looking after family/home	3
Doesn't want/need employment	4
Believes no jobs available	5
Not yet started looking	6
Other reason, please specify	7

41. May I just check, have you ever had a paid job or done any paid work?

Yes	1	- Go to Qu. 42
No	2	- Go to Qu. 44

42. When was your last full time employment?

Less than 3 months prior to admission	1
3 months up to 1 year prior to admission	2
1 year up to 3 years prior to admission	3
3 years up to 5 years prior to admission	4
5 years up to 10 years prior to admission	5
10+ years prior to admission	6

43. What was your most recent job:

Occupation:

Job title:

Describe fully:

Industry:

employee	1
self-employed	2

(a) IF EMPLOYEE

manager	1
foreman/supervisor	2
other employee	3

(i) How many employees worked in the establishment?

1-2	1
3-24	2
25-99	3
100-999	4
1,000 or more	5
DK	6

(b) **IF SELF-EMPLOYED**

Did you employ any other people?

YES, 1-5 employees . . .	1
6-24	2
25 or more	3
NO employees	4

44. Do you currently go to any type of industrial therapy or sheltered employment?

Yes (please specify)	1
No	2

45. Do you intend to look for work after you are discharged?

Yes	1	- Go to Qu. 47
No	2	- Go to Qu. 46

46. May I ask you if there is a particular reason why not?

EDUCATION

47. How old were you when you left school?

48. I would like to ask you about any education you may have had since leaving school, not counting any leisure classes.

Since leaving school, have you ever had any further education, either full-time or part-time, including day release, Open University Courses, correspondence courses, or training in nursing, physiotherapy, or a similar medical subject or as part of a Youth Training Scheme?

Yes	1
No	2

49. Now thinking just of your **full-time** education:
what type of school or college did you **last** attend full-time?

(Exclude courses of under three months)

Was it:

elementary or secondary school	1
university	2
polytechnic	3
(include Scottish central institutions)	
nursing school or teaching hospital	4
or some other type of college?	5
other (please specify)	6
-

50. How old were you when you left there, or when you stopped your course?

Age _____

51. Do you have any written qualifications, or have you passed any examinations,
whether you are making use of them or not?

- Yes 1 - Go to Qu. 52
No 2 - Go to Qu. 53

52. Would you like to tell me about them?

53. Thank you for speaking to me today. I would like to be able to contact you again about three months after you have been discharged to see how you are getting along. Would you be willing to be interviewed again?

Yes []

No []

54. What is your permanent address **plus postcode** (eg E1, E5, etc).
(Record if patient is of No Fixed Abode):

55.
a) How many years have you lived at this address?
IF UNDER ONE, CODE AS 00

- b) IF 0-4 YEARS AT ADDRESS:
How many times have you moved in the last five years, not counting moves between places outside UK?

56. If I had a problem in contacting you, would you be willing for me to record the address of your GP so I could try to contact you through him/her?

Yes []

No []

Name of GP:

Address:

57. I would also like to speak to someone who knows you well, this may be a member of your family or a friend. Do you agree to this?

Yes []

No []

If yes, please could you give details of how to contact this person.

Name:

Contact address:

58. Do you have any questions that you would like to ask me either about:

a) your medication

or b) any aspect of the study

or c) are there any further comments which you would like to add?

THANK YOU VERY MUCH FOR YOUR HELP.

Interviewer comments

1. How long did the interview take (minutes)?
2. Place of interview:
 - In-patient Hackney Hospital 1
 - In-patient St Clement's Hospital 2
 - Please specify ward

 - Other, please specify 3
3. Sex:
 - Male 1
 - Female 2
4. How reliable / unreliable do you think the client's responses were?
 - Very reliable 1
 - Generally reliable 2
 - Generally unreliable 3
 - Very unreliable 4
5. Any other comments:

6. Please complete GAF Scale rating.

7. Checked with staff Yes / No

APPENDIX EIGHT

Information collected in the community questionnaire

- **Medication views and experiences**

Questions 1 - 10 Same as recruitment questionnaire (see Appendix Seven).

Question 3b - Opinions about the effects of the medication on the symptoms of illness

This question provides additional information to the qualitative responses of question three. It is pre-coded with categorical responses.

Questions 11 - 13 - Changes to prescribed medication

These questions find out about any changes to the prescribed medication and the respondents' knowledge of why the medication had changed. This is important for understanding the role of the patient in the decisions of managing the medication and could be associated with medication adherence.

Questions 14 - 16 - Current experience of non-adherence

These questions were answered only by those people who had stopped their medication at the time of the community interview. They explore the reasons why the respondent decided to stop their medication and ask what differences stopping the medication had made to their lives, overall. This gives scope for positive and negative interpretations.

- **Service and social networks**

Question 17 - Service/Social contacts and frequency

The answers to this question build a network of all the contacts that each respondent has in the community and the frequency with which they meet. This is important information to collect when considering community care and 'quality of life'.

- **Insight**

Questions 18 - 20 Same as recruitment questionnaire (see Appendix Seven).

Question 18b - Informed

This question was taken from the 'Index of Health Related Quality of Life' (Rosser *et al.* 1992) and asked how informed the respondents felt about their state of health.

- **Stigma**

Question 21 - Stigma

This question was taken from the 'Index of Health Related Quality of Life' (Rosser *et al.* 1992) and measured feelings of stigmatization due to the respondents' awareness of their state of health (see Chapter One).

- **Current symptoms and problems** (taken from Bowling and Parkman, 1993)

Question 22 - Discharge Date

This question was used to change the focus of the questionnaire to the respondents' current health. The respondents were reassured that it did not matter if they could not remember the date that they were discharged.

Question 23 and 24 - Current symptoms and problems

These questions were particularly important for those who had varying degrees of medication adherence.

Question 25 - Other health problems

Same as recruitment questionnaire (see Appendix Seven).

Questions 26 and 27 - Medication and illness effects on daily activities

Same as recruitment questionnaire (see Appendix Seven).

● **Quality of life**

Questions 28 - 31 - Open quality of life questions

These questions were adapted from the 'Schedule for the Evaluation of Quality of Life (SEIQoL)' (O'Boyle, 1994). These were open questions to explore the five areas of life most important to the respondents'. Further, the respondents were asked to put the different areas of life in order of importance. The next question asked them to rate the quality of their lives in relation to each area they named. The 'delight-terrible faces scale' (Andrews and Withey, 1976) was adapted for this purpose. They also used the faces' scale to rate their 'overall quality of life'. Finally, they were asked to repeat the exercise, naming the areas of their life affected by their illness and rating their quality of life in relation to each area. The areas generated by this series of open questions were compared with the items included in the Lancashire Quality of Life Profile as a measure of face validity.

Questions 32 - 122 - Lancashire Quality of Life Profile

For a review of all quality of life measure used in mental health, see chapter two. The Lancashire Quality of Life Profile (Oliver, 1991) was used (see Appendix One). Using objective and subjective indicators, the Lancashire Quality of Life Profile collects information in nine life areas:

- Work/Education (7 items)
- Leisure/Participation (8 items)
- Religion (4 items)
- Finances (7 items)
- Living situation (12 items)
- Legal and safety (5 items)
- Family relations (7 items)
- Social relations (6 items)
- Health (10 items)

It includes items on general well being, positive and negative affect and self-esteem. Perceived quality of life is operationalised as a series of client judgements about objective life in each of these domains. The judgements are made using the life-satisfaction scale developed from Andrews and Withey's (1976) Delighted-Terrible scale. The final section of the profile measure asked the client to name anything that would improve their quality of life as an internal measure of content validity.

Questions 123 - 124 - Other areas of importance

These questions ensured that all other aspects of life and activities important to the respondents were reported.

- **Community care**

- Questions 125 - 135

These questions, stimulated by media attention at the time, explored the users' experiences of supervised discharge and the 'Care Programme Approach'.

- **Permission to contact others**

- Question 136b - Contacting 'a significant other'

This question was asked in the recruitment questionnaire. By repeating the question, it allowed an alternative person to be nominated who may know more about the respondent's current progress in the community. It also gave the opportunity for respondents to withdraw their consent for contacting 'a significant other' which was seen as an important ethical consideration. Equally, it allowed those who had previously not given consent, to revise their decision.

- **Further information recorded by the researcher**

The researcher recorded the length of the interview (in minutes), places of the interview and any other observations.

- Quality of Life Uniscale

This was an observer-rated measure of quality of life (part of the Lancashire Quality of Life Profile, Oliver 1991).

- Severity of illness

Same as recruitment questionnaire (see Appendix Seven).

- Record of attendance for antipsychotic depot medication

This information was collected from community psychiatric nurse, general practitioner, or out-patient services.

QUALITY OF LIFE AND MEDICATION
ADHERENCE STUDY

COMMUNITY QUESTIONNAIRE

DATE OF INTERVIEW

START TIME
FINISH TIME

Although we know about the immediate benefits of using medicine given by injection for treating the symptoms of your illness, we would like to increase our knowledge of the long term effects. In particular, we would like to know about the way people's general health and lifestyle are affected. To do this we are carrying out a study of people on your medication and would like you to take part. All replies will be treated in the strictest confidence; no individuals will be identified in the final report.

I would like to ask you about your views and opinions of the medication you receive. The answers you give are treated as confidential. Please answer as openly as possible.

1. Are you taking any medication at the moment, including any injections?
- Yes 1

No 2
- Go to Qu. 2

- Go to Qu. 14
2. Can you name them?
- Injection:

Others:
- 3a. In your opinion, what difference has the medication, including your injection, made to the symptoms of your illness?

- 3b. Since you have been taking your medication, including your injection, how would you say your symptoms have been?

Substantially worse 1
Much worse 2
Somewhat worse 3
No change or same 4
Somewhat better 5
Much better 6
All better 7

4. Do you have any problems with your medication, or your injection, for example, side-effects?

Yes 1 - Go to Qu. 5
No 2 - Go to Qu. 8

5. Can you tell me about them? (PROBE / PROMPT)

6. Do you feel that these side-effects you have just told me about, (**mention the side-effects reported by the client**) affect anything you do or anything you would like to do?

Yes 1 - Go to Qu. 7
No 2 - Go to Qu. 8

7. Would you like to tell me in what way?

8. Have you ever felt like NOT taking your medication, or NOT having your injection?

Yes 1 - Go to Qu. 9
No 2 - Go to Qu. 11

9. Would you like to tell me why?

10. What happened when you didn't take your medication or didn't go for your injection?

11. Have there been any changes to your medication or injection since you were discharged, for example, the name, how much you have or how often you take it?

Yes 1 - Go to Qu. 12
No 2 - Go to Qu. 17

12. Would you like to tell me in what ways it has changed?

13. Why did it change?

NOW GO TO QUESTION 17

14. Would you like to tell me why?
(Did you discuss this decision with anyone?)

15. How do you feel now that you are not taking any medication or receiving any injection?

16. What difference, if any, has stopping your medication (including your injection) made to your life in general?

17. At this moment in time, are you in contact with any of the following and if so, how often are you in contact with them?

SERVICE	In contact - YES / NO	FREQUENCY				
		daily	more than daily inc. weekly	more than weekly inc. monthly	more than monthly inc. 3 monthly	more than 3 monthly inc. 6 monthly
Psychiatrist						
GP						
CPN - injection						
CPN - other						
Social Worker						
Key Worker						
Occupational Therapist						
Neighbours						
Friends						
Religious Figure						
Home Help						
Family						
Counsellor / therapist						
MIND, PRA etc						
Psychologist						
Housing Officer						
Other						

Now I would like to ask you some questions about what you think about your illness. I would like to know your opinions and views. There are no right or wrong answers.

18a. Do you think there is anything the matter with you?

(What do you think it is?)

(Could it be a nervous condition?)

(What do you think the cause is?)

(Why did you need to go to hospital?)

(Do you think (*specific delusions or hallucinations*) were part of a nervous condition?

18b. In your opinion, have you been told as much as you need to know about the state of your health?

19. In your opinion, do you feel that medication helps the symptoms of your illness?

Yes	1	- Go to Qu. 20
No	2	- Go to Qu. 21
DK	3	- Go to Qu. 21

20. Would you like to tell me in what ways?

May I now ask you more about how you feel about your illness and how you feel your illness affects your life in general, when you are out and about in the community? I am interested to hear exactly what you think.

21. Do you feel discriminated against because of the state of your health? (May use the words 'treated differently' if needed).

No 1
Partly 2
A lot 3

HEALTH

I would like to ask you some questions about your health.

22. Can you remember the date you were discharged from hospital?

Day ____ Month ____ Year ____

23. Are you experiencing any symptoms of your illness now?

24. Are you experiencing any problems that **you** feel are making your illness worse?

25. Have you any other health problems, any physical health problems?

26. Do you feel that your medication or the symptoms you are experiencing affects the way you spend your day, for example, your hobbies, your leisure time?

Yes	1	- Go to Qu. 27
No	2	- Go to Qu. 28
DK	3	- Go to Qu. 28

27. Can you tell me in what ways?

For each of us, happiness and satisfaction in life depends on those parts or areas of life which are important to us. What is considered important varies from person to person. That which is most important to you may not be so important to someone else and vice versa.

We are interested in finding out what the most important areas of your life are at the moment. Sometimes it is easier to identify what is important by thinking about the areas of your life that would (or do) cause us most concern when they are missing or are going badly.

28. What are the five most important areas of your life at present - the things which make your life a relatively happy or sad one at the moment... the things you feel determine your quality of life?

Can you name them in priority order?

1st most important

2nd most important

3rd most important

4th most important

5th most important

Now that you have named the five most important areas in your life, I am going to ask you to rate how each of these areas is for you at the moment.
First I will show you an example of how the rating is done.

SHOW CARD

Here are some faces expressing various feelings. These faces range from a face expressing 'the worse life imaginable' at face number 1 to 'the best life imaginable' at face number 7, passing through 'very bad', 'bad', 'alright' (neither good nor bad), 'good' and 'very good' between the two extremes.

If I choose face number 4, it means that I am relating the quality of my life in relation to (choose an area of life not mentioned by respondent as your example) as alright (neither good nor bad). If I choose face number 2, it means that I am rating the quality of my life in this area as very bad. Choosing face 6 means rating my life in this area as very good. So if the first important area of your life is X (choose an area not mentioned by the respondent to illustrate this), and if this is going very well at the moment, I can show this by choosing face 6, or if it is going better than this I would choose face 7.

29. In relation to the five most important things that you mentioned, now can you rate your life using these faces? So please choose the face to indicate your rating of your quality of life, starting with the first most important thing you mentioned:

1st most important

2nd most important

3rd most important

4th most important

5th most important

30. Now, thinking about these five areas of your life, and how you have rated them, which face comes closest to expressing how you feel about your overall quality of life at the moment:

OVERALL QUALITY OF LIFE:

31. In relation to your illness, what would you say are the five most important areas of your life that have been affected by this? These may be the same as those that you have already named or different.

Can you name them in priority order:

1st most important

2nd most important

3rd most important

4th most important

5th most important

Now I would like to ask you about some aspects of your life and how you feel about them. Also I would like to remind you that your answers you give are treated as confidential. Please answer as openly as possible.

During this part of the interview I shall quite often ask you which of the following best describes your overall feelings about a question (for questions with asterisk).

GENERAL WELL-BEING

- 32a) Can you tell me how you feel about your life as a whole today? *
- b) Are there any particular events/reasons why you feel different today from any other day, in general?

WORK/EDUCATION

33. Do you have a job?
- | | | | |
|-----|-------|---|----------------|
| No | | 0 | - Go to Qu. 39 |
| Yes | | 1 | - Go to Qu. 34 |
| NK | | 9 | - Go to Qu. 40 |
34. What is your occupation?
35. How many hours a week do you work?
36. I understand if you don't want to answer this question, but, how much money are you paid weekly (pounds)?

How satisfied are you with : *

37. Your job? (or sheltered employment; occupation or industrial therapy; studies)

38. The amount of money that you make? - Go to Qu. 40

39. Being unemployed or retired?

LEISURE/PARTICIPATION

In the past fortnight have you:

No		0
Yes		1
NK		9

40. Been out to play or watch a sport?

41. Been out shopping?

42. Been for a ride in a bus, car or train other than for transport to and from work?

43. Watched television or listened to radio?

44. In the past year, have there been times when you would have liked to have had more leisure activity but were unable?

How satisfied are you with: *

45. The amount of pleasure you get from things you do at home?
46. The amount of pleasure you get from things you do outside your home?
47. The pleasure you get from radio or TV?

RELIGION

48. What is your religion now?

Protestant	1
Roman Catholic	2
Jewish	3
Muslim	4
Hindu	5
Other (please state)	6
None	7

49. How often have you attended religious services on the past month?

How satisfied are you with: *

- 50. Your religious faith and its teachings?

- 51. The frequency with which you attend services?

FINANCES

I would like to ask you some questions about your finances, for example, questions about the benefits you receive and whether, IN YOUR OPINION, you receive enough money to live on. Some people may find these types of questions embarrassing and you don't have to answer them if you don't want to.

- 52. What is your total weekly income (pounds)?

- 53. Do you receive state benefits?

- 54. In the past year, have you been turned down for any state benefit for which you have applied?

No 0

Yes 1

NK 9

- 55. About how much more money per week do you need to be able to live as you would wish?

56. During the past year, have you lacked the money to enjoy everyday life as you would wish?

No	0
Yes	1
NK	9

How satisfied are you with: *

57. How well-off you are financially?

58. The amount of money you have to spend on enjoyment?

LIVING SITUATION

59. Can you tell me what type of accommodation you are living in at the moment?

Hostel	1
Boarding-out	2
Group home	3
Hospital ward	4
Sheltered housing	5
Private house (owner occupied)	
Private house (rental) . . .	7
Flat	8
Other	9
None	10

60. How long have you lived here (in months)?

61. How many other people live here?

62. Do your family live here too?

No 0

Yes 1

NK 9

63. In the past year have there been times when you wanted to move or improve your living conditions but were unable to do so?

No 0

Yes 1

NK 9

How satisfied are you with: *

64. The living arrangements here?

65. The amount of independence you have here?

66. The amount of influence you have here?

67. Living with the people you do?

68. The amount of privacy that you have here?

69. The prospect of living here for a long time?

70. The prospect of returning to live in hospital?

LEGAL AND SAFETY

In the past year have you been:

71. Accused of a crime?
72. Assaulted, beaten, molested or otherwise a victim of violence? (Only code if physical contact involved)
73. In the past year have there been any times when you would have liked police or legal help but were unable to get it?

How satisfied are you with: *

74. Your general personal safety?
75. The safety of this neighbourhood?

FAMILY RELATIONS

76. What is your current marital status?

Married	1
Single	2
Widowed	3
Divorced	4
Separated	5
Other	6

77. How many children do you have?

78. How often do you have contact with a relative?

Daily	1
Weekly	2
Monthly	3
Annually	4
Less than annually	5
Not appropriate	6

79. In the past year have there been any times when you would have liked to have participated in family activities but were unable?

No	0
Yes	1
NK	9

How satisfied are you with: *

80. Your family in general?

81. The amount of contact you have with your relatives?

82. Your marriage (if applicable)?

SOCIAL RELATIONS

No	0
Yes	1
NK	9

People differ in how much friendship they need:

83. Would you say that you are the sort of person who can manage without friends?

84. Do you have anyone who you would call a "close friend" (ie who knows you very well)?

85. Do you have a friend to whom you could turn for help if you needed it?

86. In the past week, have you visited a friend?

How satisfied are you with : *

87. The way you get on with other people?

88. The number of friends you have?

HEALTH

No		0
Yes		1
NK		9

During the **past year** have you:

89. Seen a doctor for a physical illness?

90. Seen a doctor for?

91. Been in hospital for?

92. Do you take medication for?

93. Do you have any physical handicap which effects your mobility?

94. How old were you when you were first admitted to a psychiatric hospital/ward?

years

95. In the past year have there been times when you wanted help from a doctor or other professional for your health but were unable to get it?

No		0
Yes		1
NK		9

How satisfied are you with: *

96. Your general state of health?

97. How often you see a doctor?

98. Your well-being?

During the **past month** did you ever feel:

No		0
Yes		1
NK		9

- 99. Pleased about having accomplished something?
- 100. That things were going your way?
- 101. Proud because someone complimented you on something you had done?
- 102. Particularly excited or interested in something?
- 103. "On top of the world"?
- 104. Too restless to sit in a chair?
- 105. Bored?

- 106. Depressed or very unhappy?
- 107. Very lonely or remote from other people?
- 108. Upset because someone criticised you?

SELF-CONFLICT

How satisfied we are with ourselves is also a very important part of our lives. Do you agree that the following statements apply to you:

No		0
Yes		1
NK		9

- 109. You feel that you're a person of worth, at least on an equal plane with others.
- 110. You feel that you have a number of good qualities.
- 111. All in all, you are inclined to feel that you are a failure.

112. You are able to do things as well as most others.
113. You feel you do not have much to be proud of.
114. You take a positive attitude towards yourself.
115. On the whole, you are satisfied with yourself.
116. You wish you could have more respect for yourself.
117. You certainly feel useless at times.
118. At times you think you are no good at all.

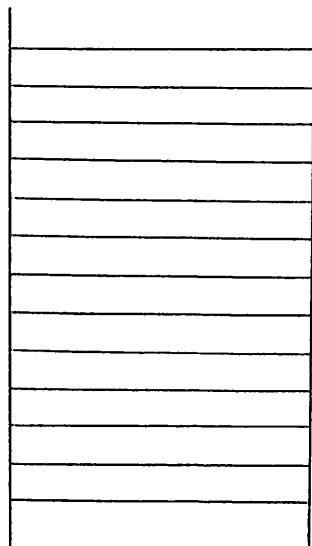
GENERAL WELL-BEING

During the course of this interview, you and I have discussed many of the conditions of your life and how you feel about them. Might we try and sum them up now?

119. Can you tell me how you feel about life as a whole? *

120. This is a picture of a ladder. I would like you to imagine that the bottom of the ladder represents the very worst outcome which you could expect to have had in your life. The top represents the very best possible outcome you could have expected. Can you please mark (X) where on this ladder that you would put your life at present? (**Ask client to mark ladder!**)

BEST POSSIBLE OUTCOME



WORST POSSIBLE OUTCOME

121. How happy has your life been over-all?

Very happy	1
Pretty happy	2
Not happy	3
Don't know	4

122. Can you name anything(s) which would improve the quality of your life?

123. Are there any other aspects of life that are important to you that you feel we haven't talked about?

124. Are there any activities that you would like to become involved in that we haven't talked about today?

125. Before you were discharged, do you know if there were any special plans made for your care in the community?

Yes	1	GO TO QU. 126
No	2	GO TO QU. 127
DK	9	GO TO QU. 127

126. How satisfied are you with these plans? *

GO TO QU. 128

127. When you left hospital, would you have liked to have had special plans made for your care in the community?

Yes	1
No	2
DK	9

128. Do you have a named key worker?

Yes	1	GO TO QU. 129
No	2	GO TO QU. 130
DK	9	GO TO QU. 130

129. How satisfied are you with your named key worker? *

GO TO QU. 131

130. Would you have liked to have had a named key worker?

Yes	1
No	2
DK	9

131. Do you know if there are any special plans concerning your treatment, medication or injection?

Yes	1	GO TO QU. 132
No	2	GO TO QU. 134
DK	9	GO TO QU. 134

132. Would you like to tell me about them?

133. How satisfied are you with these plans? *

GO TO QU. 136

134. Would you have liked to have had a treatment plan?

Yes	1	GO TO QU. 135
No	2	GO TO QU. 136
DK	9	GO TO QU. 136

135. Would you like to tell me what it would be like?

136a. Do you have any questions that you would like to ask me either about your medication, any aspect of the study or are there any further comments which you would like to add?

136b. When we first met in hospital, you said that it would be okay to talk to:

.....

to see how they think things are going for you. Is that still okay with you and can I just check that I can contact them at:

.....

.....

.....

.....

THANK YOU VERY MUCH FOR YOUR CO-OPERATION

INTERVIEWER COMMENTS

137. How long did the interview take? (Minutes)

138. Place of interview:

CPN Clinic 1
GP Surgery 2
Day Centre 3
Own home 4
Other, please specify 5

139. How reliable or unreliable do you think the client's responses were?

Very reliable 1
Generally reliable 2
Generally unreliable 3
Very unreliable 4

140. Please complete the QUALITY OF LIFE UNISCALE now.

PLEASE MARK WITH AN X THE APPROPRIATE PLACE
WITHIN THE BOX TO INDICATE YOUR RATING OF THIS
PERSON'S PRESENT QUALITY OF LIFE.

LOWEST quality applies to someone completely dependent physically
on others, seriously mentally disabled, unaware of surroundings
and in a hopeless position.

HIGHEST quality applies to someone physically and mentally
independent, communicating well with others, able to do most
things enjoyed, pulling own weight, with a hopeful yet realistic
attitude.

LOWEST
QUALITY

HIGHEST
QUALITY

Copyright: J Oliver, March 1990

141. Please complete the GAF Scale rating.

142. Checked with staff Yes / No

143. Please record the record of attendance since discharge at the Depot Clinic. Record appointments, date and time of attendance and any changes to drug regimen that may have been made.

DATE OF DISCHARGE:

DATE of appointment	TIME of appointment	DATE AND TIME ATTENDED	PRESCRIPTION	
			prescribed	received

Further comments:

LIFE SATISFACTION SCALE (LSS)

1	Can't be worse
2	Displeased
3	Mostly Dissatisfied
4	Mixed (about equally satisfied and dissatisfied)
5	Mostly satisfied
6	Pleased
7	Can't be better

APPENDIX NINE

CONFIDENTIAL

Serial Number

QUALITY OF LIFE AND MEDICATION ADHERENCE STUDY

CARER QUESTIONNAIRE

This questionnaire is part of a study investigating the long term effects of injected medication. _____ has named you as someone he/she knows well and would like you to take part in this study. I would be very grateful to know your opinions and views about his/her illness and the medication used to treat the illness.

All replies are treated as strictly confidential and no individuals can be identified in the final report of the study. If you have any questions please telephone Sally-Anne Francis on 0171 982 6000 ext. 5621 at the Dept. General Practice, Medical College of St. Bartholomew's Hospital, Charterhouse Square, London EC1M 6BQ.

Please fill in the date you are completing this questionnaire: / /1995

Please circle the number representing your reply or write it in:

1. Is _____ taking any medication at the moment, including any injections?

Yes	1	GO TO QUESTION 2
No	2	GO TO QUESTION 12
Don't know	3	GO TO QUESTION 16

2a. Please circle the type of medication below (you can circle more than one):

Tablets/Capsules	1
Syrup/Mixture	2
Injection	3
Other	4
Not sure	5

2b. If you can, please name the medication (and/or injection):

3. In **your** opinion, what difference has the medication, including the injection, made to the symptoms of _____ illness?

4. Since _____ has been taking the medication, including the injection, how would you say their symptoms have been?

Substantially worse	1
Much worse	2
Somewhat worse	3
No change or same	4
Somewhat better	5
Much better	6
All better	7

5a. Do you think that he/she has any problems with the medication, for example, any side effects?

Yes	1	GO TO QUESTION 5b
No	2	GO TO QUESTION 7
Don't know	3	GO TO QUESTION 7

5b. Can you tell me about them?

6a. Do you feel that these side-effects affects anything that _____ does or anything that _____ would like to do?

Yes	1	GO TO QUESTION 6b
No	2	GO TO QUESTION 7
Don't know	3	GO TO QUESTION 7

6b. Can you tell me in what ways?

7a. Are you aware of _____ NOT wanting to take his/her medication, or NOT have his/her injection?

Yes	1	GO TO QUESTION 7b
No	2	GO TO QUESTION 8
Don't know	3	GO TO QUESTION 8

7b. Do you know why?

8a. In the past, has _____ stopped taking his/her medication or injection?

Yes	1	GO TO QUESTION 8b
No	2	GO TO QUESTION 9
Don't know	3	GO TO QUESTION 9

8b. What happened after they stopped it?

9a. In **your** opinion, do you think that _____ should be taking any medication or receiving an injection?

Yes	1	GO TO QUESTION 10
No	2	GO TO QUESTION 9b
Not sure	3	GO TO QUESTION 10

9b. Why do you say that?

10. What is **your** opinion of the medication or injection that _____ receives?

11. In **your** opinion, what difference, if any, has receiving medication and/or an injection made to _____ life, in general?

GO TO QUESTION 16 ON PAGE 5

12. Do **you** know why?

13. In **your** opinion, what difference has stopping the medication and/or injection made to the symptoms of _____ illness?

14. Since _____ has stopped taking their medication and/or injection, how would **you** say their symptoms have been?

Substantially worse	1
Much worse	2
Somewhat worse	3
No change or same	4
Somewhat better	5
Much better	6
All better	7

15. In **your** opinion, what difference, if any, has stopping the medication and/or injection made to _____ life in general?

16. Please write **YES/NO** in the box if _____ is in contact with any of the following services. If the answer is **YES**, please tick the frequency box as to how often he/she is in contact with them. (If you are not sure, write **DK** in the box).

SERVICE	In contact - yes/no (DK)	FREQUENCY				
		daily	more than daily including weekly	more than weekly including monthly	more than monthly including 3 monthly	more than 3 monthly including 6 monthly
Psychiatrist						
GP (own doctor)						
Community Nurse (CPN) for injection						
Community Nurse (CPN) at other times						
Social Worker						
Key Worker						
Occupational Therapist						
Neighbours						
Friends						
Religious Figure						
Home Help						
Family						
Counsellor / therapist						
MIND, PRA etc						
Psychologist						
Housing Officer						
Other						

17. Is _____ experiencing any symptoms of an illness now? If so, please can you tell me about them?

18. Is _____ experiencing any problems that **you** feel are making his/her illness worse?
19. Does _____ have any other health problems, any physical health problems?

I would like to ask you some questions about different aspects of _____'s life. I would like to remind you that the answers you give are treated as confidential. Please answer as openly as possible.

WORK/EDUCATION

20. Does _____ have a job?
- | | | |
|----------------------|---|--------------------------|
| Yes | 1 | GO TO QUESTION 21 |
| No | 2 | GO TO QUESTION 23 |
| Don't Know | 3 | GO TO QUESTION 23 |

21. What is his/her occupation?

22. How many hours a week does he/she work?

GO TO QUESTION 24

- 23a. What was _____'s most recent job?
- 23b. How long ago was _____'s most recent job?
24. Do you know if _____ has any written qualifications, or has passed any examinations, whether he/she is making use of them now or not?
- | | | |
|----------------------|---|--------------------------|
| Yes | 1 | GO TO QUESTION 25 |
| No | 2 | GO TO QUESTION 26 |
| Don't Know | 3 | GO TO QUESTION 26 |

25. Would you like to tell me about them?

FINANCES

26. Do you know what _____'s total weekly income (pounds)?

27. Does _____ receive state benefits?

28. In the past year, do you know if _____ has been turned down for any state benefit for which he/she has applied?

No	0
Yes	1
Don't know	9

LEISURE/PARTICIPATION

During the period _____ do you know if _____:

29. Went out to play or watch a sport?

No	0
Yes	1
Don't Know	9

30. Went out shopping?

No	0
Yes	1
Don't Know	9

31. Went for a ride in a bus, car or train other than transport to and from work?

No	0
Yes	1
Don't Know	9

32. Watched television or listened to radio?

No	0
Yes	1
Don't Know	9

RELIGION

33a. Do you know if _____ follows a religion?

No 0

Yes 1

Don't Know 9

GO TO QUESTION 35

GO TO QUESTION 33b

GO TO QUESTION 35

33b. Can you name it?

34. Do you know how often he/she attended religious services in the period
_____?

LIVING SITUATION

35. Can you tell me what type of accommodation _____ lives in?

Hostel 01

Boarding-out 02

Group home 03

Hospital ward 04

Sheltered housing 05

Private house (owner occupied) 06

Private house (rental) 07

Flat 08

Other (please name) 09

None 10

36. How long has he/she lived there?

37. How many other people live there?

38. Does _____'s family live there too?

No 0

Yes 1

Don't know 9

LEGAL AND SAFETY

In the past year, do you know if _____ has been:

39. Accused of a crime?

40. Assaulted, beaten, molested or otherwise a victim of violence?
(Only code if physical contact involved).

FAMILY RELATIONS

41. What is _____'s current marital status?

Married	1
Single	2
Widowed	3
Divorced	4
Separated	5
Other (please name)	6

42. Do you know how many children _____ has?

43. How often does _____ have contact with a relative?

Daily	1
Weekly	2
Monthly	3
Annually	4
Less than annually	5
Not appropriate	6

HEALTH

During the **past year** do you know if _____ has:

44. Seen a doctor for a physical illness?

45. Does _____ have any physical handicap which effects his/her mobility?

46. Do you have any suggestions which you would feel would:

a) improve _____'s quality of life?

b) help _____ to overcome his/her mental health problems?

THANK YOU VERY MUCH FOR YOUR HELP

Please return this questionnaire to: Sally-Anne Francis, Department of General Practice, Medical College of St Bartholomew's Hospital, Charterhouse Square, LONDON EC1M 6BQ

APPENDIX TEN

American Psychiatric Association (1987) *Diagnostic and Statistical Manual of Mental Disorders* (3rd edn., revised) (DSM-III-R). Washington, DC: APA.

Diagnosis of Schizophrenia (295.XX)

- A. Presence of characteristic psychotic symptoms in the active phase: either (1), (2), or (3) for at least one week (unless the symptoms are successfully treated):
- (1) two of the following:
 - (A) delusions
 - (B) prominent hallucinations (throughout the day for several days or several times a week for several weeks, each hallucinatory experience not being limited to a few brief moments)
 - (C) incoherence or marked loosening of associations
 - (D) catatonic behaviour
 - (E) flat or grossly inappropriate affect
 - (2) bizarre delusions (i.e., involving a phenomenon that the person's culture would regard as totally implausible, e.g., thought broadcasting, being controlled by a dead person)
 - (3) prominent hallucinations (as defined in [1(b)] above) of a voice with content having no apparent relation to depression or elation, or a voice keeping up a running commentary on the person's behaviour or thoughts, or two or more voices conversing with each other
- B. During the course of the disturbance, functioning in such areas as work, social relations, and self-care is markedly below the highest level achieved before onset of the disturbance (or, when the onset is in childhood or adolescence, failure to achieve expected level of social development).
- C. Schizoaffective Disorder and Mood Disorder with Psychotic Features have been ruled out, i.e., if a Major Depressive or Manic Syndrome has ever been present during an active phase of the disturbance, the total duration of all episodes of a mood syndrome has been brief relative to the total duration of the active and residual phases of the disturbance.
- D. Continuous signs of the disturbance for at least six months. The six-month period must include an active phase (of at least one week, or less if symptoms have been successfully treated) during which there were psychotic symptoms characteristic of Schizophrenia (symptoms In A), with or without a prodromal or residual phase, as defined below.

Prodromal phase: A clear deterioration in functioning before the active phase of the disturbance that is not due to a disturbance in mood or to a Psychoactive Substance Use Disorder and that involves at least two of the symptoms listed below.

Residual phase: Following the active phase of the disturbance, persistence of at least two of the symptoms noted below, these not being due to a disturbance in mood or to a Psychoactive Substance Use Disorder.

Prodromal or Residual Symptoms:

- (1) marked social isolation or withdrawal
- (2) marked impairment in role functioning as wage-earner, student, or homemaker
- (3) markedly peculiar behaviour (e.g., collecting garbage, talking to self in public, hoarding food)
- (4) marked impairment in social hygiene and grooming
- (5) blunted or inappropriate affect
- (6) digressive, vague, overelaborate, or circumstantial speech, or poverty of speech, or poverty of content of speech
- (7) odd beliefs or magical thinking, influencing behaviour and inconsistent with cultural norms, e.g., superstitiousness, belief in clairvoyance, telepathy, "sixth sense", "others can feel my feelings", overhauled ideas, ideas of reference
- (8) unusual perceptual experiences, e.g., recurrent illusions, sensing the presence of a force or person not actually present
- (9) marked lack of initiative, interests or energy

Examples: Six months or prodromal symptoms with one week of symptoms from A; no prodromal symptoms with six months of symptoms from AS; no prodromal symptoms with one week of symptoms from A and six months of residual symptoms.

- E. It cannot be established that an organic factor initiated and maintained the disorder.
- F. If there is a history of Autistic Disorder, the additional diagnosis of Schizophrenia is made only if prominent delusions or hallucinations are also present.

APPENDIX ELEVEN

Case reports of respondents followed-up greater than six months after discharge

CASE 08

The researcher met Case 08 incidentally on one hospital ward. She was unable to be interviewed at that time and so arrangements were made to meet one week later in the hospital depot clinic (where she reported to be receiving her injection). A letter was written to Case 08 to remind her of the meeting. Case 08 did not attend. Consulting depot clinic records showed that Case 08 had not attended for 2 months. The researcher contacted the Locality Team for information about the medication administration of this client. Case 08 had not been assigned a key worker, however, the researcher was given the telephone number of a care worker. This number had been disconnected. The researcher wrote directly to Case 08 with an appointment to meet on the hospital ward. Case 08 did not attend. The researcher wrote to Case 08 informing her of a home visit. (A member of the academic department (LM) where the researcher was based agreed to accompany the researcher). A neighbour reported that no-one lived at the address. The researcher went back to the medical records and found a letter including a hostel address. The researcher wrote to Case 08 with another home visit date. Case 08 was not at home when the researcher called. The researcher contacted Case 08's hostel key worker who arranged another home visit date, with Case 08, on behalf of the researcher. This visit was a success.

CASE 11

No Part II of the discharge summary was lodged in the medical notes, therefore, the discharge plans for this respondent were unknown. The researcher contacted the Locality Team CPN (community psychiatric nurse). The nurse explained that Case 11 was rarely in when he called to administer his injection and therefore had not received any medication for some time. The researcher confirmed that Case 11 did not have a violent history and that visiting him at home would be safe. The researcher wrote to Case 11 informing him of a home visit. A colleague (LM) accompanied the researcher to Case 11's home. This was a council flat, on the top floor of a high rise block, in Hackney, East London. On arrival at Case 11's flat, the front door and lights were smashed and boarded up. There was no answer. The researcher wrote with another home visit date and returned a second time with LM. Case 11 was at home this time and part-completed the questionnaire. The only furniture in the room was three dining chairs and many filled black bin sacks. The researcher and LM returned for a third visit to complete the questionnaire. At this stage, Case 11 was proud to show the addition of a table he had received from social services.

CASE 22

There was some difficulty locating Case 22's notes between the ward, the Consultant's secretary and the Medical Records Department. The CPN responsible for Case 22 was contacted by letter, but he was on leave. The replacement CPN did not want to help the researcher because she felt that she did not know Case 22 very well and preferred that the researcher waited for the return of the regular CPN. On the return of the regular CPN, the next depot was due when the researcher was on annual leave. Case 22 was finally met in the CPN clinic; the interview was only part-completed. At this stage, the regular CPN was going on a one-year sabbatical. Arrangements had to be made for the researcher to meet the replacement CPN to organise a subsequent meeting with Case 22. On the second meeting,

the community interview was complete.

CASE 29

The discharge summary named the CPN responsible for visiting Case 29 at home, to administer the depot medication. The researcher wrote to the CPN asking if she could accompany him on a visit to the home. The CPN did not reply to the letter. Finally, after many telephone calls, the researcher spoke to the CPN who explained that he was no longer responsible for Case 29. The researcher contacted the replacement CPN, initially by letter and then by telephone call. Again, repeatedly trying to contact the CPN wasted time. The new CPN explained that Case 29 had decided to be responsible for his own medication and was now attending another CPN's clinic in a local health centre. The researcher wrote to the third CPN and gained permission to meet and interview Case 29 in the health clinic. The researcher wrote to Case 29 and arranged a successful meeting in the health clinic.

CASE 33

Arrangements were made for Case 33 to receive her depot medication at Hackney Hospital's depot clinic, however, her attendance was sporadic and rarely on the day expected. The researcher asked Case 33, by letter, to meet the researcher in the depot clinic, but she did not attend. The researcher arranged a home visit and informed Case 33 in writing. LM accompanied the researcher. Case 33 was not at home. A second visit was arranged and Case 33 was not at home, however her neighbour informed the researcher that she attends a day centre most days. The researcher contacted the social worker who could give the name of the day centre. The day centre was contacted and asked for their permission for the researcher to interview Case 33 on the site. A letter was written to Case 33 to inform her of the meeting. A successful interview was completed.

CASE 35

Medical notes for Case 35 could not be found for some time. Medical records and the Consultant's secretary both reported that the notes had not left the ward while the ward reported that they no longer had them. Finally, the researcher discovered them on the ward. The researcher contacted the CPN responsible for administering the depot injection. The CPN reported that he met Case 35 back on the ward. The researcher wrote to Case 35 arranging to meet him on the ward, for the community interview, after his next injection. On that day, Case 35 did not attend. The researcher arranged a second visit for 3 weeks time when the next depot was due. Case 35 did not attend. The notes were checked and the Consultant had extended the regime from 3 weekly to 4 weekly. The researcher met Case 35 on the third visit.

CASE 36

The discharge summary stipulated the date that Case 36 was discharged from her section but did not complete the date that she was discharged from the hospital. The researcher asked for this information from ward staff, however, they were unable to provide the discharge date. The researcher contacted the Consultant's secretary who was unable to help with the missing information and suggested contacting one of the psychiatrists. The psychiatrist on the ward was asked, however, there had been an August change over of junior staff and he did not know Case 36. The researcher wrote to the Consultant Psychiatrist for the information. This letter was followed-up with a phone call. Finally, the researcher spoke to the Senior Registrar who provided the discharge date. The CPN was contacted to find out the arrangements for administering the depot injection. Case 36 visited the CPN's clinic in

the health centre to receive her injection. Case 36 was sent a letter explaining that the researcher wanted to interview her after she received her depot medication. Case 36 did not attend. The researcher checked the CPN's notes and realised that Case 36 had changed her address since being discharged. Subsequent arrangements were made with Case 36 and the interview was completed with 2 visits at the health centre.

CASE 50

From the medical notes, it was established that Case 50 received his injection from the CPN at home. The CPN was contacted to ask if the researcher could accompany her on a home visit. The CPN explained that Case 50 did not like people calling on him and she wanted to ask his permission first. The researcher left many phone call messages for the CPN to find out whether Case 50 agreed to be interviewed. The CPN did not return the calls. Finally, the researcher was told that the CPN had gone holiday. The researcher contacted the replacement CPN who was willing for the researcher to accompany him on a visit. Case 50 completed a successful interview.

CASE 56

The researcher arranged three separate appointments at the Hackney depot clinic and Case 56 did not attend any. On the fourth attempt, the CPN of the Locality Team was contacted who arranged for me to accompany him on a home visit. Case 56 did not answer. The CPN and researcher visited a friend's house of Case 56, however, he had not seen Case 56 that day. The CPN subsequently organised for Case 56 to meet him in the Locality Team offices and invited the researcher to interview him there. The interview was a success.

APPENDIX TWELVE

Five areas of life that contribute to quality of life generated using adapted Schedule for the Evaluation of Individual Quality of Life (SEIQoL) questions.

Notes: Case numbers precede the comments and priority ranking follows the comments in parantheses.

● Work/education

- 03 To find a job. I'm a copy typist. (3rd)
- 09 Doing an M. Phil. Planning my research for an M. Phil. (1st)
- 11 Work. I am unemployed. (1st)
- 26 I can't read. I'd like to. (1st)
- 29 If I could find a job to occupy my time and relieve the boredom and earn a living. (3rd)
- 34 A work or a past-time. An occupation. Something that satisfies one in life, something that would make me feel social and trustworthy. Something to make me feel responsible. (2nd)
- 40 The chance to join a school. (4th)
- 45 Education. Community college. (1st)
- 49 Education. (Not prioritised)
- 64 Education. Knowledge. I study at home. (2nd)
- 66 [The] people [I] work with. (2nd)
- 68 To go back to work. (1st)
- 70 Looking for work. (3rd)
- 89 To have a job. (1st)

● Leisure activities/social life

- 01 Listening to the radio - enjoy the radio. (3rd)

- 03 Playing the piano. (2nd)
- 04 Playing drums. (4th)
- 04 My poetry. (5th)
- 07 Going out to the post office for my pension and church. Seeing the people. I have a chat. (3rd)
- 07 Shopping. I like going shopping. I see people out. (4th)
- 07 Television. Just like watching it. (5th)
- 08 Television. (3rd)
- 11 Going on holidays. (4th)
- 14 Reading. (5th)
- 21 I'd like to be doing things. Not much time spent doing things at the moment. (2nd)
- 22 Listening to the radio. (2nd)
- 22 Watching TV. (3rd)
- 22 Going shopping. (4th)
- 22 Going to the launderette. (5th)
- 24 I like playing cricket. I ain't played it in years. I'm a fast bowler. (4th)
- 24 Having nothing to do. I get bored. Don't know what. Not work. (5th)
- 27 Radio. (1st)
- 27 Going to the shop in the morning. I can go on my own now. I didn't use to like going out on my own. (2nd)
- 28 I like going to seaside places. I'm going to Margate this Sunday on a coach. (4th)
- 35 Shopping. I enjoy going to Sainsbury's. I feel pleased with myself. (4th)
- 35 Smoking. Drinking. (5th)
- 45 Library. Could be [better] if services were improved. (2nd)
- 45 Leisure services. (3rd)

- 46 Playing music. (2nd)
- 46 Roller skating. (3rd)
- 46 Dancing. Not much opportunity. (4th)
- 49 Music. (Not prioritised)
- 53 Radio at weekends. (1st)
- 59 Paul McCartney, John Lennon, Elvis and Rock 'n' Roll. (1st)
- 59 Turkish Delight. I love Turkish Delight. (3rd)
- 59 Arnold Schwarzneger in the films. Cinema. (4th)
- 59 I like going to the Lyceum Theatre. (5th)
- 60 Driving with my sister in her car. Going places. (4th)
- 62 News. I like watching the six o'clock news, but the news is always bad news, isn't it? (3rd)
- 66 Music. (3rd)
- 68 Television and video. (2nd)
- 68 Music. (3rd)
- 70 Listening to the radio. (4th)
- 72 Pop music. I've got a cassette player. (1st)
- 72 Smoking. (5th)

● **Religion**

- 01 Religious programmes on the TV. (4th)
- 33 Going to church. It's important to me. I'm a Christian. (1st)
- 34 Spirituality. A belief in something to keep me going. A world beyond ourselves. (5th)
- 36 Going to church. It's good for me. It helps me. (4th)
- 46 Read my bible. Praying. (1st)

- 58 Relationship with God. (1st)
- 68 Religion. I was brought up by nuns. I feel guilty though 'cos I'm not practising but I don't want to. (5th)

● **Finances / standard of living**

- 09 Having a car. It's great being able to get out and about, but I've been broken into twice now. (4th)
- 11 Money. You need money to do things. My money is okay. (2nd)
- 14 I like to have money. Haven't got none. I like buying people things but I can't buy nothing at the moment. (2nd)
- 14 Cheering people up but I haven't got no money so I can't take them anything and I can't go round and cook for them. (4th)
- 21 To go out and be happy... have a good time. At the moment, I can't go out because I haven't got no money. (1st)
- 24 Plenty money. I'd like plenty of money. I get different amounts sometimes but when it's over a hundred, it's alright. I should get £184 a week, but I don't get it. I haven't got none today. (1st)
- 29 Mother in Ghana and brothers and sisters. I don't get to see them. I'd like to but I can't afford the fare. (4th)
- 34 Money. I hate asking or the beggar when poverty is around. A certain amount of security. [It's] not as bad as those in Rwanda. (4th)
- 36 Buying things for the home. I enjoy making the home look nice. (3rd)
- 54 Money. (Not in priority order)
- 72 Buying new clothes. To look nice. (3rd)
- 89 To have a car. (4th)

● **Living situation**

- 03 I want to go back to my own flat. I pay the rent. (1st)
- 04 Living with family I've been placed with [Adult Fostering Scheme]. (1st)

- 09 Having a nice flat. It's nice here. I'd prefer a communal house, but this, this is okay. (5th)
- 11 House. Home. I want to be rehoused. I've been to see one but it wasn't suitable. (3rd)
- 11 I don't like living alone. (5th)
- 21 It makes me sad that I haven't got anything. Nothing is mine in my room. (3rd)
- 28 My old age. I worry where I'll live and who will look after me after Mum's gone. (5th)
- 40 It's quiet living here. (2nd)
- 50 Flat. Cleaner. I just can't be bothered. (5th)
- 53 Not happy here. [hostel] (2nd)
- 60 My flat. I've got a bed. I want central heating. (2nd)
- 66 Independent housing. I want to move from Nicholas House. [hostel] (4th)
- 79 I need a new flat. (2nd)
- 89 To have my own flat. (3rd)

● **Safety/legal**

- 14 I want to move out of Hackney. I don't like it here. I want to live in the country. The people in Hackney are either really nice or really violent. I'm afraid one day, I'll be mugged. There was this old woman and old man in town [Hackney] who had a accident. They was in a car. The man, he was bleeding and there was these kids watching and then they went and stole her handbag. It was real bad. I want to live in Buckinghamshire or Bedford. (1st)
- 28 I was in the park and they were taking the piss out of me. I've been mugged six times. (2nd)
- 40 Housing Association where I was living threw out my belongings when I was in hospital. For example, my text books in Russian. The MIND have contacted them about compensation. We haven't heard yet. (1st)
- 49 People picking on me. (Not prioritised).

● **Relationships with family, relatives**

- 01 Cooped up in this house alone, very lonely. The family don't really appreciate me. They don't love me. (1st)
- 07 Family. My children look after me and visit. (1st)
- 09 Supporting my mother. My father died last year. (3rd)
- 26 Mum (3rd)
- 28 Mum. I wish she could get about more. (3rd)
- 29 Family. (1st)
- 29 I have a 21 year old daughter [who] doesn't want to know me because of my failed marriages. This is the third time I have been married it makes me sad. (2nd)
- 30 Seeing my son makes me happy. That's all. I don't see him often. (1st)
- 31 Seeing my children. Nothing else. They live with my mother. (1st)
- 34 Family. My mother and father. (3rd)
- 36 Children. They keep me going. I'd be lost without them. (1st)
- 36 Sisters. Brother. They're family. (2nd)
- 40 To have communication with the relatives. I feel happy when I receive a letter. My brother is in Russia and is married with a baby. He is not writing at the moment. (3rd)
- 54 Travelling. I want to go to America to live. My sister is there. I have a sister in America and a sister in Australia. My sister from America send me clothes. She came out last year and stayed. We had a good time. I want to move to America to be with her. (Not in priority order)
- 54 I miss my parents they died. (Not in priority order)
- 54 I want to be with my daughter. I want to communicate with her but she doesn't want to communicate with me. (Not in priority order)
- 56 Family. I see my brother every few months and I phone my mother. She nags me. She wants me to go to France to get her a passport but I don't want to go. (1st)
- 58 Relationship with Mum. (3rd)
- 60 Seeing my sister and niece and nephew. (1st)

62 My son. His grandmother takes care of him and so I can't see him all the time. He visits on Sundays. Sandra arranged that [key worker]. I want to get him back full-time that's what I'm going to do. (1st)

62 Keeping in contact with my family. (2nd)

66 My family are important. My sisters and my parents. I see them every few months. (1st)

89 To go to Barbados. Family over there. (5th)

● **Relationships with others inc. intimate relationships**

01 I don't enjoy myself. I've never been on holiday. I'd like to go on holiday but I want to go with someone but I've got no friends. (2nd)

04 Friends. Spending time with them. (2nd)

08 Friendship. Acquaintances. We're all friends here. Sometimes they come into my room to watch TV. (2nd)

09 Seeing friends every evening. I see someone every evening. It's just the day time it can be lonely 'cos all my friends work. (2nd)

27 Going out with Arthur and Leslie. We have a laugh. Sometimes we stay in. We make coffee and sit in my room. (3rd)

33 Meeting people. At church and here [Luncheon Club], I like to have friends and a chat. (2nd)

34 To feel secure within life. Not to feel disliked or unwanted. Friendship. Not to be liked for the sake of being liked. (1st)

35 Relationships with a woman. (3rd)

40 Getting lonely. Needing people to visit but it is difficult getting people to visit. (5th)

50 Wife or girlfriend. I'd like to have a relationship again. (2nd)

54 I went to Claybury for ten years and when I came out I was divorced. I'm sad I got divorced. I never knew why. (Not in priority order)

56 Getting on with each other. (2nd)

56 Friendship and having a good relationship. (3rd)

58 Relationship with a woman. (2nd)

- 58 Good friends. (4th)
- 60 Boyfriend. I don't see him much. (5th)
- 64 People, in general. Acquaintances. (3rd)
- 89 To have a girlfriend. (2nd)

● **Own health inc. unwanted effects of medication**

- 22 Sleep. I like to sleep. (1st)
- 28 My illness. I wish I could get rid of it. I can't control it sometimes. Voices talk to me in my head and tell me what to do. (1st)
- 35 Sleep. (1st)
- 50 Health. It affects everything. I can't do anything because of this illness. (1st)
- 53 Don't sleep very well. (3rd)
- 56 My illness. (4th)
- 56 I wish I could sleep properly. (5th)
- 58 Good health. (5th)
- 66 The injection affects muscles. Can't enjoy sport as much as I used to. (5th)
- 68 Keeping well for the doctor. (4th)
- 70 Health. Taking my medication. (2nd)
- 72 Illness. Dread it every morning. (2nd)
- 79 I need a prescription for down there. It's burning. (3rd)

● **Contact with mental health services and staff**

- 01 I like it that Danielle comes [CPN]. I look forward to Danielle coming. (5th)
[Note that the client was deaf and he lived in a high rise block of flats. The CPN had to arrange the time she would visit, he would stand in the window to watch for her so that he could buzz her in].
- 04 O.T. It's good. We do pottery and art and things. (3rd)

- 07 Receiving my medication every 3 weeks. The nurse [CPN] comes here. I like him visiting. (2nd)
- 08 People nagging. In the hostel. You know, do this, do that. (5th)
- 24 People being kind to me. Down Strauss [ward] they got me a jacket and some shoes. Fitted well they did. These here [hostel staff] they're alright. (2nd)
- 33 The Luncheon Club. It gives me my dinner and see people. I do keep fit sometimes. (3rd)
- 50 Danielle. [CPN] I think a lot of her. I got a postcard all the way from Australia. She's out there on holiday. Gregg's alright. (4th)

● **Conversation/communication**

- 08 Receiving letters from afar. I don't have any often, but is nice if you do. (4th)
- 14 Having conversations. I should converse more, especially with friends and family. (3rd)
- 24 I like to have a joke with someone or a joke with me. I like to enjoy myself. (3rd)
- 59 Conversation and coffee. That's nice. (2nd)

● **Self-care / looking after oneself**

- 26 Like washing my hair. (5th)
- 26 Having a bath. I like to bathe. (4th)
- 35 Food. I find it hard to get going shopping. (2nd)
- 49 Washing clothes. (Not prioritised)
- 60 Clothes. Wearing nice clothes to look nice. (3rd)
- 70 Food. Eating is important. I stopped eating before when I was ill and stopped my medication. I lost weight. (1st)
- 72 Good food. The food here is okay sometimes. (4th)

● **Pets**

- 26 My birds [pets]. (2nd)

50 Cat. She keeps me company. Don't you, girl? (3rd)

79 Cats. (1st)

● **Other**

08 Ambition. You've got to have goals. (1st)

49 Christmas. (Not prioritised) (Interview date: 27.10.94)

64 Living in the first world as opposed to the third world. (1st)

64 An awareness of others. (4th)

64 To be progressive in one's thinking. (5th)

70 Seeing the sunshine. (5th)

APPENDIX THIRTEEN

**Rating of current quality of life in relation to all areas of life named
(ranks 1-5)**

Appendix Table 1 Rating of current quality of life in relation to all areas of life named (ranks 1-5): n=3-40[†]

	Leisure activities / social life [‡]		Relationships with family, relatives [§]		Relationships with others (incl. intimate relationships) [§]		Work / Education		Living situation [‡]		Own health (incl. unwanted effects from medication) [‡]		Finances / Standard of living [§]	
	(n=41)		(n=23)		(n=18)		(n=14)		(n=14)		(n=13)		(n=12)	
	No.	No. (%)	No.	No. (%)	No.	No. (%)	No.	No. (%)	No.	No. (%)	No.	No. (%)	No.	No. (%)
Best life imaginable	3	30 (75)	3	11 (55)	1	9 (53)	1	3 (21)	1	4 (31)	0	5 (42)	1	3 (27)
Very good	18		3		4		1		1		0		0	
Good	9		5		4		1		2		5		2	
All right	6	6 (15)	4	4 (20)	1	1 (6)	3	3 (21)	3	3 (23)	0	0 (---	2	2 (18)
Bad	2	4 (10)	2	5 (25)	2	7 (41)	6	8 (58)	3	6 (46)	4	7 (58)	3	6 (55)
Very bad	1		1		2		1		2		1		0	
Worst life imaginable	1		2		3		1		1		2		3	
Total number of respondents	40		20		17		14		13		12		11	

[†] Cases 53 and 54 could not use the rating scale for the life areas they each named.

[‡] Case 53 did not rate his current quality of life in relation to this area.

[§] Case 54 did not rate her current life quality of life in relation to this area.

Appendix Table 1 ctd. Rating of current quality of life in relation to all areas of life named (ranks 1-5): n=3-40[†]

	Religion / spiritual life		Contact with mental health services and staff		Self-care / looking after oneself		Conversation / communication		Safety and legal issues		Pets		Other areas [‡]	
	(n=7)		(n=7)		(n=6)		(n=4)		(n=4)		(n=3)		(n=6)	
	No.	No. (%)	No.	No. (%)	No.	No. (%)	No.	No. (%)	No.	No. (%)	No.	No. (%)	No.	No. (%)
Best life imaginable	2	6 (86)	2	6 (86)	0	4 (57)	2	3 (75)	0	0 (----	0	3 (100)	3	5 (83)
Very good	2		3		2		0		0		3		2	
Good	2		1		2		1		0		0		0	
All right	0	0 (---)	0	0 (---)	3	3 (43)	1	1 (25)	0	0 (----	0	0 (----	1	1 (17)
Bad	0	1 (14)	0	1 (14)	0	0 (---	0	0 (---	1	4 (100)	0	0 (----	0	0 (---
Very bad	0		1		0		0		2		0		0	
Worst life imaginable	1		0		0		0		1		0		0	
Total number of respondents	7		7		7		4		4		3		6	

[†] Cases 53 and 54 could not use the rating scale for the life areas they each named.

[‡] Case 08: “Ambition, you’ve got to have goals.” [Rating: best life imaginable]; Case 49: “Christmas.” [Rating: very good]; Case 64: “Living in the first world as opposed to the third world.” [Rating: best life imaginable]; Case 64: “An awareness of others.” [Rating: best life imaginable]; Case 64: “To be progressive in one’s thinking.” [Rating: very good]; Case 70: “Seeing the sunshine.” [Rating: alright].