

VOLUME 1

**RECOVERY FROM PSYCHOSIS: STORIES OF ESCAPE, ENLIGHTENMENT
AND ENDURANCE**

**A qualitative study of 15 accounts of recovery after one or more psychotic episodes,
using Interpretative Phenomenological Analysis and Narrative Analysis**

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D.Clin. Psy. 2002

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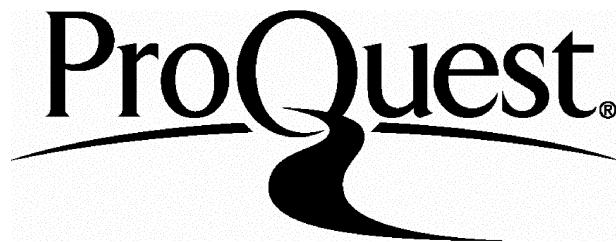
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CONTENTS

	<u>Page</u>
ABSTRACT	i
Acknowledgements	ii
Dedication	iii
Preface	iv
1. INTRODUCTION	1
Overview	1
Psychosis: Background and definitions	2
Recovery: Background and definitions	9
Overview of literature on psychosis and recovery	14
Studies of psychosis in the general population	15
Stress-vulnerability models	16
The role of biology in psychosis and recovery	19
Psychopharmacological treatments for psychosis	24
Studies of familial influence	27
Studies of coping	28
Psychological models of psychotic symptoms	29
Self-monitoring deficit and theory of mind deficit models	29
Hallucinations as errors of interpretation	32
Delusions as defence	33
Multifactorial models of delusions and hallucinations	35
The role of self-focused attention and meta-cognition in psychosis	39
Implications of psychological models for intervention	40
Psychotherapeutic approaches to psychosis and treatment:	
psychodynamic and systemic	43
Social, religious and cultural studies of psychosis and recovery	45
The subjective experience of psychosis and recovery	47
Psychosis and recovery: first person accounts	47
Why study people's subjective experience of psychosis and recovery?	48
Thematic analysis in studies of psychosis and recovery	49
Narrative studies	59
Summary and rationale for the current study	61
Aims of the current research	65
Research questions	65
2. METHOD	66
Overview	66
Choice of methodology	67

Relationship between the two parts of the analysis	73
Participants	75
Inclusion Criteria	76
Ethical considerations	84
Procedure	85
Development of interview schedule	86
Ending the interviews	87
Transcription	87
Interpretative Phenomenological Analysis	88
Credibility checks and validity	90
Narrative analysis	92
Identification of tone, core narrative and genre	92
Analysis of language and meta-narratives	94
Analysis of turning points and stuck points	95
Credibility checks and validity	96
‘Owning one’s perspective’	97
3. RESULTS	100
Overview	100
Results of Interpretative Phenomenological Analysis	105
Results of narrative analysis	127
Core narratives, tone and narrative genre	127
Analysis of the use of language and meta-narratives	139
Analysis of ‘turning points’ and ‘stuck points’	148
4. DISCUSSION	154
Overview	154
Psychological and emotional themes	156
The importance of ‘making sense’ for recovery from psychosis	156
Responses to psychosis: intrapersonal, interpersonal and systemic	160
Telling stories: Communication and ‘finding a voice’	161
‘Working out where you stand’: social and political aspects	163
Narrative analysis	164
What does the analysis of narrative genre tell us about recovery?	164
Narratives of escape	164
Narratives of enlightenment	166
Narratives of endurance	168
Recovery as a process of ‘doing meaning’, ‘doing identity’, and ‘doing agency’	169
The medical meta-narrative	171
The psychological/ psychotherapeutic meta-narrative	172
The societal/ cultural approach and meaning, identity and agency	173
The role of reclaiming language and experience in recovery	176
What did individuals mean by ‘recovery’?	177
Pathways to recovery	179

Critical Reflection	181
Recruitment	181
Interviewing	183
Analysis	184
Addressing questions of validity	186
Areas for further research	199
Implications for psychology, psychiatry and mental health services	202
Conclusion: A whole person approach – a whole systems approach	205
 REFERENCES	 207-234
 APPENDICES	 235-286

LIST OF FIGURES

	<u>Page</u>
Figure 1 – Stress-diathesis model of schizophrenia	18

LIST OF TABLES

	<u>Page</u>
Table 1 – Table showing details of participants	78
Table 2 - Table showing analysis of core narrative, tone and narrative genre	127

ABSTRACT

The aim of the present study was to explore recovery from psychosis. Gaps in the literature were identified, specifically with regard to a lack of research focusing on recovery, non-clinical populations, and the subjective experience of psychosis and recovery. The first aim of the study was to explore psychological and emotional themes which emerged across accounts of recovery from psychosis. The second aim of the study was to examine the kind of stories individuals told about their recovery, allowing for a focus on the narrative aspects of the accounts as wholes, for example their genre, tone, core narrative, kinds of social and cultural language and meta-narratives drawn upon, as well as key 'turning points' and 'stuck points'. Semi-structured interviews were conducted with fifteen individuals who described themselves as recovered or recovering from psychosis. The interviews were transcribed in full. They were analysed using Interpretative Phenomenological Analysis (IPA) in order to examine the psychological and emotional themes which emerged. Narrative analysis was used to analyse the narrative aspects of the accounts. Four clusters of themes emerged from the IPA analysis: the first cluster examined the importance of making sense of the psychosis for recovery, whether as linked to previous experiences of trauma, or to a physical condition, or to part of being a creative, sensitive person, for example. The second cluster addressed themes of the responses to psychosis, by the self, others and systems: whether they were characterised by fear and co-ercion, for example ('beating up') or understanding and acceptance ('tea and sympathy'). The third cluster 'Telling stories', focused on the theme of 'Deception and silence versus honesty and openness', examining the kinds of stories which were told within different contexts. The fourth cluster, 'Working out where you stand' addressed wider themes of human rights and responsibilities within social, political and legal frameworks. In the narrative analysis it was found that the narratives could be categorised as narratives of 'escape', 'enlightenment' and 'endurance'. This suggested different understandings of and pathways to recovery, linked to different experiences of psychosis and different experiences within the mental health system. Key aspects which emerged in the analysis of language, meta-narratives, turning points and stuck points, were the roles of agency, identity and meaning in the recovery process. Recovery was seen to be a fundamentally dialogic process in which the person who has experienced psychosis is able or unable to exercise their autonomy, make meaning from their experiences and hold onto or create a valued identity in interaction with those around them and within wider systems. The results are discussed in light of other research in the field and implications of the study are suggested. The need for future research to elaborate on the findings is stressed.

Acknowledgements

I wish to acknowledge the contribution of a number of people to this thesis. First of all, I owe my thanks to my supervisors, Dr Rufus May and Dr Linda Clare. The topic of the thesis was Rufus' idea. I could not have accessed the participants in the time available without his help. His courage and commitment to furthering public and professional awareness of what it is like to 'be mad' and what kind of helping makes the most sense, has made this thesis possible. Linda has been a rock – a calm, supportive and expert presence who has contributed invaluable to my analysis and write-up.

I owe my thanks to John Rhodes for many fascinating and enlightening discussions on psychosis and recovery and for his contributions to this field, in terms of qualitative studies, case-studies and outcome studies. I would also like to thank Dr Dave Harper for some key discussions particularly in thinking about qualitative analysis and the different approaches to it. I am very grateful to the Centre for Narrative Research at UEL for organising a number of invaluable workshops where it has been possible to learn from experts in the field of narrative research. In particular, I am indebted to Dr Corinne Squire for her personal correspondence. I also owe thanks to 'keep-well/ Strangefish conferences' for organising the conference 'Moving Beyond Maintenance – Making recovery a reality in mental health services' last year which was a great help in my thinking. I am very grateful to Anne Cooke for her key role in setting me on my way towards this piece of research and to Lambeth Mind for help in recruitment. I would also like to thank all those in the Critical Mental Health Forum who have enlivened the process of thinking about and doing this research and provided valuable validity checks.

I owe an enormous debt to the individuals who came forward to be interviewed and who shared with me stories of pain, anger, humiliation, struggle, courage and triumph. It is only my hope that I can do justice to their years of experience and thoughtfulness which they brought to the interviews.

I owe my thanks, too, to my colleagues who have discussed aspects of the research and analysis with me, especially Rachel Butterfield, Louise Crocker, Tracy Millar and Elizabeth Newton.

I am very grateful to my children, Grace and John, for their tolerance of their absent mother and for keeping me sane with their delightful presences in any spare moment.

I owe a different kind of debt to my husband, Chris. It is hard to imagine how I could have written this thesis without him.

Any errors or limitations in this study are entirely my own.

Dedication

I would like to dedicate this thesis to the memory of those I have known who seemed unable to find guides and signposts through their struggles. I would also like to dedicate it to those I have met who have faced incredible journeys and been brave enough to tell the tale.

Preface

This thesis examines 'recovery from psychosis'. Psychosis refers to a group of symptoms which are common to a number of diagnoses (APA, 1994). It is the purpose of this research to examine recovery from psychosis broadly, not to focus on particular diagnoses. It has been suggested that this approach may be useful in psychosis research and practice (BPS, 2000). However in covering the literature, reference will be made to particular diagnoses, such as schizophrenia and bipolar disorder, since some of the important research has been conducted according to these diagnoses. It is common practice in clinical research to refer to those with 'psychosis' and a diagnosis of 'schizophrenia' or 'schizoaffective disorder' synonymously. Here 'psychosis' refers to a broader group, including those who experienced one or two episodes and never received a diagnosis. It could be argued that recovery in this group must be very different from recovery in the diagnosed groups. On the other hand, it may be that there are shared important factors in individuals recovering from psychosis, regardless of diagnosis. It is common in the first episodes of psychosis not to make a diagnosis. It is also well-established that the relapse of psychotic symptoms (and thus the likelihood of being given a diagnosis of schizophrenia, for example) is affected by a combination of factors including psychological and social factors. Examining those who do not relapse, then, as well as those who do, has important implications for recovery, both theoretically and clinically.

CHAPTER 1

INTRODUCTION

Overview

Having unusual perceptual experiences such as hearing voices or seeing visions, and holding unusual (and apparently unfounded) beliefs, are phenomena found across cultures and throughout history. They have been variously understood using religious, socio-cultural, medical and psychological frames of reference. In the last hundred years or so certain constellations of these experiences have been understood as symptoms of an underlying brain pathology. Some researchers have sought to develop psychological models of the onset and maintenance of some of these phenomena. Models which demonstrate the interaction of a combination of factors have also been proposed. Studies in the general population seem to suggest that many more people hear voices, for example, than come to the attention of psychiatric services. This may suggest that these kind of experiences need not always be problematic. In addition, evidence from longitudinal studies suggests that, contrary to early theories, the course of psychosis may not always

be one of deterioration but that it can sometimes be characterized by gradual stabilisation or recovery.

This chapter will focus first on definitions of ‘psychosis’ and ‘recovery’. It will then review a range of literature relevant to the present study. As the field is vast, this review will necessarily be selective, but it will aim to cover the key areas outlined above including evidence from research into biological, psychological and social factors in relation to psychosis and in particular to recovery. Following this, the chapter will focus on qualitative studies which to date have explored subjective experience and meaning-making in accounts by individuals who have recovered from or coped effectively with mental health difficulties. Finally, the rationale for the present study will be addressed and the research questions will be set out.

Psychosis: background and definitions

Psychosis is a medical term which refers to a range of mental phenomena with a variety of aetiologies. The word ‘psychosis’ seems to have been first used around 1850 to talk about any psychological disturbance (Gregory, 1987). However since 1900 it has been used to refer to particular illnesses and symptoms: ‘*the illnesses being those in which the patient’s basic competence as a person is called into question, the symptoms being those which seem to indicate some gross disorder of perception or thought (such as hallucinations and delusions)*’ (Gregory, 1987, p.657). Some psychoses have traditionally been termed the ‘organic psychoses’

and are generally agreed to be the result of degenerative changes in the brain.

Another group, traditionally termed 'functional' psychoses, has included diagnoses such as schizophrenia and bipolar disorder. These, according to Gregory (1987) '*arouse considerable controversy within the general public, partly because their symptoms are dramatic but more importantly because research has (as yet) failed to discover any convincing, as opposed to plausible, causes for them – and in the absence of any specifiable physical causes it is possible and legitimate to question even whether the medical model is the appropriate one to apply to psychosis*' (p.658). A variety of biological factors have been suggested to underlie these forms of psychosis and the Diagnostic and Statistical Manual IV no longer makes the distinction between 'functional' and 'organic' psychoses in its framework (APA, 1994). However it remains the case that no single disease entity has been found to account for psychotic presentations such as those classified under the heading of schizophrenia (Siebert, 1999). 'Psychosis' is thus essentially a descriptive term which refers to experiences such as hearing voices, seeing things or holding unusual beliefs but which in itself does not imply the likely causation or course of these experiences. A further important aspect of the definition of 'psychosis' concerns the individual's beliefs about his or her experience. According to DSM IV, a narrow definition of psychosis includes the stipulation that the individual must have no 'insight' into the hallucinatory nature of the experiences (APA, 1994, p.273). A wider definition includes hallucinations which the individual understands as such. A still wider definition includes disorganised speech, behaviour and thought, as well as

catatonic behaviour, which are all symptoms linked to the diagnosis of schizophrenia. For present purposes, the first two definitions will be relevant. As will be discussed in greater detail in a subsequent section, the distinction between individuals who interpret their hallucinatory experiences as such, and those who interpret them as 'real' or attribute them externally, has become a key aspect of psychological theories of psychosis and is thought to be linked to the development of psychopathology (e.g. Garety, Kuipers, Fowler, Freeman & Bebbington, 2001).

Berrios (1996) suggests that historically it was delirium rather than dementing conditions that functioned as the clinical model for the current notion of psychosis. Delirium, like psychosis, is identified by '*a clinically significant deficit in cognition or memory*' (APA, 1994, p.123), for example unusual perceptual experiences or beliefs. Some research psychiatrists argue that the present distinction between 'delirium' and some forms of psychosis is a false one (e.g. Charlton, 2000). Charlton argues that disturbances in sleep which are currently noted as factors in 'delirium' in DSM IV could equally be factors in some psychoses as currently diagnosed, although this link is not made in the current diagnostic manual. Thus he would like to see 'delirium' reinstated as a more common diagnosis and distinguished from other psychoses which may have different aetiological factors (Charlton, 2000).

Historically, there have been attempts to distinguish psychoses which are thought to be linked to brain pathology from other types of psychosis, as discussed above.

In some cases this has been unequivocally successful, as in the identification of various types of dementia (e.g. Alzheimer's disease or vascular dementia).

Arguably, it has not been as easy to identify an underlying brain pathology in many other instances of psychosis. Emil Kraepelin is regarded as one of the founding fathers of this attempt to identify underlying brain pathologies by the observation of psychosis as presented in his patients. His categories of 'dementia praecox' and 'manic depressive insanity' which he put forward in 1899 remain enshrined, albeit under different names, within the current diagnostic system.

Bleuler (1911/1950) later renamed 'dementia praecox', calling it 'schizophrenia', partly due to his observation that the illness did not behave like a dementia in that not all patients showed a gradual deterioration. Despite a century of research, according to an expert in the neurobiology of mental illness, '*neither the etiology of schizophrenia nor its pathophysiology has been clarified*' (Tamminga, 1999).

Tamminga goes on to argue that, '*current treatments, even with the new antipsychotics, do not cure psychosis or schizophrenia. Full psychosis treatment will probably have to await a correct articulation of schizophrenia pathophysiology*' (p.283).

In considering the influence of Kraepelin on psychiatry, Hoff (1996) suggests:

'Kraepelin's psychiatry became so influential because it offered a pragmatical, clinically and prognostically oriented nosology, developed by a self-confident author who focussed on rather straightforward quantitative and naturalistic research methods and claimed to abandon speculative aspects from psychiatry as

much as possible...this anti-speculative impetus brought about the danger of underestimating qualitative, 'subjective' aspects and generally speaking, philosophical foundations that psychiatry necessarily has.' (p.273)

Kraepelin was interested in detecting mental illness as '*natural disease entities*' (Hoff, 1996, p.274). His philosophical position was one of unreflecting materialism. In contrast, more recent neurologists and philosophers (e.g. Damasio, 1994; Dennett, 1991) have sought to think profoundly about the elaborate connectedness of the mind and the brain – the interactions between the physical, emotional, cognitive and agentive aspects of being human. For example, Damasio's studies of neurologically impaired individuals have suggested that emotion and feeling states are closely bound up with rationality and thought, and that rationality breaks down in the absence of feelings. These considerations might suggest that a phenomenon such as psychosis could arise from a complex dynamic interaction between emotional, biological, and cognitive factors. Such ideas are compatible with many current models of psychosis which will be discussed in more detail below (e.g. Bentall, Corcoran, Howard, Blackwood & Kinderman, 2001; Garety *et al.*, 2001; Nuechterlein & Subotnik, 1998). These models could also suggest that different factors might have different 'loadings' for any individual at any given point in time, and that some psychoses may arise mainly from biological factors, others from mainly psychological or emotional factors, for example. Attempting to be more precise about individual aetiologies clearly has important implications for interventions also.

Kraepelin's work marked a trend at the beginning of the twentieth century towards separating psychosis out into different disorders. This approach has dominated research and practice until recently, sidelining previous 'continuity' theories of psychosis (Berrios, 1996). However in the last decade or so there has been a revival of the notion of the 'psychotic continuum' with an interest both in 'schizotypy' in the general population and the differences between clinical populations and those who hold unusual beliefs or hear voices and are not diagnosed as psychotic (e.g. Davies, Griffin & Vice, 2001; Morrison, Wells & Nothard, 2002; Peters, Day, McKenna & Orbach, 1999). In addition, it has been questioned whether the diagnoses most commonly associated with psychosis, such as schizophrenia, schizoaffective disorder and bipolar disorder, represent separate underlying pathologies or whether they describe a range of symptoms and processes which cannot be discretely defined. Interestingly, Kraepelin himself noted twenty-one years after his initial identification of dementia praecox and manic depressive illness: '*It is incorrect to attribute signs to specific disease processes... We shall have to get used to the fact that our much used clinical check-list does not permit us to differentiate reliably between manic-depressive illness and dementia praecox*' (Kraepelin, 1920). This view has been echoed recently in a BPS publication drawing together the latest research in psychosis and making mention in particular of the diagnoses of bipolar disorder, schizoaffective disorder and schizophrenia, which concludes: '*There is good reason to believe that mental health and 'mental illness' (and different types of*

mental 'illness') shade into each other and are not separate categories' (BPS, 2000, p.18). A recent psychiatric study has also argued for the utility of a dimensional approach to psychosis in clinical practice (van Os *et al.*, 1999).

In the context of the above research and doubts as to the scientific reliability and validity of such diagnoses (e.g. Bentall, 1998; Bentall, Jackson & Pilgrim, 1988; Boyle, 1990; Charlton, 2000), much recent psychological research has chosen to take a symptom-based approach. Theories have been developed either focusing on one kind of psychotic symptom, such as the model developed by Bentall *et al.* (2001) of persecutory delusions, or with the aim of accounting for a range of symptoms, for example the model developed by Garety *et al.* (2001) which addresses itself to all the positive symptoms of psychosis. There seems to be a trend away from trying to theorize about or account for discrete diagnoses such as schizophrenia, and indeed some even argue that this would be an impossible task (e.g. Bentall, 1998). At least pragmatically, the recent focus in psychology research on psychotic symptoms seems to have borne fruit with rapidly developing theories and interventions designed to broaden our understanding and ability to intervene in this complex domain.

Recovery: Background and definitions

Recovery from psychosis assumes a different significance depending on the kind of psychosis to which one refers. For example, the notion of swift recovery is implicit in the diagnosis 'brief psychotic disorder' and would be expected in a diagnosis of 'drug-induced psychosis' or 'psychosis due to a general medical condition'. However Kraepelin's notion of 'dementia praecox' assumed that in these cases there could never be recovery from psychosis, since it was defined as a degenerative condition. Bleuler's observation that in fact the course of this diagnosis seemed to vary led him to move away from the idea that this condition could be categorised as a 'dementia' and to rename it 'schizophrenia'. He proposed that it could follow one of eleven courses (Bleuler, 1978). He included in these 'simple (continuous) courses', 'undulating courses' and 'atypical courses'. He thought that 22% of individuals who received a diagnosis of schizophrenia made a full recovery after one or more discrete episodes. Others could show an improvement over time while in others the condition could become more acute or remain chronic.

These observations seem to have been borne out by subsequent studies. In longitudinal research (e.g. Ciompi, 1980; Huber, Gross, Schuttler & Linz, 1980; Tseung, Woolson & Fleming, 1979) there is evidence that after a psychotic episode about one third of people make a full recovery, about another third have periods of recovery and periods of further psychosis, and about another third seem to follow a more chronic course. Harding, Brooks, Ashikaga, Strauss & Breier

(1987) followed 269 patients with a diagnosis of schizophrenia selected on the basis of their 'chronicity' and found that after an average of 32 years follow-up, 26% were employed, 49% were in or had been in long-term intimate relationships; 90% lived independently or semi-independently and 68% had only 'mild symptoms' like mild insomnia and functioned at a level most people would consider 'normal'. On the basis of such evidence, Kruger (2000) suggests schizophrenia '*may be viewed as an 'episodic' condition like some forms of arthritis or asthma that regularly remits and for which the long-term prognosis is very good*'. Despite this, little research has focused on individuals who have recovered from psychosis.

Defining 'recovery' is not necessarily straightforward and a number of types of recovery have been suggested. Birchwood and Jackson (2001) delineate 4 types of recovery: *symptomatic* or *clinical* recovery in terms of whether the person continues to experience psychotic symptoms or not, *complete* recovery which refers to an absence of symptoms and a return to previous social functioning, *social* recovery referring to employment and social functioning and *psychological* recovery which refers to the absence of other psychological difficulties and is considered the most difficult to achieve. Trials of medication or cognitive behavioural therapy, for example, aim for recovery in the clinical or symptomatic sense. A person meets the criteria for recovery or recovering if their symptoms reduce or disappear. The notion of 'social recovery' is popular in the psychiatric rehabilitation literature (e.g. Anthony, 1993) and amongst some users (e.g.

Coleman, 1999a). ‘Complete recovery’ and ‘psychological recovery’ are least explored in the literature. This seems to be partly due to the tendency for research to focus on those who are currently symptomatic and it might also reflect a difficulty in recruiting participants no longer involved with clinical services. It is likely that these different notions of recovery are not entirely mutually exclusive, for example recovering socially may only be possible once symptoms are at a certain level and successful social recovery may in turn impact on symptomatology. It also seems likely that recovery for any individual will involve a variety of factors interacting in a unique way. Further, if the notion of a psychotic spectrum is accurate, or if further research reveals more about discrete pathways to psychotic symptoms, it may be that a clearer picture can emerge about sub-groups who, through various interventions, can expect clinical or social recovery. Similarly, sub-groups may emerge who may always expect to experience psychotic symptoms, whether or not they are socially disabled by them.

Various factors have been linked to outcome in psychosis including ‘recovery style’ (McGlashan, 1987; McGlashan & Carpenter, 1981). Two recovery styles have been identified : ‘integration’ and ‘sealing over’. ‘Integration’ is characterised by factors such as an individual’s perception of the continuity of their experience and personality before, during and after the psychosis, taking responsibility for the psychotic experiences, using the psychosis as a source of information and being aware of pleasant and painful aspects of it. ‘Sealing over’

is characterised by separating the psychotic experience from the self, not engaging in investigating or discussing the experiences, and viewing the psychosis negatively. Individuals employing an 'integration' style were found to have significantly better outcomes in terms of relapse and social functioning than those using a 'sealing over' style (McGlashan, 1987). More recent research has examined the connection between early attachment experiences, negative self-evaluations, recovery style, and depression in people adjusting to the onset of psychosis (Drayton, Birchwood & Trower, 1998). People using a 'sealing over' recovery style were found to be significantly more depressed, made more negative self-evaluations, and perceived their parents as less caring than the 'integrators'. The researchers conclude that individuals with 'a poorly developed sense of self' defend against the threat of psychosis using denial. There is a need for research to explore in more detail the multiple factors associated with recovery.

Anthony (1993) suggests that recovery from serious mental health problems is a multi-dimensional concept which can include aspects of self-esteem, adjustment to disability, empowerment and self-determination. For Coleman (1999a) recovery is not about the presence or absence of 'symptoms' but about regaining an ability to function in society and achieving one's own goals. Studies of recovery from serious mental health problems (e.g. Ridgeway, 2001) suggest that some of the key elements of recovery are: that each person's recovery is different; that supportive others are key in the process; that the power to recover lies primarily with the service-user, not with professionals; that recovery is a process

which can involve setbacks as well as growth; and that recovery may involve recovering from the consequences of mental distress (e.g. social, financial) as well as the distress itself. In this way, recovery can be understood as a multi-faceted concept which includes personal and social dimensions. Recovery on each dimension is understood to exist along a continuum so that each individual's recovery will be unique to them and may not be static but may alter on different dimensions over time.

'Recovery' as a term also has a particular social and political context in current debates on mental health care. It is a term which is being used currently to denote a new approach to working with people with mental health problems, for example, in the USA, New Zealand and increasingly also in the UK. The 'recovery model' currently being implemented in the USA emphasizes the promotion of recovery in contrast to life-time dependency (Anthony, 1993). It promotes the idea that services should try to enable people, through supported education, employment, or other means, to achieve goals they set themselves. This approach stresses that mental health services should try to empower people to make their own choices and decisions and to take risks. It stresses that people need to take an active role in their own recovery, rather than adhering to the previous 'good patient' model of compliance with medication and acceptance of an illness role. The language of much of the work on 'recovery' draws on the experiences of political movements such as the feminist movement, gay rights or

anti-racist movements. It talks about giving people a voice, opportunities, rights, and combating exclusion and discrimination. To recover from mental health problems and regain a meaningful life is regarded in this view as not just a matter for health but also a matter for society at large (Anthony, 1993; Coleman, 1999b; Ridgeway, 2001).

Overview of the literature on psychosis and recovery

This review will firstly cover studies of psychosis in the general population and discuss some of the issues this raises about psychosis as a clinical and non-clinical phenomenon. Then, using a vulnerability-stress model as a starting point, it will discuss research areas in the field including studies of genetics, neurodevelopment, neurophysiology and pharmacological treatments. It will be argued that although these research areas have provided some valuable knowledge about underlying biological factors in psychosis and have given rise to the use of medications which are generally effective in the management of symptoms, there remain aspects of psychosis and recovery which require other approaches. In particular, while medications have facilitated partial or full symptomatic recovery for many, this approach has generally not been as successful in promoting social recovery, psychological recovery, or complete recovery. In addition, some individuals who are termed 'treatment-resistant' do not respond to the antipsychotic medications. This has paved the way in this country for psychological theories of psychosis and cognitive behavioural therapy to become seen as an important adjunct to pharmacological treatments and these will be

reviewed. Finally, it will be argued that for a full understanding of the process of recovery from psychosis, it is also important to study how individuals make meaning out of their experiences and to examine the role individuals play in their own recoveries. Qualitative studies of psychosis and recovery from mental illness will be reviewed, highlighting methodological issues and gaps in the literature.

Finally, the rationale for the present study will be outlined.

Studies of psychosis in the general population

According to Tien (1991), 10 to 15 per cent of the non-clinical population have had a hallucination during their lifetime. One study examined differences between individuals who were diagnosed to be delusional and members of 'new religious movements' (Peters, Day, McKenna & Orbach, 1999). They found that the main differences between the groups were on measures of preoccupation and distress in relation to the beliefs, not the beliefs *per se* nor measures of conviction. Thus the researchers suggest that it may be more important *how* a person believes something than *what* they believe. The study provides evidence for the importance of taking a dimensional approach to psychosis and for 'continuum' theories of psychotic experience (e.g. Claridge, 1994). A survey in Holland of people who heard voices found that the difference between individuals who sought help for their voice-hearing and those who did not was associated with the perceived power and malevolence of the voices (Romme & Escher, 1994). Where

the voices were experienced as benevolent or not powerful, individuals did not generally come to the attention of clinical services.

Using medical definitions, about 1 person in 100 will receive a diagnosis of schizophrenia in their lifetime (Birchwood *et al.*, 1989) and a roughly similar number a diagnosis of bipolar disorder (Weissman *et al.*, 1988). However as the above evidence suggests, it may not be hallucinations on their own which are pathological, but instead a number of factors (including the nature of the hallucinations and the individual's response to them) may lead someone to be diagnosed with a mental illness. These factors will now be reviewed.

Stress-vulnerability models

Since the 1970s a number of stress-vulnerability models of schizophrenia have been developed which may also be relevant to psychosis more broadly (e.g. Nuechterlein & Subotnik, 1998; Zubin & Spring, 1977). These models suggest that individuals vary according to how vulnerable they are to developing psychosis under conditions of stress. In these models, vulnerability is assumed to be biological in origin, although this assumption has been criticised (Boyle, 2002) and other theorists might put more emphasis on psychological vulnerability due to early experiences of relating (e.g. Jackson, 2001; Klein 1935). As will be discussed in a subsequent section, biological, psychological and social factors are likely to interact and early psychological experiences and neurodevelopment may

in some cases be particularly difficult to disentangle. Nuechterlein and Subotnik (1998) present a tentative heuristic framework for the factors associated with vulnerability and protection in relapse and illness course (see Figure 1, below).

Personal vulnerability factors include dopaminergic dysfunctions, information processing resources, autonomic hyperreactivity and schizotypal personality traits. These are broadly presented as biological factors, although there may be psychological factors which contribute to personal vulnerability, as will be discussed subsequently. Personal protectors are also highlighted such as coping and self-efficacy. These are likely to be crucial in psychological models of recovery from psychosis. Antipsychotic medication is also cited as a personal protective factor which interacts with coping and self-efficacy, contributing to outcome. Environmental protectors include effective family problem solving and supportive psychosocial interventions. Environmental stressors include critical or emotionally overinvolved attitudes towards the patient, an overstimulating social environment and stressful life events. According to this model, all of these factors interact to produce intermediate states which lead to prodromal symptoms and then to psychotic symptoms, and difficulties in social and occupational functioning. Although not emphasized in this model, these factors are of course relevant not only to relapse into psychosis, but also remission of symptoms and recovery. The following sections examine the research into these various factors in more detail.

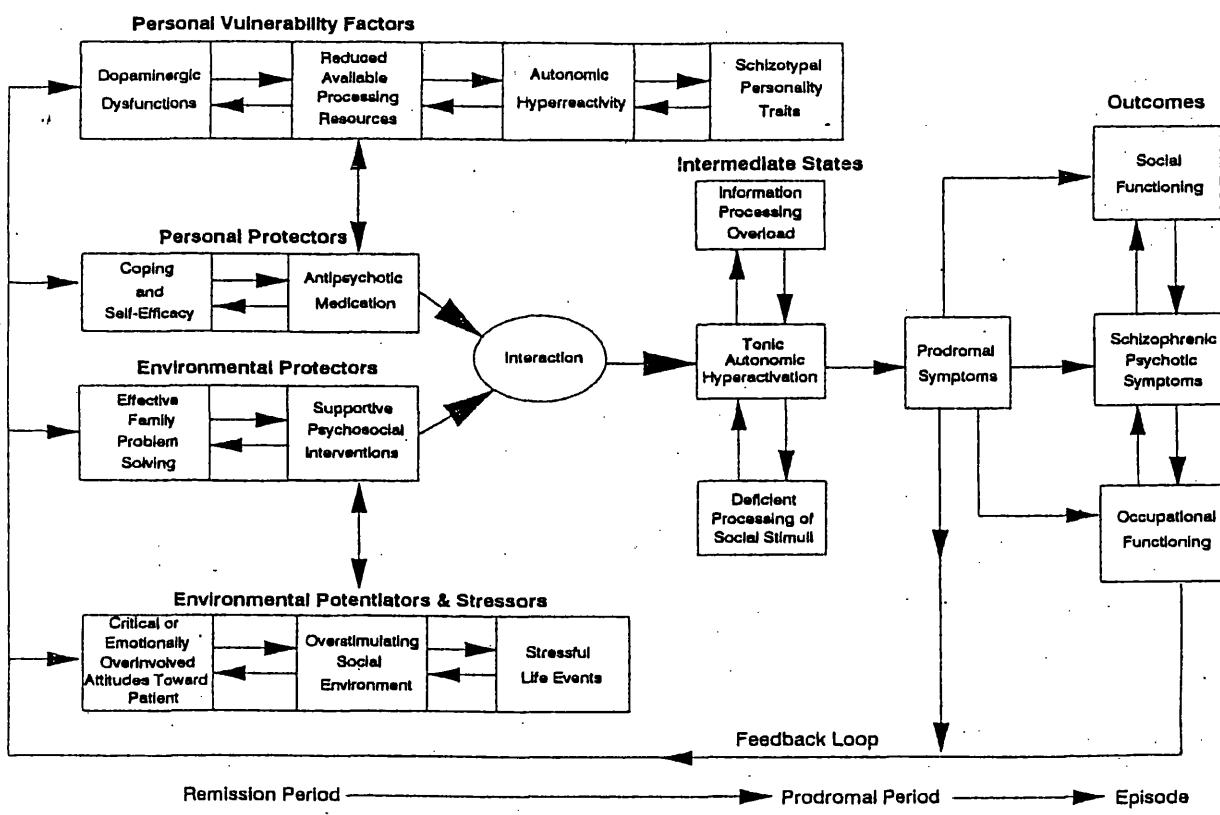


Figure 1: Model showing some of the possible psychobiological vulnerability factors, environmental stressors and protective factors in relapse and illness course in schizophrenia. (Nuechterlein & Subotnik, 1998).

The role of biology in psychosis and recovery

Biological research focuses on a number of areas including genetics, neuroanatomy and neurophysiology. These will be discussed in turn along with some of the strengths and weaknesses of these studies and their implications for recovery.

Some of the early studies of genetic influence had serious methodological limitations; for example Kallman (1938) included participants whom he had posthumously diagnosed as having schizophrenia, and it could be argued that he artificially inflated the supposed genetic component due to unreliable diagnostic practice. More recent studies, for example Kendler and Gruenberg (1984) found a life-time risk of 3.7% for schizophrenia among first degree relatives compared with a 0.2% risk in controls. The risk for relatives increased to 8.6% when other psychotic diagnoses were included. Similar statistics are suggested for the genetic component of bipolar disorder (Nurnberger & Gershon, 1992). This suggests there may be a genetic component to developing psychosis. Gottesman and Shields (1982) analyzed a number of twin studies and reported a heritability statistic of 60% for schizophrenia. At the same time, they noted a discordance in monozygotic twins of 54%, suggesting that the influence of environmental

components is also strong. In a study by Tienari *et al.* (1994) of adopted-away offspring of mothers with a diagnosis of schizophrenia, where they rated the adoptive families on levels of disturbance, they found that schizophrenia was only expressed in the adoptees in families rated 'disturbed', again suggesting the crucial interaction of genetic and environmental factors. It was considered that this genetic risk may consist of a non-specific predisposition, such as a general sensitivity to the environment, which only leads to serious psychopathology in unfavourable circumstances (Lehtonen, 1994). A further study in Finland (Myhrman *et al.* 1996) found that in the 1966 birth cohort, children from unwanted pregnancies had twice the risk of developing schizophrenia. It has been suggested that this may be further evidence for unfavourable psychological environments having an impact on the development of such psychopathology (Garety *et al.*, 2001). Thus psychosis and schizophrenia do not seem to be inherited in a straightforward way like some inherited illnesses or disabilities, but instead they appear to develop due to a combination of factors. This has important implications for recovery: whether a person who receives a diagnosis such as schizophrenia, bipolar disorder, or schizoaffective disorder should view it as 'coming to terms with a condition' or whether it can be 'outgrown' or 'cured' or 'adapted to' by medical, psychological or social interventions, for example.

Neurodevelopmental theories of schizophrenia also come under the biological umbrella, although they are conceptually quite different from the genetic

hypothesis. This strand of research seeks to find associations between perinatal difficulties and the subsequent development of schizophrenia. For example, O'Callaghan, Gibson and Colahan (1992) found that low birth weight, premature births, being 'small for date', prolonged labour, hypoxia and foetal distress were associated with schizophrenia. However, Done *et al.* (1991) did not find any associations. Studies have used imaging techniques to explore whether individuals with perinatal and birth complications show indications of brain damage such as enlarged ventricles. A recent review indicates that 9 studies support an association, whereas 8 other studies found no relationship or an inverted one (Birchwood & Jackson, 2001). While the research remains inconclusive, it seems plausible that a subgroup of individuals with a diagnosis of schizophrenia may have symptoms which relate to an earlier brain insult *in utero* or around birth. However, questions remain such as why these symptoms should not manifest themselves in many cases until adolescence or later.

The implications for recovery remain unclear also. Perhaps a disability model rather than a recovery model would be more appropriate in these cases. On the other hand, it is difficult to explain periods of remission or improvement over time if the psychosis is due entirely to brain insult. Since the hypothesis which links schizophrenia to foetal brain insult is clearly very different from the genetic hypothesis, it suggests that there may well be very different pathways to experiencing psychosis and/ or receiving a diagnosis of schizophrenia and that

these may have different implications for recovery which require further investigation.

Investigations into neuroanatomy have sought to find evidence for structural differences in the brains of individuals diagnosed with schizophrenia. One strand of research has explored the size of brain ventricles, suggesting that individuals with schizophrenia have on average larger ventricles than controls, which represents a reduction in brain tissue. Raz and Raz (1990) offer a meta-analysis of these studies which indicates that not all studies have found significant results and that more research is needed to confirm or disconfirm the significance of the results overall. Criticism of these studies has included the observation that the effects of taking neuroleptic medication can contribute to the atrophy of brain tissue and that appropriate control groups should consist of individuals with a history of legal and illegal drug use or those with a diagnosis of severe depression or anxiety (Boyle, 2002).

Studies exploring the role of neurotransmitters in the brain constitute another area of biological research. For example, the 'dopamine hypothesis' developed from the observation that neuroleptic drugs which control psychotic symptoms act by blocking the receptiveness of certain (dopaminergic) neurones. In a process of inverse reasoning, researchers have suggested that psychosis may be caused by an overactivity of dopaminergic neurones (Birchwood, Hallet & Preston, 1989; Birchwood & Jackson, 2001; McKenna, 1994). This logic has been criticised by

some. Johnstone (2000) claims this is equivalent to saying that headaches are caused by a lack of aspirin. There is also evidence that amphetamines and other street drugs which affect the dopaminergic system can produce psychotic-type symptoms in individuals who take them (e.g. Harris & Bakti, 2000). However neither of these pieces of evidence points conclusively to psychosis or schizophrenia being *caused* by abnormal dopamine activity. At the level of the brain, neurotransmitters and neurochemicals are always involved in the production of thoughts and feelings. However, this works both ways: thoughts and feelings also influence the chemicals released in the brain and this impacts on the brain's functioning both in the shorter and longer term. Therefore it might be important to study what kind of psychological responses can overactivate the particular neuronal systems. Studies of orphaned Romanian infants with disorganized attachments have indicated that impaired early attachment relationships are associated with pervasive changes in the organization of the hypothalamic-pituitary-adrenal (HPA) axis which regulates reactions to stress (Lyons-Ruth & Jacobvitz, 1999). This suggests that experiences of fear, for example, or insecurity, can exert a lasting influence on the brain's functioning at a structural or neurochemical level. More immediately, Gottschalk, Fronczek & Buchsbaum (1993) have studied the physical cerebral correlates of the cognitive state of 'hopefulness', providing evidence that the sense of hope involves 'the participation of brain areas that deal with the functions of cognition, language, perception, vision, audition and emotions'. Bentall (2001) has made a similar point with regard to persecutory delusions: while he recognises that certain areas

of the brain have been shown to be activated in functional neuroimaging studies of individuals with such delusions, he nonetheless argues that this does not imply they are necessarily entirely biological in origin, and maintains they may be amenable to psychological interventions. Focusing on biological factors as causal and as the only focus of treatment while excluding the role that thoughts and emotions play in affecting neurochemical balance in the brain may limit the potential for understanding how individuals can take an active role in their recovery.

Psychopharmacological treatments for psychosis

Since the 1950s, with the introduction of neuroleptic medication for psychosis, and for schizophrenia in particular, much research on treating psychosis has focused on underlying biological factors and on trials of different types of medications aiming to ameliorate psychotic symptoms (McKenna, 1994). Beginning with the introduction of drugs such as chlorpromazine and haloperidol in the 1950s and 60s (the ‘neuroleptics’), psychiatric treatment was revolutionized and these medications became a cornerstone of treatment, at least for schizophrenia. Lithium has been developed as the drug treatment of choice for bipolar disorder, although one recent study suggests that the effects of medication are more apparent on particular symptoms than on diagnoses (Moncrieff, 1997). In this study individuals were given a neuroleptic, lithium, both or neither.

Delusions and hallucinations were found to respond to the neuroleptic, while mood swings responded to the lithium, regardless of diagnosis (Moncrieff, 1997).

While neuroleptics were seen to ameliorate positive symptoms in a majority of individuals taking them, they were criticized 1) for being of no benefit or little benefit to about a quarter of individuals in trials; 2) for being unable to prevent the exacerbation of symptoms over time in many more individuals; 3) for being unable to address any of the ‘negative symptoms’ (McKenna, 1994). According to McKenna *‘negative symptoms remain a formidable clinical problem: perhaps the most typical outcome of neuroleptic treatment is the schizophrenic patient whose florid symptoms are well controlled, but who is permanently handicapped by lack of volition, flattened affect, and poor self care, for which nothing can be offered.’* (p.214). Further limitations of these medications are linked to the adverse effects experienced by some people in addition to their anti-psychotic effects. These can include depression and restlessness on starting to take the medication; extrapyramidal side-effects including Parkinsonianism, akathisia, dystonias, and tardive dyskinesia; anticholinergic adverse effects such as dry mouth, constipation and memory problems; risk of cardiac arrest; risk of liver disease; risk of serious blood disease; weight gain; sexual dysfunction; and loss of motivation (BPS, 2000). Researchers have also highlighted the limitations of neuroleptics in addressing the cognitive deficits shown by the majority of individuals with a diagnosis of schizophrenia (Harvey & Sharma, 2002). They argue that it is cognitive difficulties which constitute as much if not more of a problem for

individuals' social functioning than positive symptoms, and that this must form the focus of future treatment research. The latest research in the field focuses on the newer 'atypical' neuroleptics such as clozapine, olanzapine and risperidone, and trials suggest these may carry benefits in terms of having fewer side-effects, being cost-effective and possibly improving cognitive performance (e.g. Essock *et al.*, 2000; Meltzer & McGurk, 1999). However some negative effects remain, such as weight gain, and the risk of serious blood-disease (in the case of clozapine) such that routine blood-tests are required if a person is taking this medication.

Despite the effectiveness of medications in helping to control symptomatology in the majority of individuals (in bringing about clinical or symptomatic recovery), it has been argued that an over-emphasis on the biological aspects of psychosis and treatment and a neglect of psychological, emotional and social aspects can hinder social and psychological recovery (Alanen, 2000; McGrory, 2000). Researchers and clinicians have shown that it is possible to facilitate recovery from psychosis using psychotherapeutic techniques, whether cognitive-behavioural (Garety, Fowler & Kuipers, 2000), or psychodynamic and systemic (Alanen, 2000). In these approaches, medications are used as an adjunct to psychotherapeutic work: for some individuals they are not thought necessary, and for others they are discontinued after an initial period (Alanen, 2000; Mogren, 2002). Continuous prescription of anti-psychotic medication with no other intervention is not the treatment of choice (Alanen, 2000). Clearly, many factors need to be considered

in offering the optimum interventions in psychosis. This review will now consider the research which examines psychological and social factors in psychosis and recovery.

Studies of familial influence

Studies of the influence of families on relapse in schizophrenia (e.g. Vaughn & Leff, 1976; Leff & Vaughn, 1980) have shown that individuals who have extensive face-to-face contact with families characterised by high levels of hostility, criticism or over-involvement (termed high 'expressed emotion') are likely to relapse more quickly. On the basis of this research, family interventions have been developed that attempt to lower the 'expressed emotion' in at risk families, and there is good evidence for the effectiveness of these (Lam, 1991).

However there is no coherent theory to account for these findings and family management approaches emphasize that the family has had no role to play in the aetiology of the family member's difficulties. It has been argued that this makes the approach internally inconsistent (Johnstone, 1999) while others (Birchwood & Smith, 1987) have suggested that the research points towards the adjustment difficulties of some families in coping with a member with a severe mental illness. As discussed earlier, it is likely that psychosis and schizophrenia develop

due to a combination of factors, some of which will be environmental and some of which may have to do with family patterns of interaction. In any case, the evidence is robust that family interventions offer one of the most successful psychological interventions for schizophrenia (Pilling *et al.*, 2002a).

Studies of Coping

During the 1980s a number of studies began to explore the strategies individuals use to cope with and ameliorate their psychotic symptoms. For example, Falloon and Talbot (1981) asked 40 individuals who experienced auditory hallucinations which did not respond to medication about their coping strategies. These included behavioural strategies such as sitting, lying down, walking or running; working; pursuing hobbies, watching TV or listening to music; and initiating or withdrawing from contact with others. Other studies report similar results for a wide range of psychotic symptoms and diagnoses (e.g. Breier & Strauss, 1983). From such beginnings, Tarrier and colleagues in Manchester developed 'Coping Strategy Enhancement' (e.g. Tarrier *et al.*, 1993) which aims to help the individual to develop their already existing coping strategies by a detailed analysis of symptoms, antecedents, consequences and strategies already in use. Such strategies mainly include attentional and behavioural strategies. Identifying that individuals can develop strategies for managing, and in some cases reducing, psychotic symptoms has marked an important development in psychosis research.

However these studies have limitations in focusing mainly on behavioural strategies without considering wider issues of meaning and beliefs about psychotic symptoms. The following sections discuss the research into psychological models of psychosis.

Psychological models of psychotic symptoms

Self monitoring deficit and theory of mind deficit models

Frith (1992) has suggested that some psychotic symptoms such as hearing voices and the experience of 'thought insertion' or 'alien control' (also called 'passivity experiences') could be explained by a 'self-monitoring deficit' in the mind. Frith's hypothesis is that if individuals can initiate thoughts but cannot monitor their will to initiate, they may believe that other people are thinking, or speaking in their head. Similarly if they initiate actions but are unable to monitor this initiation, they may experience a feeling of being controlled by something outside of themselves. Frith's model further accounts for the negative symptoms of schizophrenia as a breaking down of the links between 'goals/plans' and 'willed intention' (the symptom here would be lack of volition) and between 'goals/plans', 'stimulus intention' and 'action' (accounting for impairments in task processing). Frith developed the model to take account of delusions of

reference, of persecution and of third person auditory hallucinations (Frith, 1992).

He suggests these symptoms arise from a 'theory of mind deficit', where individuals are unable to infer accurately what other people are thinking. He further suggests that asocial behaviour and blunted affect may arise from an impairment of theory of mind which stems from an early developmental disruption and that this has an earlier onset than 'positive' psychotic symptoms.

Frith's model predicts that people experiencing 'negative symptoms' or delusions of reference or persecution, or who show incoherent speech, will perform poorly on theory of mind tasks. It does not predict that this will be the case for people experiencing 'passivity symptoms'. This prediction has been tested in recent studies, where participants are asked to make inferences about what characters are thinking from statements that they make (e.g. Corcoran, Mercer & Frith, 1995).

The results from recent studies suggest that people with a diagnosis of schizophrenia do worse on theory of mind tasks compared with non-psychiatric controls and also, in most cases, when compared with psychiatric controls (Garety & Freeman, 1999). The most robust finding is that negative symptoms and incoherent speech are associated with problems in understanding the mental states of others. However there is also evidence that these symptoms may be linked to a more general cognitive deficit (Garety & Freeman, 1999). A further important finding is that currently symptomatic patients generally perform worse than patients in remission, who show no deficit. This suggests that the 'theory of mind' deficit, if it exists, may not be an organic 'flaw' but may be linked to how the

brain functions when experiencing 'positive' or 'negative' symptoms (Garety & Freeman, 1999).

Frith (1999) suggests that neuropsychological investigations have implications for the development of forms of cognitive therapy which could link the experience of delusions and hallucinations with other cognitive processes such as memory and reasoning. Nuechterlein and Subotnik (1998) argue that '*Since available pharmacological treatments have only limited impact on core cognitive deficits in schizophrenia, innovative attempts to change these cognitive abnormalities are critically needed*' (p.37). They suggest that cognitive interventions which are targeted to alter the 'cognitive deficit' might reduce the occurrence or impact of specific symptoms. Such treatments (e.g. Wykes, Reeder, Corner, Williams & Everitt, 1999) have suggested focusing on planning ability, strategy formulation and use, working memory and monitoring ability. However a recent meta-analysis of outcome studies of such 'cognitive remediation' approaches has concluded that these do not appear to be reliably effective and cannot be recommended for clinical practice (Pilling *et al.*, 2002b).

Although Frith's model offers a neat description of the symptoms associated with schizophrenia, perhaps one of its major limitations is its existence in something of a vacuum with regard to theories of cognitive and emotional processing. For example, a crucial piece of evidence from the research is that these 'cognitive deficits' seem to disappear when a patient is in remission. This could imply that it

is temporary cognitive deficits which have led to the psychosis. Another (not mutually exclusive) explanation might be that certain psychotic experiences such as hearing frightening voices or holding paranoid delusions might exert a powerful influence on the individual, limiting their cognitive capacity for processing other kinds of information. In a state of constant vigilance, threat or fear, it is possible to see how 'planning ability' might be affected, for example, or even 'theory of mind' which is a complex cognitive manoeuvre. For models which take into account these kind of factors, it is necessary to turn to the work of Bentall, Garety and Hemsley.

Hallucinations as errors of interpretation

The Slade and Bentall (1988) model of psychotic hallucinations views hallucinations (like hearing voices) as errors of interpretation. Bentall, Baker & Haven (1991) found that hallucinators were more likely than controls to make external attributions about stimuli for which they were not sure of the source. The effects of reinforcement have also been suggested as a factor in the maintenance of these beliefs (or external attributions) which may have had the function of providing meaning at a confusing and difficult time (Chadwick, Birchwood & Trower, 1996). This 'error of interpretation' has become a key aspect of psychological models of psychosis (see e.g. Garety *et al.* 2001; Morrison, 1998)

and of psychological approaches to intervention (see e.g. Chadwick *et al.* 1996; Fowler, Garety & Kuipers, 1995; Nelson, 1997).

Delusions as defence

It had been suggested that delusions – in particular, persecutory delusions – serve to maintain self-esteem (e.g. Kinderman & Bentall, 1996). The argument here is that persecutory delusions allow people to attribute negative events to others, thus avoiding negative self-representations. This hypothesis is based mainly on two sets of experimental findings: one related to attributional style, and the second concerning overt and covert self-esteem.

Using the Attributional Style Questionnaire, it was found that people with persecutory delusions showed an ‘extreme self-serving bias’, attributing negative events to factors outside of themselves and positive events to factors internal to them (Bentall, Kinderman, & Kaney, 1994). This hypothesis was subsequently refined in that participants with persecutory delusions showed a personalising bias for negative events, attributing them to identifiable others, not situations or chance (Kinderman & Bentall, 1997). However their attributions were not particularly self-serving in that they were not more likely than controls to attribute positive events internally or negative events externally. The specific finding has been summed up as ‘a tendency to blame other people when things go wrong’ (Garety & Freeman, 1999).

Studies have also sought to explore how delusions (particularly persecutory delusions) may have the function of reducing awareness of a discrepancy between the actual state of the self and the desired view of the self, to avoid anxiety and depression. Evidence was found for a discrepancy between overt self-esteem and covert self-esteem in people with delusions using the Emotional Stroop Task (Bentall & Kaney, 1989). However, others have found evidence of overt low self-esteem in people experiencing persecutory delusions as well as other positive symptoms of psychosis (Freeman *et al.*, 1998). The frequent observation that depression, low self-esteem and delusions are often found together argues against this model of delusions as defence, although it could be argued that delusions help prevent self-esteem from falling any further (Garety & Freeman, 1999).

In a recent review and theoretical integration, it has been emphasised that early experience, perceptual abnormalities, motivational factors, and information processing deficits may act together in the onset and maintenance of persecutory delusions (Bentall, Corcoran, Howard, Blackwood & Kinderman, 2001). This new integrated model proposes that causal attributions affect self-representations which in turn influence future attributions: this has been named the 'attribution-self-representation cycle'. It is argued that the biases in this cycle cause negative events to be attributed to external agents and contribute to the creation and maintenance of a paranoid world-view. A further suggestion is that adverse early

experience may be a factor in the development of cognitive vulnerability in paranoid thinking.

Such a model has implications for the role that psychological therapy could play in recovery from persecutory delusions, for example by testing out and challenging negative external attributions. Before discussing this in more detail, further research which posits multiple factors in the onset and maintenance of delusions and hallucinations will be examined.

Multifactorial models of delusions and hallucinations

Garety and Hemsley (1994) devised a multifactorial model of the formation and maintenance of beliefs and delusions, which emphasizes that past experience, affect, self-esteem, information processing style and motivation can play a part in some delusions, as can biases in perception and judgment. This model also illustrates how some processes – such as selective attention and confirmation bias – operate to form and maintain delusions in the same way as with ‘normal beliefs’.

Garety and colleagues have paid particular attention to the nature of the information processing style in people experiencing delusions. Some earlier studies suggested that people with delusions had a tendency to ‘jump to conclusions’ (Garety & Hemsley, 1994), but these studies were based on the

assumption that people in general reasoned logically. Later studies used Bayesian inference tasks where participants are asked to state the probability that a coloured bead has been drawn from one of two containers, when they have previously been shown that the containers contain different amounts of coloured beads (e.g. Huq, Garety & Hemsley, 1998). Participants with delusions did not show worse Bayesian reasoning than controls. However, they showed a tendency towards the early acceptance of hypotheses – that is, they were more willing to state which container was being drawn from, on the basis of less evidence. Thus, in certain circumstances, this tendency to ‘jump to conclusions’ on the basis of little evidence may contribute to delusion formation (Garety & Freeman, 1999).

Further studies exploring whether this bias is found in other more normative tasks have replicated the above findings, showing that people with delusions do not have a probabilistic reasoning bias when in possession of all the information. However they have a tendency to seek less information before reaching a decision. Therefore, Garety and colleagues have revised their hypothesis, suggesting that people with delusions show a ‘data-gathering bias’ (Garety & Freeman, 1999). A further noteworthy finding is that emotional salience affects people’s reasoning in general and possibly affects the reasoning of people with delusions to a greater extent (Dudley et al, 1997). This highlights the role of emotional states in the formation and maintenance of delusions.

More recently, Garety *et al.* (2001) have attempted to draw together the findings of psychological research on models of psychotic symptoms into a new cognitive model. This is an advance on previous models as it attempts a fuller integration of social and emotional factors as well as cognitive factors. It suggests there may be two routes to developing psychotic symptoms – one via cognitive disturbance and one via affective disturbance alone. In both cases, they posit the crucial role of the ‘hypothesis of externality’ in determining whether the person will go on to be psychotic. That is, if a person begins to hear voices, or think unusual thoughts, they can either attribute this to themselves – their mind playing tricks, or feeling under stress – or they can develop the belief that these phenomena are externally caused. Garety *et al.* (2001) claim that ‘The externalizing appraisal is thus a defining decision’ (p.191) since the definition of psychosis is that the individual should make external attributions regarding causation. They discuss the factors which might influence individuals to adopt the externalizing appraisal and to maintain it. These are firstly, *reasoning processes*- for example, the data gathering bias, an externalising attributional style and poor social understanding or theory of mind which could be maintained by social isolation. Lack of ‘belief flexibility’ is also associated with poorer outcome (Garety *et al.*, 1997). The second factor is *dysfunctional schemas and adverse social environments*. The hypothesis here is that where emotional factors influence the content of the psychosis, for example where a voice tells someone they are ‘a piece of dirt’, they may be less likely to reject this as a ‘trick of the mind’ if it fits with dysfunctional schemas they already have. Garety and colleagues suggest that ‘*earlier adverse experience*,

*such as social marginalization, childhood loss [...], or severe childhood trauma, may create an enduring cognitive vulnerability, characterised by negative schematic models of the self and the world (e.g. beliefs about the self as vulnerable to threat, or about others as dangerous) that facilitate external attributions and low self-esteem' (p.190). Such schemas would serve to maintain an ongoing engagement with the psychotic phenomena. Fowler (1999) has further found in a study of in-patients with first episode psychosis that severe trauma histories are more common in individuals with symptoms which do not respond to medication. It is suggested that traumatic experiences and adverse social environments can contribute to treatment resistance (Garety *et al.*, 2001).*

The third factor thought to contribute to the maintenance of psychotic appraisals is *emotion and cognitive processes associated with emotion*. Birchwood and Iqbal (1998) have studied the link between depression and residual psychotic symptoms, suggesting in particular that feelings of hopelessness and uncontrollability are a factor in maintaining symptoms. Garety *et al.* (2001) discuss how information processing biases, safety behaviours and meta-cognitive beliefs, previously used to understand the maintenance of anxiety disorders, also have relevance for the maintenance of psychotic beliefs and experiences. The fourth factor is termed *the secondary appraisal* and refers to the individual's view of the experience of psychosis itself. How the person appraises their psychosis will influence their behaviour and how they engage with treatment. In particular, appraisals of the experience as stigmatising and humiliating, which could

influence the development of depression and through this the maintenance of psychotic symptoms, are discussed (Birchwood & Iqbal, 1998; Garety *et al.*, 2001).

The role of self-focused attention and meta-cognition in psychosis

Wells and Matthews (1994) propose what they call a self-referent executive function (S-REF) model which suggests that vulnerability to psychological difficulties is associated with a cognitive-attentional syndrome characterised by heightened self-focused attention, attentional bias, ruminative processing and activation of dysfunctional beliefs. They also suggest an involvement of meta-cognitive beliefs in vulnerability to and maintenance of psychopathology.

Previous studies have shown the importance of beliefs about voices (e.g. Chadwick & Birchwood, 1994) in the degree to which they cause distress – beliefs about the voices as powerful or malevolent being associated with distress.

Morrison (1998) has analysed auditory hallucinations according to a model of 'panic', suggesting (in line with Garety *et al.*, 2001) that it is in the misinterpretation and catastrophization of symptoms (bodily sensations of anxiety in panic, or hallucinations in schizophrenia) that psychopathology develops.

Cognitive factors predisposing the 'normal population' to auditory and visual hallucinations have been studied (Morrison, Wells & Nothard, 2000) and the model has been further developed to include the interpretations of delusions (Morrison, 2001). The hypothesis that the development of negative beliefs about hallucinations underlies the transition to psychopathology seems a valuable line of

investigation and one which suggests the importance of intervention at a meta-cognitive level. The significance of this meta-cognitive factor alone, however, remains to be investigated.

Implications of psychological models for intervention

These models have developed alongside psychological interventions, building on the evidence that individuals can affect the course of psychosis by behavioural and cognitive strategies. Cognitive-behavioural therapy has also developed in the light of findings that a significant number of individuals continue to show moderate to severe psychotic symptoms whilst on antipsychotic medication (Kane, 1996) and that individuals may not comply with psychopharmacological treatments due to the range of negative side-effects (BPS, 2000).

Various specific cognitive strategies have emerged from these psychological models of psychosis. For example, models which indicate the role of information processing style (e.g. Garety & Hemsley, 1994; Garety *et al.*, 2001) in the formation and maintenance of delusions, suggest that strategies such as encouraging a client to *test their beliefs* by collecting evidence for and against them in specific situations could change delusional thinking. Research has shown that people who experience delusions are able to reason logically, given the evidence, so this would imply this strategy could be effective. This has been shown in controlled studies (e.g. Chadwick & Birchwood, 1994; Garety *et al.*,

1994; Chadwick *et al.*, 1996; Fowler *et al.*, 1995) where interventions focusing on delusions produce reductions in levels of preoccupation, conviction and distress. Where delusions cause emotional distress, helping individuals to re-evaluate their beliefs may have the important added effect of altering their mood and feelings. This dual effect of CBT on delusions is crucial, bearing in mind the frequency of co-morbid depression, anxiety and suicidal ideation (Birchwood & Iqbal, 1998; Fowler *et al.*, 1995; Chadwick & Birchwood, 1994; Garety *et al.*, 1994).

The role of beliefs about hallucinations - the 'error of interpretation' of Slade and Bentall (1988), the 'externalizing hypothesis' of Garety *et al.* (2001), or the 'metacognitions' of Morrison (1998) - suggest a role for cognitive therapy in exploring and challenging how people think about their hallucinations. Several studies have shown that clients' conviction about their voices being generated externally to themselves can be weakened considerably and in some cases extinguished (Chadwick & Birchwood, 1994; Bentall *et al.*, 1994; Garety *et al.*, 1994). The distress associated with a voice can be alleviated by helping individuals to challenge their beliefs about the voice (see Chadwick *et al.*, 1996; Chadwick & Birchwood, 1994; Bentall *et al.*, 1994; Garety *et al.*, 1994). This strategy follows the ABC model used in cognitive therapy which posits that changing a person's thoughts or beliefs about an event can change their feelings in relation to that event. As noted above, beliefs that a voice is very powerful and malicious are associated with distressing psychotic symptoms (Chadwick & Birchwood, 1994; Romme & Escher, 1993). Romme and Escher (1993) found, in

their nationwide survey of people who heard voices, that appraisals of voices in terms of their power and malice were key determinants of whether individuals were distressed and sought help for their voice-hearing. Chadwick & Birchwood (1994) reported that encouraging clients to question the omnipotence and omniscience of their malign voices not only reduced their distress significantly, it also, crucially, reduced their voice-hearing considerably.

Using these kind of strategies, several randomised controlled trials have demonstrated the effectiveness of CBT as a treatment for psychosis, reducing distress and in some cases reducing symptomatology for months at a time (e.g. Drury *et al.*, 1996a; Drury *et al.*, 1996b; Garety *et al.*, 1997; Sensky *et al.*, 2000; Tarrier *et al.*, 1998; Tarrier *et al.*, 1999). A recent study has also suggested that CBT may be effective in a group format (Wykes *et al.*, 1999). A meta-analysis of studies of effectiveness of CBT for individuals with a diagnosis of schizophrenia has suggested its usefulness for patients with treatment-resistant symptoms (Pilling *et al.*, 2002a). An interesting, though as yet unexplained observation, is that participants seem to improve more after treatment has ended than during the treatment phase. Pilling *et al.* (2002) call for further research to investigate CBT across a variety of patients and to examine factors mediating treatment success. Recent overviews of this work also emphasise the need to adapt treatment to the individual (Garety, Fowler & Kuipers, 2000; BPS, 2000). In any case, psychological interventions are now recognised as an important part of the approach to treating psychosis (Department of Health, NHS Executive, 1999).

As models of psychosis develop, the effectiveness of new techniques will also need to be addressed. For example, if the Wells and Matthews (1994) model of psychopathology is adapted for psychosis, the effectiveness of attentional training in this population as well as work on meta-cognitions will need to be assessed. If the elements of the Garety *et al.* (2001) model of psychosis are incorporated into therapy, it may be that trauma-related cognitive therapy and schema-focused work will require assessment as part of a cognitive-behavioural toolkit for psychosis.

Psychotherapeutic approaches to psychosis and treatment: psychodynamic and systemic

Although not widespread as a treatment in the National Health Service in the UK, psychodynamic psychotherapy together with biological, social and family approaches forms a cornerstone of treatment for people with a diagnosis of schizophrenia in countries such as Finland (Alanen, 1997) and there is growing evidence for its effectiveness (Alanen *et al.*, 2000). Evidence for its effectiveness in the UK is limited at the moment to exploratory and single-case studies (e.g. Jackson & Williams, 1994). It has recently been argued that, since psychological approaches to working seriously with psychosis are so under-developed and under-researched, it is necessary to keep an open mind about which treatments are likely to prove effective in the longer-term (Paley & Shapiro , 2002).

Other approaches to psychosis include the systemic/ family therapy and narrative approaches. The systemic approach views problems as existing within systems – within a family, between ‘professionals’ and a ‘patient’ on a ward, or within society. It tends to emphasise the socially constructed nature of concepts like ‘schizophrenia’ and is interested in the meanings this kind of term holds for an individual or a family. Rather than locating a problem within individuals, it tries to address the difficulties of individuals within their context, by addressing multiple parts of the system. It seeks to explore ways of changing one or more of these parts, assuming that change in one part of the system will bring about change in other parts. The narrative approach, as developed for example by Michael White, draws on the systemic approach and has formulated the problems experienced by individuals with a diagnosis of schizophrenia as ‘problems in living’ (White, 1987). White has identified the cultural associations relating to a person diagnosed with schizophrenia as reflecting the idea of someone who represents ‘*a spectacular failure to become a person*’ (White, 1987). He argues that when people start to identify with such a label, their opportunities for breaking out of a ‘*problem-saturated story*’ become very limited. ‘*News of difference*’, where the person behaves in a way which suggests they are capable, or hopeful, for example, can be easily overlooked if it does not fit into the frozen identity of being ‘*schizophrenic*’. Recovery can take place, according to this view, when attention is paid to alternative stories and these are deliberately worked on, such as stories which describe individuals’ strengths, not just their difficulties.

Evidence of the effectiveness of this type of approach with psychosis is limited at present to case studies (e.g. White, 1996).

Social, religious and cultural studies of psychosis and recovery

The systemic approach suggests that cultural context plays a role in recovery from psychosis. Studies have shown how the socio-economic status of a society affects recovery rates from schizophrenia (Warner, 1994, 2000; Waxler, 1979; WHO, 1979). That is, the more economically underdeveloped countries seem to have better recovery rates than societies in stages of later capitalism with higher levels of technology. One possible explanation for this is that it is easier to return to the workforce where there are tasks which are relatively less intellectually demanding, for example in agriculture, and that this easier reintegration into the society via work promotes recovery. Another hypothesis might be that there is less stigmatisation of mental health problems in these cultures and that the social response is one of support and integration, rather than exclusion or identification of the individual as 'different', and that this affects recovery. Foucault (1961/2001), in his analysis of the development of European attitudes towards 'madness' since medieval times, suggests that there has been a progressive tendency for those in power to distance themselves from the concept or experience of insanity (of which 'schizophrenia' and 'psychosis' are commonly held to be typical) through incarceration in asylums, dehumanisation, or even

diagnosis. Foucault argues that in medieval times madness was viewed more as existing on a continuum – albeit at a disturbing end - with what it means to be human and to experience different aspects of existence. As capitalism grew and rationality was increasingly prized as the highest ideal, people who were not seen to be conducting themselves in a rational manner nor providing economically useful labour were increasingly marginalised and incarcerated in asylums. The argument here might be, then, that psychosis may at times be part of human experience but how this experience is handled by society has a crucial bearing on the long-term impact on individuals in terms of their recovery or otherwise.

The religious and/ or cultural aspects of psychosis are also important to many people's experience but are often ignored or overlooked by health professionals. Some experiences such as 'hearing voices' can be viewed as an integral part of someone's religious experience and the term 'recovery' therefore would not seem appropriate since the person does not view the experiences as a problem (Davies, Griffin & Vice, 2001; Romme & Escher, 1993). Some kinds of hearing voices (e.g. hearing the voice of 'the devil') might be considered a problem within the religious framework and recovery might be understood to have to take place through a religious process of confession and absolution, prayer, or spiritual healing, for instance (Porter, 2002). Roberts & Holmes (1999) describe the role of Hindu mythology in working with a young man in understanding and recovering from psychosis. The latter case suggests it may be possible to offer interpretations of experience within the person's frame of reference which can

promote recovery, without necessarily having to draw from an alternative frame, such as medicine or psychotherapy.

The subjective experience of psychosis and recovery

Some recent studies have sought to develop our understanding of mental health problems and recovery by exploring the subjective experience of individuals. This has been possible in part due to the development of qualitative research methods in psychology, building on work in the social and human sciences.

Psychosis and recovery: first person accounts

The largest sources of subjective material about psychotic experiences (and/or recovery) at the present time are either literary, whether ostensibly fictional or overtly autobiographical (e.g. Kavan, 1940, 1948; Frame, 1961; Vonnegut, 1975), or first-person accounts published for a 'mental health' readership (e.g. Anonymous, 1983; Lovejoy, 1984; Leete, 1988, 1989, 1994; Deegan, 1988, 1990, 1993 ; Spaniol & Koehler, 1992; Campbell & Davidson, 1999; May, 2000).

Further first-person accounts are to be found in publications by The Mental Health Foundation (Faulkner & Layzell, 1999; Reid, 2001) and MIND (Baker & Strong, 2001). Hornstein (2002) offers a discussion of first-person accounts of

madness, and in some cases recovery, written over the last century. She comments on the diversity of written styles and experiences – from the desperate dullness of some accounts of living a life which seems devoid of meaning, to gripping tales of adventure as individuals struggle through adversity. The focus here, however, will be on the relatively small body of rigorous research that has been published in this area and which has sought to analyse key aspects of written and verbal accounts of recovery from severe mental illness.

Why study the subjective experience of psychosis and recovery ?

In two seminal papers in the early 1990s, Strauss and Davidson indicated the need to go beyond quantitative studies of recovery from psychosis (Davidson & Strauss, 1992; Strauss, 1994). In the first paper, Davidson and Strauss analysed a series of interviews they had conducted with a woman with a diagnosis of schizophrenia who had taken part in the Yale Longitudinal Study of Prolonged Psychiatric Disorder, a research project which used questionnaires and structured interviews. They claimed that her account of recovery reflected key themes they had come across with other participants they had interviewed. In particular, they identified '*the rediscovery and reconstruction of an enduring sense of self as an active and responsible agent*' as key to the recovery process. Strauss (1994) subsequently highlighted the need to focus on subjective experience as part of the research enterprise:

'Even though the research interviews [in the Yale study] are broad in coverage and have extended open-ended sections, there appeared to have been something about the way in which the data were collected and recorded that all but prevented Dr Palman and even me, who had done the interviews, from being able to write anything that nearly approximated this woman's experience. It struck us furthermore how little the psychiatric format – present illness, past history, family history, etc. – allows for noticing or recording the person's experience. From such a format, it is in fact almost impossible for the person to be discoverable.'

(p.8)

Strauss concludes there is a need to develop a concept which can reflect both 'subjective' and 'objective' descriptions. He suggests that this concept might be 'the person's story' (p8).

Thematic analysis in studies of psychosis and recovery

A number of studies to date have used qualitative methods to analyse individuals' accounts of psychosis. Rhodes and Jakes (2000) offer a qualitative analysis (using features of interpretative phenomenological analysis and grounded analysis) of the correspondence between four individuals' delusions and their personal goals, suggesting that if understood metaphorically, delusional talk can point towards key concerns in a person's life. Knudson and Coyle (2002) present an interpretative phenomenological analysis of two individuals' accounts of voice-

hearing. They argue that examining individuals' interpretative frameworks is important in understanding more fully the impact of voice-hearing and, more specifically, how coping strategies are used. For example, one participant understood his voice-hearing as representing aspects of himself, related to unexpressed anger and sexuality. His main strategy was noticing when he was feeling angry, for example, and attempting to express his anger. He stated this reduced his voice-hearing. On the other hand, another participant held a number of beliefs about her voice-hearing simultaneously, including the belief that it might be related to previous drug-taking either through biological mechanisms or morally (as a penance), that it might be genetic, that it might be a part of her, and that it might be stress-related. Knudson and Coyle (2002) argue that the variety of strategies she uses to control the voices (e.g. sensory stimulation, social contact, physical exertion, challenging the voices) reflects the diversity of factors in her explanatory framework. They further argue that teaching coping techniques is unlikely to be successful unless the techniques fit with the individual's explanatory framework, thereby emphasising the importance of exploring and understanding subjective experiences and accounts.

A number of studies in the USA have analysed first-person accounts of recovery from severe mental illness thematically (Jacobson, 2001; Ridgeway, 2001; Smith, 2000; Young & Ensing, 1999). Some of the studies analyse previously published accounts of recovery from mental illness (Jacobson, 2001; Ridgeway, 2001) while

others use an interview-based technique to elicit accounts from participants (Smith, 2000; Young & Ensing, 1999). Studies vary in their focus, depending on the particular qualitative methodologies chosen and the perspectives of the researchers. One study (Jacobson, 2001) uses dimensional analysis and describes four central dimensions of recovery:

- recognizing the problem;
- transforming the self;
- reconciling the system;
- reaching out to others.

Thus this study highlights the systemic nature of recovery, indicating that it seems to take place at a number of levels including at the level of the problem, the self, others, and the system. It further examines different explanatory models which individuals use in their accounts of recovery, including a biological model, an abuse or trauma model, a model combining biological and environmental factors, a spiritual or philosophical model, a political model, and a 'spirit-breaking' model (which refers to an understanding of the problem as 'the dehumanizing transformation from being a person to being an illness' (p.253)). It discusses how different models suggest different pathways to recovery, through the four dimensions outlined above. This study, drawing on 30 published accounts of recovery, is a valuable contribution to the literature particularly due to its scope and its identification of the crucially systemic nature of recovery, as well as its identification of diverse explanatory models and how these influence the recovery process. However, it has limitations in that, firstly, the accounts appear to describe

recovery from a wide range of mental health difficulties which are not made clear; secondly, some of the accounts analysed are different works by the same person (for example, four texts by Patricia Deegan are analysed); thirdly, published accounts may exhibit particular characteristics compared with accounts given verbally and do not allow for detailed exploration of particular topics by the researcher; fourthly, these are accounts by individuals living in the USA which may have particular cultural implications; and fifthly, this study does not focus in detail on psychological or emotional themes.

In a study focusing thematically on recovery narratives (Ridgeway, 2001), the themes identified are:

- the reawakening of hope after despair;
- breaking through denial and achieving understanding and acceptance;
- moving from withdrawal to engagement and active participation in life;
- active coping rather than passive adjustment;
- reclaiming a positive sense of self;
- moving from alienation to a sense of meaning and purpose;
- recovery is a complex and non-linear journey;
- recovery involves support and partnership.

This analysis offers a useful outline of key concepts in recovery which could point towards the development of a model of recovery with important practical implications. However it is based on the analysis of only four recovery narratives,

all written by white American women. Clearly further research is needed to explore whether these themes are shared with diverse groups. This study is also individualistic in focus, in that the themes centre on the individual's role in recovery. Taken together with the Jacobson (2001) study, the two offer a more holistic account of recovery which detail key themes, as well as the role of systems and explanatory frames of reference. This suggests that qualitative studies, which tend to use small sample sizes and vary in the focus of their analysis, can complement one another and increase their utility if synthesised into an integrated whole.

Another study using grounded theory analysis developed a model of recovery based on 2 focus groups and 7 in-depth individual interviews with people with 'psychiatric disabilities' which included people with a range of diagnoses including bipolar disorder, schizophrenia, major depression, schizoaffective disorder, psychotic depression, borderline personality disorder and post traumatic stress disorder (Young & Ensing, 1999). The model draws out three stages in the recovery process, 'Initiating recovery: Overcoming 'stuckness"'; the 'Middle phase' which involves 'Regaining what was lost and moving forward'; and the 'Later phase: Improving quality of life'. Each of these stages is characterised by particular themes: overcoming 'stuckness' involves acceptance of illness, developing motivation to change and finding a source of hope; the middle phase includes discovering and fostering self-empowerment, for example through learning and self-redefinition and returning to basic functioning; the later phase

involves striving to attain an overall sense of well-being and striving to reach new potentials of higher functioning.

Young and Ensing (1999) offer a detailed model of recovery which includes a range of themes from the concrete (e.g. 'abuse of alcohol') to the more abstract (e.g. 'motivation') and draws on the experiences of eighteen individuals. The participants were 6 males and 12 females, with a range of ages from 26-59 years and an ethnic mix including 5 African Americans and 13 European Americans.

This study therefore draws on a broader range of participants than the previous studies discussed. However limitations of the study include its focus on the individual in recovery and the relative neglect of wider social and cultural factors.

As with most qualitative studies, the sample size is small and further qualitative studies are needed to explore whether similar themes emerge over a larger number of participants. The authors also argue that more attention needs to be paid in further studies to the specific internal states that constitute recovery from the perspective of the participants, not just to the 'hows' of recovery. This would be an important focus of future qualitative research in psychology.

Smith (2000) also explores recovery 'from a severe psychiatric disability' (schizophrenia, bipolar disorder, and major depression) using interviews with 10 participants. She finds themes which overlap with Young and Ensing's study including:

- the importance of developing a sense of what recovery means to the individual;
- acceptance;
- finding the desire for change;
- finding ‘the right kinds of medication’;
- finding supportive people;
- meaningful activities;
- a sense of control and independence;
- maintaining a positive outlook.

She also identifies ‘barriers to recovery’ such as

- stigma;
- remaining ‘symptoms’ (either associated with the person’s mental state, or with the effects of medications they are taking);
- lack of financial resources;
- limited access to services;
- occasional life pressures.

This study offers a useful template for recovery research in focusing not just on what helps recovery, but also what hinders it. One interesting aspect of this study is the emphasis in the analysis on the ‘acknowledgement of one’s own disability’ (p.150) as a key aspect of recovery. This is highlighted in the section on ‘the meaning of recovery’ as well as in ‘turning points towards recovery’ and ‘critical

factors involved in recovery', the first of which is listed as 'the right kinds of medication' (p.151). As in the Young and Ensing (1999) study, 'acceptance of illness' is identified as an important aspect of recovery. This contrasts with the analysis of recovery narratives by Jacobson (2001) who found that individuals used different explanatory models for their experiences and some recovery narratives explicitly rejected the illness model. There could be a number of reasons for this discrepancy. One possible explanation might be that some individuals write accounts for publication partly as a form of protest, and that these accounts reflect different experiences of and attitudes towards recovery to those found when individuals are recruited through mainstream mental health services. Another explanation might be that the orientation of the researcher affects how the analysis develops, so that a researcher approaching the material with a biomedical understanding of mental illness might highlight this aspect, whereas another researcher might focus on the socially constructed nature of mental health problems, for example. This suggests the importance of a variety of researchers with different assumptions and backgrounds (including a range of professionals and users) in carrying out a considerable number of qualitative studies, and also drawing on a wide range of participants, for the experience of recovery from mental health difficulties to be adequately explored. In recognition of this need for a diversity of perspectives, a recent study in New Zealand (where all mental health services have been required by government policy to use a recovery approach since 1998) has analysed 20 Maori and 20 non-Maori narratives of recovery and one of the interviewees led and wrote up the research

(Lapsley, Nikora & Black, 2002). This is another example of a study in which acceptance of an 'illness model' was not found to be a prerequisite of all recovery narratives, highlighting the diversity of individuals' experiences and of individual research studies.

There have been a few studies of managing mental health difficulties in the UK

and these have been mainly undertaken by mental health users and charities.

A user-led study (Faulkner & Layzell, 2000) undertook a qualitative analysis of 71 interviews on the subject of living with mental distress (33 of the participants had psychotic diagnoses). Their report on the findings suggest a number of areas which overlap with the above studies including the importance of relationships and informal support, finding meaning and purpose and taking control and having choices. A recent study undertaken by the National Schizophrenia Fellowship on 'self-management' of schizophrenia asked fifty people with a diagnosis of schizophrenia to share their views about self-management. This is defined as 'the ways we cope with, or manage, or minimise, the ways the condition limits our lives, as well as what we do to thrive, to feel happy and fulfilled, to make the most of our lives despite the condition' (Martyn, 2002). The overarching themes were 'Maintaining morale, finding meaning'; 'Relationships with other people'; 'An ordinary life: coping'; 'An (extra)ordinary life: thriving; and 'Managing 'having schizophrenia''. These were extremely valuable initial studies which raised a number of key aspects which individuals find helpful in managing their difficulties including the importance of finding meaning, having control and

choices and finding supportive relationships. However the focus in these studies was not specifically on recovery. In addition, there was no detailed examination of psychological and emotional themes.

MIND have conducted one of the first recovery-focused studies in the UK, using a survey method and asking members about their experiences of recovering from and coping with their mental health problems (Baker & Strong, 2001). They found that factors associated with helping recovery were talking to friends and family, eating well, working and volunteering, hobbies, and physical exercise and activity. Some of the main factors identified as hindering recovery were: the attitude of the general public, low self-esteem, the benefits' trap, low income, mental health professionals, lack of choice in treatments, acts of discrimination, and racism. Further studies are needed to examine these factors in more detail and to explore within a theoretical framework how these factors operate as part of the biopsychosocial process of recovery.

Narrative studies

There is a growing literature which uses narrative methods to analyse individuals' accounts of illness, injury, disability and trauma, in recognition of the crucial role played by narrative and the construction of meaning in recovery from or acceptance of disruptive or traumatic life experiences (e.g Crossley, 2000a; Frank, 1993; Gray, 2001; Harvey, Mishler, Koenen & Harney, 2000; Kleinman, 1989; Langer, 1996).

There have been a few studies to date examining stories of mental illness according to narrative genre. Hyden (1995) uses a narrative analysis of a single case, arguing that one man's story of recovery from psychotic depression can be understood as a 'moral quest'. He suggests that the man reconstructs his experience once he finds a 'platform' from which to speak and formulate 'a voice'. The platform involves some ability to re-identify himself with previous aspects of his personality (e.g. through work, or interests) and then to begin to ask questions about responsibility for his experiences, thinking about his own role and the role of family members, which can re-orient him to how to live his life in the present and the future. This study is important in suggesting how a focus on narrative necessarily involves considering the social and cultural context in which stories are constructed and told. The reconstruction of the account as a 'moral quest' indicates that the story is about the participant's attempt to find a meaningful role in society as an individual who has experienced mental health

problems and thus found himself temporarily marginalised from mainstream roles and expectations. Further studies are needed to extend this research and to explore the nature of recovery narratives beyond the single-case study.

Stern *et al.* (1999) interviewed family members caring for a relative with a severe mental illness and analysed these accounts using narrative methods. In a study which drew out key themes and types of narrative, they identified two types, 'chaotic or frozen' narratives, and narratives of 'restitution or reparation'. They suggest that the main task facing a carer is to reconstruct a sense of meaning after the severe disruption of a serious mental illness in the family. In the chaotic/frozen narratives the illness remains a series of random, incomprehensible events. They suggest this has important implications for helping families to cope with these kind of events. They highlight the need for future studies to address similar issues from the point of view of the 'ill person'.

Ridgeway (2001) uses a narrative analytic method to draw out a 'core narrative' from 4 published narratives of recovery from severe mental illness. She identifies a shift in the core narrative from one in which people feel stuck and hopeless - '*I have a mental disorder and will never get better*' - to a more complex and dynamic life-story: '*I am a unique individual struggling with a psychiatric disorder, and through my attitudes and daily actions, with the help of caring others, I can and have reclaimed a meaningful life. I tell the story of my ongoing*

journey of recovery so that others may recover as well.' She stresses the need to adapt mental health services and the language used by 'professionals' with 'users' to reflect the importance of this kind of dynamic narrative for the recovery process.

In brief, a number of qualitative approaches have been used in exploring the subjective experience and interpretative frameworks of individuals with psychosis, or other longer-term mental health difficulties and in exploring recovery. However few of these have explored in depth psychological and emotional aspects of recovery and none have focused exclusively on recovery from psychosis. As with all qualitative studies, the number of participants is normally small and further studies are required to research whether similar themes emerge across studies.

Summary and rationale for the current study

Most research in the last century into psychosis has addressed biological and genetic aspects of the onset, maintenance and treatment of symptoms. This has yielded some valuable results, for example medications which have been found to be effective in eliminating or reducing psychotic symptoms (Schwartz *et al.*, 1993). However medication is not reported to be helpful in all cases, and in a proportion of cases it is only partially helpful. In addition there are risks associated with taking anti-psychotic medication, particularly in the long-term,

and some individuals report finding some of the drugs' effects distressing, disabling or unwanted. In addition, studies in the population at large have indicated that many more people have hallucinatory experiences than come to the attention of clinicians and this, in combination with studies which have examined individuals' use of coping strategies to manage their symptoms, has prompted further research into the psychological aspects of voice-hearing and delusional beliefs. Various models of psychotic experiences have been proposed, suggesting that beliefs about the experience, related self-schemas, corresponding emotional responses and information-processing style may all be implicated in the maintenance of or recovery from these experiences. The development of detailed questionnaires has allowed researchers to explore more fully the psychotic experiences of individuals along different dimensions and to chart improvements likewise in a more refined way. Interventions are developing which take account of these new models of psychosis, including techniques to address beliefs about hallucinations, the normalisation of such experiences and the challenging of voices or delusional beliefs through tentative questioning and the consideration of the evidence.

In the last few years, some researchers have sought to examine the subjective experience of psychosis and recovery in greater detail, using qualitative methods drawn from the social and human sciences. The rationale for this has been that as conscious, interpretative creatures, the study of human beings and the human mind requires methods distinct from those employed solely in the natural

sciences. In addition, subjective experience has an impact on the individual's response to psychosis, for example how the person constructs their experience will influence their coping strategies, degree of hopefulness about the future and motivation, thus also affecting outcome.

Thus qualitative research to date has examined some of the themes associated with recovery such as hope, support from others, re-finding a positive identity and regaining a sense of control and meaning (Jacobson, 2001; Ridgeway, 2001; Smith, 2000; Young & Ensing, 1999). As most qualitative studies have small sample sizes, further studies are needed to corroborate these findings. The MIND survey and Mental Health Foundation study (Faulkner & Layzell, 2000) have larger sample sizes but their findings are broad and atheoretical. Further research needs to examine in more detail how recovery works for individuals, physically, psychologically, emotionally, and socially, taking into account existing psychological theories.

In addition to the dearth of research on the subjective experience of psychosis and recovery, there is also very little research on individuals who do not use clinical services. Despite the research which shows that many people have hallucinatory experiences and do not seek help, or that following a psychotic episode a third of people recover, or that the prognosis for the majority of people who experience psychosis is good in the longer term, very little work has focused on non-clinical

populations. This is an important omission since people who have recovered may give us clues about how best to facilitate recovery in those seeking help from clinical services.

Some recent studies, in particular from organisations with links to the user-movement, have begun to collect evidence from their members about what they feel helps them to live with or recover from severe mental health problems (Baker & Strong, 2001; Faulkner & Layzell, 2000). However there is a need to incorporate and expand this type of study in clinical research, for example by exploring in more depth the psychological and emotional aspects of the experience of psychosis and recovery and linking it to psychological theory.

It has been suggested that the person's 'story' could be an important concept for understanding the experience of recovery from severe mental and emotional distress/ illness (Strauss, 1994). Narrative methods have been used to look at individuals' accounts of recovery from or acceptance of illness, trauma and disability (e.g. Crossley, 2000a; Frank, 1993; Gray, 2001). There is a small amount of research that uses narrative methods for analysing accounts of recovery from psychosis and relatives' experience of caring for someone with psychosis (e.g. Hyden, 1995; Stern *et al.*, 1999). However there is much scope for expanding the work in this field.

Aims of the current research

The aims of the current research were to address the gaps in the literature

1. by not recruiting participants through clinical services and focusing on individuals who described themselves as recovered or recovering;
2. by exploring in detail the subjective experience of psychosis and recovery, focusing on psychological and emotional themes
3. by further investigating how individuals construct and tell their stories of recovery

Research questions

The research questions were as follows:

1. What psychological and emotional themes emerge in accounts of individuals who describe themselves as recovered or recovering from one or more psychotic episodes?
2. What kind of stories do individuals tell about their recovery from psychosis and what are the implications of this?

CHAPTER 2

METHOD

Overview

This is a qualitative study which uses the methods of Interpretative Phenomenological Analysis (IPA) and narrative analysis to examine the accounts of fifteen individuals who describe themselves as recovered or recovering from one or more psychotic episodes. The individuals were interviewed using a semi-structured interview schedule. The interviews were taped, transcribed and analysed by the methods set out below. Methods were chosen that were most appropriate to the aims of the study, as reflected in each of the two research questions.

Choice of methodology

Question 1: What psychological and emotional themes emerge in accounts of individuals who describe themselves as recovered or recovering from one or more psychotic episodes?

The first aim of the study was to examine the subjective experience of recovery from psychosis, focusing in particular on emotional and psychological themes. A methodology which allows for an in-depth analysis of themes and one which is epistemologically oriented to analysing subjective experience was required. One such methodology is Interpretative Phenomenological Analysis (IPA; Smith, 1996; Smith, Flowers & Osborn, 1997; Smith, Jarman & Osborn, 1999; Willig, 2001). This methodology has developed within health psychology but is currently being employed more widely, for example within clinical psychology, since it allows previously neglected aspects of human psychology (for example, the detailed processes of how individuals make meaning out of their experiences) to form the focus of study. As Smith (1996) argues:

'the neglect, thus far, of qualitative approaches within mainstream psychology has produced a distorted agenda of what counts as legitimate inquiry and an impoverished map of psychological knowledge. A particular methodological commitment has tended to be privileged over substantive concerns and topics have been neglected precisely because they would prove difficult to quantify' (p.265).

While thematic analysis is a key aspect of many qualitative methodologies (see e.g. Willig, 2001), IPA has the advantage that its methods have been clearly set out (e.g. Smith, Jarman & Osborn, 1999; Willig, 2001), the fundamentals of its theoretical basis have been explored (e.g. Smith, 1996; Smith, Flowers & Osborn, 1997), and there are precedents for its use within British psychology research (e.g. Clare, 2002; in press; Jarman, Smith & Walsh, 1997; Knudson & Coyle, 2002; Macran, Stiles & Smith, 1999; Pearce, Clare & Pistrang, 2002; Rhodes & Jakes, 2000).

Briefly, IPA is phenomenological in that it '*is concerned with an individual's personal perception or account of an object*' (Smith, 1996). It regards what individuals say about a phenomenon as legitimate data from which to infer knowledge about their experience of that object or event. Edmund Husserl, one of the major philosophers associated with the idea of phenomenology, has described this approach as '*eine neuartige Wissenschaftlichkeit*' ('*a quite new way of being scientific*'); Husserl, 1928/1997) and suggested it serve as a radical science fundamental to psychology as well as retaining a function within philosophy. The argument in phenomenology is that when trying to understand certain kinds of knowledge (such as how humans think about things or what is contained in consciousness, for example) the only way it is possible to do this is by inferring knowledge from what a person says about their experiences and by adopting methods which allow this to form the basis of study. IPA is contrasted with discourse analysis in that it claims to be able to say something about people's

thinking (Smith, Jarman & Osborn, 1999), whereas in discourse analysis the focus tends to be on language and the function of language (Potter & Wetherell, 1987; 1995) though uses of it vary (Willig, 2001). However it shares with discourse analysis a rejection of the notion of 'objectivity': *'it is concerned with an individual's personal perception or account of an object or event as opposed to an attempt to produce an objective statement of the object or event itself'* (Smith, Flowers & Osborn, 1997, p.69). In addition to the phenomenological aspect of IPA, the interpretative aspect stresses that it is only through a process of interpretation by the researcher that the process of analysis can take place: it both *'depends on and is complicated by the researcher's own conceptions'* (Smith, Jarman & Osborn, 1999, p. 218). This recognition of the role of the researcher in interpretation distinguishes it from grounded theory, for example, in which this contextual element of the research process is not made explicit (Willig, 2001). In addition, it has been argued that IPA is more appropriate for studying individual accounts of psychological processes, since grounded theory was originally designed to develop theories of social processes, whereas generally in psychology the researcher is aiming to develop rich descriptive accounts of the nature of particular experiences, not to develop explanatory theories (Willig, 2001).

The process of analysis is addressed in a subsequent section.

Question 2: What kind of stories do individuals tell about recovery from psychosis?

The second aim of the study was to explore the nature of people's stories of recovery from psychosis. This part of the study sought to draw out cultural and social aspects of recovery from psychosis by examining the kinds of language and cultural 'meta-narratives' individuals used in their accounts. It also sought to explore how individuals construct their experiences within a narrative framework.

In addition this part of the study aimed to be able to analyse the accounts holistically and draw comparisons and contrasts between the accounts. The methods of narrative analysis were selected as most appropriate for this aspect of the study.

There is a growing literature which uses narrative methods to analyse individuals' accounts of illness, injury, disability and trauma, in recognition of the crucial role played by narrative and the construction of meaning in recovery from or acceptance of these experiences (e.g. Crossley, 2000a; Frank, 1993; Gray, 2001; Harvey *et al*, 2000; Kleinman, 1989; Langer, 1996). It has also been argued that the narrative approach is a theoretically rich methodology which can enable research to inform practice (e.g. Andrews *et al.*, 2001; Crossley 2000a, Crossley, 2000b), something that is crucial in the field of clinical psychology. As in IPA, the theoretical roots of narrative analysis lie both in philosophy and in psychology. Philosophically, the approach is derived from hermeneutics which holds that human beings are

constantly involved in meaning-making and that our knowledge of the universe and each-other is inextricably entwined with the interpretative enterprise. In this respect it is similar to IPA (which emphasises the role of interpretation) although there is even more emphasis on the contextual basis of understanding. Hence there is more emphasis in the analysis on social and cultural aspects of language use and on narrative structure. MacIntyre (1981), working from a philosophical perspective, has recently articulated the hermeneutic position:

'It is because we all live out narratives in our lives and because we understand our own lives in terms of the narratives that we live out that the form of narrative is appropriate for understanding the actions of others.' (p.212)

Theorists arguing for a narrative approach in psychology have maintained that 'the story' can be understood as a 'root metaphor' in psychology (Sarbin, 1986), and that how people think about and structure their experiences in terms of narrative affects, and at times determines, how these experiences will impact on their lives (Crossley, 2000a; Gergen, 1992; Lieblich, Tuval-Mashiach & Zilber, 1998; Riessman, 1993). Sarbin (1986) refers to '*the storied nature of human conduct*' and Polkinghorne (1988) argues that a science of psychology cannot be complete without an acknowledgement of the importance of language, meaning, and interpretation for how human beings think, feel and act in the world.

Others have noted how crucial it is for human beings that their lives, and in particular their suffering, should mean something (Roberts & Holmes, 1999).

Roberts and Holmes (1999) suggest that stories are *the* way people make meaning, and that to lose a sense of the importance of the stories individuals hear or tell in a context which is meant to be healing can be very damaging. Roberts (2000) further argues that in an increasingly ‘evidence-based’ world, the evidence from individuals’ stories must be used in conjunction with evidence from large-scale quantitative studies, in order to ensure the inclusion of the specific as well as the general, and the subjective as well as the objective, in informing best clinical practice . Crossley (2000a) highlights that narrative often has a moral element, linking the protagonists to values recognised by a society. She argues that using a narrative approach in psychology allows researchers to grapple, however partially, with key aspects of human experience such as pain, suffering, the meaning of existence, morality, and the nature of the self and of relationships with one another and within society. Narrative analysis has been found to be particularly useful in researching areas in which there are powerful social and cultural narratives through which individuals must navigate with their own stories (e.g. Crossley, 1999; Freeman, 2001; Plummer, 1995). Since this is clearly the case with mental illness broadly, and psychosis in particular, narrative analysis was selected as an appropriate methodology.

After reviewing the literature on narrative methodology and considering previous studies, the research question ‘*What kind of stories do individuals tell about recovery from psychosis?*’ was further sub-divided into the following questions for the purposes of the analysis:

- i) Which genres of narrative, core narratives and tone emerge in individuals accounts of recovery from psychosis, and what does this tell us about the process of recovery?
- ii) What kinds of language and meta-narratives of psychosis and recovery do individuals draw on, and how are these used in the accounts?
- iii) What can an analysis of the 'turning points' and 'stuck points' in the narratives tell us about the process of recovery?

The process of analysis is addressed subsequently.

Relationship between the two parts of the analysis: IPA and narrative analysis

The research as a whole aims to offer an analysis of the accounts of recovery from psychosis at a number of different levels. At the first level, the analysis offers a bottom-up in-depth thematic analysis using IPA which identifies discrete meaning-units and groups these into themes across the accounts. The aim of this is to provide the reader with knowledge of key aspects of the subjective experience of recovery from psychosis, as experienced by the participants in this study, and as interpreted by this researcher. This part of the analysis, while starting with an analysis of individual interviews, works towards identifying themes which are presented in aggregate across the group.

At a different level, the analysis aims to look at particular aspects of the accounts using narrative analysis. The aim of this part of the analysis is to explore the kinds of stories individuals tell about recovery from psychosis. This can inform research and practice in a number of ways. For example, it may indicate what kind of stories can facilitate a recovery narrative (which is relevant to fields as diverse as GP-patient communication or narrative therapy, for instance). It may provide information about how individuals negotiate between their own and society's narratives about mental illness and recovery, which could have implications for health service provision as well as for public health campaigns. Examining 'turning points' can provide vital clues about key moments in an individual's experience of recovery from psychosis which may elicit important findings for how services can best promote recovery.

The part of the narrative analysis which examines language and meta-narratives focuses on social and cultural levels of meaning, exploring how individuals' narratives use and adapt the available ways of talking about psychosis and recovery. The analysis of 'turning points' selects particular narrative moments characterised by their presentation in the accounts as crucial to the recovery process (where 'something changed') and examines how these are described and what seem to be their key aspects. For the purposes of these two types of analysis, discrete sections of a number of interviews are selected for analysis. Finally, the analysis of genre, tone and core narrative offer an analysis focusing on the accounts

holistically, and aiming to provide 'top-down' or holistic-form elucidation of important aspects of the accounts.

It is expected that the different elements of the analysis will offer complementary accounts of the phenomena under investigation and together will provide a richer, more complete and more detailed analysis than would be offered by any one method alone. It is possible that some similarities may emerge between different aspects of the analysis (e.g. between analysis of themes and aspects of 'turning points' or 'meta-narratives'). However it would not be anticipated that any aspect of the analysis would provide results which would refute or contradict any other aspect.

Participants

Participants were recruited as healthy volunteers. An advertisement for the study was distributed (see Appendix 1) to groups which users and ex-users of services attend, and at a conference attended by a significant number of users and ex-users of the psychiatric system. The advertisement was also placed in the newsletter of a user-group in South London. News of the study also spread by word of mouth, and

participants were invited to introduce others to the study ('snowballing'). The field supervisor also informed contacts he had about the study.

Inclusion criteria

The inclusion criteria were that individuals should identify themselves as recovered or recovering from one or more psychotic episodes. In keeping with the nature of the study, objective criteria for recovery were not specified, since part of the study aimed to explore the meaning of recovery for individuals. Participants were not required to have been recovered (according to their definition) for a particular time-frame since the study aimed to explore the process of recovery both in the shorter and longer term. Participants had to be between 18 and 70 years old (inclusive). The study focused on adults, not children or adolescents, hence the younger age limit. An older age-limit was set as it was considered that the impact of ageing might raise different issues with regard to recovery from psychosis than was the focus of this study. In all cases, participants' accounts included at least one hospital admission that they understood to be a direct result of their experience of psychosis.

The aim was to have a purposive sample, *not* a random sample. This sample would include a roughly equal number of men and women and a range of ages and ethnicities. The aim was also to recruit individuals with a range of experiences of psychosis (e.g. different diagnoses; lengths of time since last admission; number of episodes). As this was one of the first studies of its kind, it aimed to be broad in scope, in line with its exploratory nature. The participants included six males and

nine females; eight individuals in their thirties, five in their forties, one in their fifties and one aged seventy; ethnically, there were twelve white British individuals, two white non-British and two Asian British. Four of the participants could be described as 'well-educated', with its implications of social privilege. The social background of participants varied, with some presenting themselves as from privileged backgrounds, while others commented on their working-class roots. All had undertaken some form of further training or higher education, some before their psychosis, some afterwards, and some both before and subsequently.

In keeping with the qualitative approach, the following are brief descriptions of the participants (see Table 1, below). For reasons of confidentiality, all names are pseudonyms and some identifying information has been omitted.

Table 1: Descriptions of participants

Participant 1

Peter	
<i>Age, gender and ethnicity:</i>	Peter is a white British man in his 40s
<i>Education and profession:</i>	Peter is well-educated with a background in medicine and business.
<i>History of difficulties:</i> He had his first 'breakdown' aged 34 when he was a successful businessman. This was followed by a number of other admissions to hospital over the next 6 years or so, including being brought in by the police and treated under section. Initially he says he was diagnosed as a 'cocaine addict' by a psychiatrist who he says was an alcoholic. This he says is despite the fact he has never taken street drugs. He says it was discussed amongst his team whether he was 'manic-depressive' or 'schizophrenic'. He discovered that if he said he did not hear voices, he would be likely to be diagnosed with manic-depression and this is the diagnosis he then received. He has a medical training and realised that he had a thyroid deficiency which was untreated. When this began to be treated he says he noticed a marked improvement in his mental health.	
<i>Outcome and present status:</i> He has not been admitted to hospital since 1996. He believes he has been helped to recover by having treatment for his thyroid, counselling, and learning how to monitor himself. He checks his state of mind using a questionnaire he has devised himself. He takes treatment for his thyroid and occasionally small amounts of self-administered psychiatric medication, for example in the event of sleep deprivation. He is now campaigning for increased awareness of physical aspects such as the thyroid in psychosis. He is also taking legal action with regard to his initial misdiagnosis as a 'cocaine addict' and the poor treatment he feels he has received within the psychiatric system. He is self-employed.	

Participant 2

George	
<i>Age, gender and ethnicity:</i>	George is a white British man, aged 70
<i>Education and profession:</i>	George is well-educated and following his recovery trained as a teacher and went on to have a successful career in broadcasting.
<i>History of difficulties:</i> From the ages of 20 to 40 he had four admissions to psychiatric hospital with a diagnosis of paranoid schizophrenia. He describes at that time hearing voices and having visual hallucinations as well as being 'paranoid about compulsory treatment'. On his last admission he met a man who taught him about a technique called 'time-sharing' in which the person relaxes and allows the voices to take over and gradually become integrated within them. On this admission he was also permitted to leave hospital without medication. Previously he said he had found the medication had made it very difficult for him to hold down a job.	
<i>Outcome and present status:</i> He has had no subsequent admissions to hospital. He says that after about a year of 'time-sharing' he ceased to be troubled by voices. He regards himself as fully recovered. Now he has retired from broadcasting he is trying tell others about how he managed to recover from schizophrenia and to campaign against compulsory treatment. He is married with grown up children.	

Participant 3

Mary	
<i>Age, gender and ethnicity:</i>	Mary is a white British woman in her 40s.
<i>Education and profession:</i>	Mary describes herself as from a working-class background. When she left home she trained as an artist.
<i>History of difficulties:</i> She had her first admission to psychiatric hospital as an art student when she experienced 'ideas of reference' and 'paranoia'. She has had four subsequent admissions for psychosis and one following an attempted suicide. Her last admission was about 4 years ago. Her diagnoses have included anxiety, depression, psychotic depression, psychotic episode without schizophrenic features, schizo-affective disorder, and psychotic episodes brought on by stress. She rejects these diagnoses and understands her experiences as part of being a sensitive, creative person. She describes herself as like a 'lightening conductor' for negative feelings around her. About 2 years ago she felt things 'going a bit strange' again but she 'handled it' with the help of her partner and without seeking help from services.	
<i>Outcome and present status:</i> Mary works part-time as an advocate, looks after her daughter, writes and does art. She does not take psychiatric medication. She regards herself as sensitive but increasingly able to manage her sensitivity around others and to channel it into her creative activities.	

Participant 4

Martha	
<i>Age, gender and ethnicity:</i>	Martha is a white British woman in her 50s.
<i>Education and profession:</i> Martha left school at 16 and worked for a time for her father who ran a small business in her native town. She later trained as a school teacher.	
<i>History of difficulties:</i> She describes being admitted to hospital 3 times between the ages of 16 and 23 with a 'manic' psychosis (she was not given a diagnosis). The two latter admissions were to a hospital which had been set up as a 'therapeutic community' in the 1960s. She views the understanding approach she found there, the therapeutic work and family therapy meetings as having enabled her to work through her psychosis. She understands her psychosis in the context of her family and of being a sensitive person. She describes never having been ill again in this way since her 20s, though she had a period of depression later in her life which she managed with the help of weekly counselling.	
<i>Outcome and present status:</i> Martha has no mental health difficulties currently and in addition to bringing up her three children has been working in mental health as a nursing assistant and as a support worker.	

Participant 5

Patricia
<i>Age, gender and ethnicity:</i> Patricia is a white British woman in her 40s
<i>Education and profession:</i> Patricia describes herself as from a working class background. She has been a trained occupational therapist since the age of 22.
<i>History of difficulties:</i> She has been epileptic since the age of 18 and experienced a period of depression around this time. Since 1991 she has had a number of admissions to hospital with when hearing voices and believing others were plotting against her. She has been given a diagnosis of schizophrenia. She has found that long-term psychodynamic psychotherapy has helped her in her recovery as well as medication.
<i>Outcome and present status:</i> Her last admission to hospital was in 1995. She continues to take anti-psychotic medication regularly while working full-time as an occupational therapist.

Participant 6

Kate
<i>Age, gender ethnicity:</i> Kate is a white British woman in her 30s.
<i>Education and profession:</i> She has a university degree and has studied art. She has also taught English as a foreign language.
<i>History of difficulties:</i> She has been admitted to hospital a number of times since her early 20s and describes her diagnosis as 'manic-depression'. When psychotic she describes herself as vulnerable to sexual abuse inside and outside hospital. She connects this to her experiences of being sexually molested as a child by other children. She links the difficulties she has emotionally to difficult relationships within her family, particularly with her mother and sister. What she describes as helpful in recovery are not drinking alcohol, not smoking cannabis, not drinking tea or coffee, eating healthily, using homeopathic drops and breaking off abusive relationships. She also finds writing helpful.
<i>Outcome and present status:</i> She has not had an admission for 3 years and has been 'drug-free' for 2 years. She is not currently employed but does some voluntary work.

Participant 7

Suraya
<i>Age, gender, ethnicity:</i> Suraya is a non-British white woman in her 30s.
<i>Education and profession:</i> Suraya was training as a nurse when she had her first 'breakdown'. Since her recovery she has taken an arts degree. She makes films and works for a mental health organisation.
<i>History of difficulties:</i> She describes having two psychotic admissions within 2 years in her 20s and being given a diagnosis of 'manic depression' and prescribed lithium which she was told she would need to take for life. She connects her experience of psychosis with her experience of being sexually abused as a child. She says that what she found helpful in recovery was four years of humanistic therapy.
<i>Outcome and present status:</i> She stopped taking medication some years ago. She has no current psychological difficulties. She works in mental health and the arts.

Participant 8

Simon
<i>Age, gender, and ethnicity:</i> Simon is a white British man in his 30s.
<i>Education and profession:</i> He went to art college and worked in printing. Following his recovery he trained as an art therapist. He works in mental health.
<i>History of difficulties:</i> He describes experiencing psychosis in his early twenties at a time in his life when he seemed to have reached a 'dead-end'. He also describes severe depression at this time. He had one hospital admission when he was 'acting strangely' but says he was never told if they had given him a diagnosis. He was not compulsorily treated or detained in hospital. After a time he describes deciding to 'let go of being that mad' and returning to the city he had been living in. He describes his struggles subsequently as being more with anxiety and depression, and he has explored various therapies which have helped him.
<i>Outcome and present status:</i> He has never taken psychiatric medication, even when in hospital. He does not describe any psychological or emotional difficulties currently. He works for a mental health organisation.

Participant 9

Hugh
<i>Age, gender and ethnicity:</i> Hugh is a white British man in his 30s.
<i>Education and profession:</i> Before he experienced psychosis, he ran his own hardware business. Subsequently he retrained as a chef.
<i>History of difficulties:</i> He has a diagnosis of paranoid schizophrenia. He began to hear voices when he was 26 at a time when he lost his business and was made homeless. He views his psychosis as a condition like 'diabetes' which he manages by taking medication and monitoring the stress-levels in his life.
<i>Outcome and present status:</i> He looks after his young daughter, is engaged in voluntary work with a number of mental health groups and is self-employed as a 'mental health advisor'. He continues to take anti-psychotic medication. He regards himself as recovered.

Participant 10

Richard
<i>Age, gender and ethnicity:</i> Richard is a white British man in his 30s
<i>Education and profession:</i> Richard's education was interrupted as he began having difficulties as a teenager. However as an adult he has taken a number of courses in colleges of continuing education.
<i>History of difficulties:</i> He received a diagnosis of schizophrenia at the age of 19 and has had 3 hospital admissions. He says he has been on major tranquillisers since 1976 and has also been treated with ECT.
<i>Outcome and present status:</i> Richard continues to take medication and works voluntarily for a mental health organisation. He likes the idea of 'recovery' and of being able to work and have choices. However he also thinks the concept of 'disability' could be useful for him.

Participant 11

Donald
<i>Age, gender and ethnicity:</i> Donald is a white British man in his 40s.
<i>Education and profession:</i> He has qualifications in accounting and worked in the City before experiencing psychosis.
<i>History of difficulties:</i> At the age of 25 he began to hear voices, was diagnosed with schizophrenia and spent 6 of the next 10 years as an in-patient under section being treated with ECT and a wide range of different medications. He did not find that any of these treatments helped him and he continued to hear voices. For him recovery began with being able to make sense of the voices in terms of relationships with people in his life, including his experience of being sexually abused as a boy by a Catholic priest. A psychiatrist later changed his diagnosis to 'post-traumatic stress disorder, now resolved'.
<i>Outcome and present status:</i> He now regards himself as recovered in that he functions fully in society, is married with children and runs a very successful business. He continues to hear voices at times but these do not prevent him from functioning or achieving his goals. He does not take medication.

Participant 12

Indra
<i>Age, gender and ethnicity:</i> Indra is an Asian woman in her 40s.
<i>Education and profession:</i> She is a qualified social worker.
<i>History of difficulties:</i> She describes having had 2 hospital admissions. On her first admission she was given a diagnosis of paranoid schizophrenia. At this time she was experiencing being raped by something outside of herself and was hearing voices. On her second admission her diagnosis was changed by the psychiatrist to 'depressive psychosis' as a result of childhood trauma in consultation with her psychotherapist who told him about her experiences of being sexually abused as a child. Indra thinks that 7 years of psychotherapy have helped her to recover from her emotional and psychological difficulties. She does not view hearing voices as the sign of an illness and thinks she will 'probably hear voices 'until the day I die'. She believes that for recovery to happen, people have to take into account all aspects of a person including their history, cultural and religious background.
<i>Outcome and present status:</i> She is working part-time as an advisor. She continues to hear voices but these do not constitute an obstacle for her at the moment. Some of them she finds help her and others she is able to manage. Her last admission was about 2 years ago. She is gradually weaning herself off anti-depressants and anti-psychotic medication with the support of her psychiatrist and GP.

Participant 13

Cathy
<i>Age, gender and ethnicity:</i> Cathy is a white British woman in her 40s.
<i>Education and profession:</i> She worked for the armed forces until retiring two years ago.
<i>History of difficulties:</i> She has had 2 psychotic episodes with 'ideas of reference' and 'paranoia' in the last 2 years. She has had one hospital admission, leading up to which she was treated brutally at the hands of the police. She has been given a diagnosis of schizophrenia and told she will need to take medication for the rest of her life.
<i>Outcome and present status:</i> She is on a low dose of anti-psychotic medication, has no symptoms and is trying to find work. She is trying to wean herself off anti-psychotic medication without the support of her psychiatrist.

Participant 14

Miriam
<i>Age, gender and ethnicity:</i> Miriam is a white British woman in her 40s.
<i>Education and profession:</i> Her training is in art and she works as an artist.
<i>History of difficulties:</i> She had one admission to hospital during a psychotic episode in her 20s. She received a diagnosis of schizophrenia. Shortly afterwards she asked to be admitted again with severe depression and was given a diagnosis of reactive depression. She felt at that time in grave danger of becoming a 'chronic psychiatric patient' like her father had been. However she felt that the 'therapeutic ward' which she was on for 6 weeks during her second admission helped her to understand her problems and her family.
<i>Outcome and present status:</i> She works as an artist and has not used services for twenty years.

Participant 15

Meera
<i>Age, gender and ethnicity:</i> Meera is a British born Asian woman in her 30s.
<i>Education and profession:</i> She is a qualified social worker.
<i>History of difficulties:</i> She describes experiencing psychosis at two times in her life with 'ideas of reference' and 'paranoia' as well as various 'delusions'. She also describes periods of anxiety and depression. She had one brief admission to hospital about a year prior to the interview and was followed up by a home-treatment team.
<i>Outcome and present status:</i> She is doing part-time voluntary work and exploring the meaning of her experiences through reading and talking with others. She does not describe current difficulties and is not taking medication.

Ethical considerations

Ethical approval was sought and received from UCL/UCLH Ethics Committee (see Appendix 2). Participants normally contacted the researcher via a telephone number given on the advertisement for the study. Most of the participants were interviewed at UCL and whenever possible were sent the 'Information Sheet' (see Appendix 3) explaining what their involvement in the study would entail and its rationale before they made the journey. In two cases participants were interviewed at their homes, at

their request. The same procedure was followed. Before the interviews, participants signed a consent form that stated that their participation in the study was voluntary and they were free to withdraw their consent at any time (see Appendix 4). It was also made clear to participants that if they became distressed during or after the interview a debriefing session could be arranged with a qualified psychologist. This offer was not taken up by any of the participants. Participants were offered £10 as a thank-you gesture for their time and also to cover travel-expenses in getting to UCL. One participant declined her £10, and another donated his to charity.

Procedure

When participants had been informed about the study and written consent obtained, their agreement was sought for beginning the interview. When they indicated they were ready, the recording began. The interview began with a standard question for each participant:

'As you know the conversation we are about to have is part of a study to try and help understand what enables people to recover from –or perhaps live meaningfully with – psychotic experiences. Perhaps to begin with, you could tell me something about yourself and what has brought you to the point of sitting here talking to me about recovery?'

This question was designed to be as open as possible and to elicit a detailed subjective and narrative account. The question also kept the focus of the interview in the first instance on recovery, though often individuals started by describing their experiences of psychosis. The rest of the interview was partially guided by a semi-

structured interview protocol (see Appendix 5) and partially led by the participants' accounts and the researcher's reflections on the material they brought.

Development of interview schedule

The interview protocol was developed by examining other studies in the field and focusing on neglected areas such as psychological and emotional aspects of recovery. It was also developed in collaboration with my field supervisor who has considerable experience in this area and could suggest the kind of questions that might be useful. Guidelines for semi-structured interviewing were also followed in developing the protocol (Smith, Harre & van Langenhove, 1995). Areas covered were:

- Does the person think 'recovery' is a good word? What does it mean to him/her?
- What does the person feel he/she has recovered from?
- How does the person understand the psychosis? Has this changed over time?
- What kind of things does the person feel helped him/her in his/her recovery? What kind of things did not help? Did different things help at different times?
- Does the person think there were particular 'turning points'? What did these involve?
- Are there any aspects of the experience of the psychosis that the person values?
- If the person had to make recommendations to someone about helping people recover from psychosis, what would he/she say?

For the full protocol, see Appendix 5.

Ending the interviews

Interviews lasted between about 40 minutes and 1.5 hours. Interviews were limited to an hour wherever possible, in view of the richness of the data collected.

Interviews were ended by asking participants if there was anything more they wanted to add, so that there was a mutually agreed ending. After the tape-recorder was turned off participants were asked if they were happy with the interview and if they would like to be sent a copy of the transcript when it was typed. All but one person said they would like a copy. Participants were asked if they would like feedback on the analysis and all participants said they would. They were told they could send additional material, or comments on the interview or analysis at any time if they felt it would contribute to the study. A number of the participants sent further thoughts they had following the interviews.

Transcription

The process of transcribing the interviews was done as each interview was completed. The transcription was undertaken in accordance with the requirements of this study, which involved careful attention to language and meanings but not detailed recording of linguistic features of speech, such as intonation or pauses. A consistent approach to signifying certain aspects of the dialogue was developed.

For example, '...' refers to a pause, '[?]' refers to a word or words which are inaudible. Paraverbal features of the interaction were placed in round brackets e.g. '(laughs)'. '_____ ' refers to names of people or places which have been omitted for reasons of confidentiality. Italics, question marks and exclamation marks were

also used to indicate special emphases (mainly following the compilation of guidelines for transcription compiled by Pistrang, 1995). A sample section of transcript can be found in Appendix 6.

When the interviews were transcribed, a copy was sent to each of the participants who had requested it. A letter was enclosed, thanking them for participating in the research, and inviting them to respond to reading their transcripts. Three people responded with comments and additions.

Interpretative Phenomenological Analysis

The interpretative phenomenological analysis proceeded in a series of steps as outlined by Smith, Jarman & Osborn (1999) and Willig (2001). The researcher had an initial familiarity with the interviews through the processes of interviewing and transcription. The first stage of the analysis involved the reading and rereading of the transcriptions, writing notes in the left-hand margin. According to Smith, Jarman & Osborn (1999) the researcher should '*note down anything that strikes you as interesting or significant about what the respondent is saying*' and '*Some of your comments may be attempts at summarizing, some may be associations or connections that come to mind, others may be preliminary interpretations*' (p.220).

This stage of the analysis is illustrated in Appendix 7.

The second stage of the analysis involves extracting themes by ‘*using key words to capture the essential quality of what you are finding in the text*’ (Smith, Jarman & Osborn, 1999, p.221). These emerging themes were noted in the right-hand margin. Examples of this stage of the analysis are also given in Appendix 7. This procedure was followed for each interview.

The third stage of the analysis involved identifying connections between themes and grouping them together. Initially this was done within each interview (see Appendix 8).

Following this, the researcher made a note on separate sheets of all themes noted in each interview. These themes were then analysed to see how they clustered together across interviews. Some themes clustered easily together and could be given an appropriate label, either a descriptive label or one which used an ‘*in vivo*’ quotation (see Willig, 2001). Other themes were more difficult to place, and writing these on small pieces of paper which could then be manually sorted into piles enabled the researcher to think carefully about how these should be clustered together. The researcher at this stage often referred back to the texts from which the themes had emerged to ensure that connections between themes reflected what the individuals had said (see Appendix 9). This procedure generated a ‘master list’ of themes (Appendix 10). These are defined as the ‘*major themes which seem to capture most strongly the respondent’s* [in this case respondents’] *concerns on this particular topic*’ (Smith, Jarman & Osborn, 1999, p.223). A number of themes which were

interpreted as being of less importance were dropped at this stage. A complete set of quotations was identified for each theme in the master list by going back to the interviews and noting, for each theme marked, which new theme in the master list it represented. Appendix 11 shows how this was done with the earlier samples of text given in Appendix 7. Appendix 12 shows a complete set of quotations for the themes in the first cluster 'Making sense: How mad was I really?'

Credibility checks and validity

One of the supervisors with extensive experience of IPA read all the interviews and cross-checked the analysis of themes in a selected number. She suggested points where the analysis might be improved, or where themes could be named in closer correspondence with the texts. The analysis was re-worked until we achieved consensus on the key themes. In addition, two colleagues also familiar with IPA read interviews and drew out themes to check against the researcher's analysis for two interviews. Meetings were arranged regularly to discuss the process of the analysis as it progressed. One of the supervisors further checked the clustering of themes with quotations from the interviews and it was discussed how these should be collated into the final 'master list'.

Copies of the transcripts and a summary of the analysis were sent to the participants. Five responded. Their comments relevant to the analysis are presented in Appendix 13. These were used in order to think further about the analysis and as

part of a process of credibility checking and validation. This process will be detailed further in the 'Discussion', following the presentation of the results.

A resume of the results was also presented to a group of users/ former users and workers in mental health. Notes made from their comments are presented in Appendix 14. Again, these comments will be discussed further in examining the credibility of the study subsequently. Further in-depth conversations took place with two of the participants as we prepared to co-present the results of the research at a national conference. Some of their comments are presented in Appendix 15. These highlighted certain aspects of the study, such as the variety in individuals' frameworks of understanding and different pathways to recovery. These issues are taken up again in the discussion. Comments from the audience at this national conference are included in Appendix 16 in order to address questions of validity and credibility further. Their relevance for the study will be addressed in the discussion.

This part of the analysis was also presented at the IPA conference in London in 2002. It met with an enthusiastic response and it was suggested that, along with a number of other qualitative studies of psychosis, it should be submitted as a symposium for the BPS conference in 2003 (Smith, personal communication).

Narrative analysis

The second phase of the analysis used narrative methods to draw out different aspects of the accounts. Each interview was approached afresh using narrative analytic methods.

Identification of tone, core narrative and genre

The process of the analysis began by reading through the interviews and trying to identify features of the narratives as wholes. This was in contrast to the IPA part of the study where from early on in the analysis the accounts are separated into themes. Crossley (2000a) shares with McAdams (1993) the suggestion that the first focus of a narrative analysis should be on 'narrative tone' – an attempt to characterise something about the narrative as a whole. Crossley (2000a) states that this is 'the most pervasive feature' of a narrative and 'is conveyed both in the content of the story and also the form or manner in which it is told'

(p.89). Each interview was analysed closely, focusing on the tone of the account throughout. Features of what was said as well as how the story was structured were considered. For example, Miriam's account begins:

'I think it's something that I've just thought about so much over so many years. Um...Maybe I've thought so many different things about it, it's not easy to come to a sort of definitive set of feelings...they probably change quite a lot, you know'.

There are frequent pauses in her narrative and she comments later: '*I'm always asking myself what terms I want to use, I suppose*'. The way the interview was

conducted (she repeatedly paused for thought and the tape-recorder was stopped) gave further credence to the prominence of a thoughtful tone in her account.

However as the interview progressed, a new tone emerged which was one of protest, for example where she comments '*I do feel now a sense of...anger really, that they could be so hopeless about me*'. Thus the tone of Naomi's narrative was characterised as thoughtful/ protesting.

This procedure, of attending to the content and structure of the narratives, was followed for each narrative in order to identify narrative tone.

Mishler (1986) describes a process of drawing out the 'core narrative' and this was also done in the early stages of the analysis. This involves summing up the narrative in a few words, in an attempt to capture the key plot. As in the analysis of tone, considering the full content as well as the structure of the narrative is crucial to this aspect of the analysis. It can also be useful to take into account the analysis of tone, as this is often reflected in the 'core narrative'. For example, in reading Peter's narrative, the core narrative was identified as 'battling a corrupt system'. This fitted with much of the content of the narrative and also reflected the tone of 'protest' identified in the narrative.

Closely linked to these aspects was the analysis of narrative genre which was informed by theories of narrative genre (e.g. Gergen & Gergen, 1983; Lacey, 2000; Mishler, 1986; Todorow, 1990) as well as by other studies, for example in the

literature on health and illness which have used this method (see Crossley, 1999; Frank, 1995; Gray, 2001; Plummer, 1995).

For this part of the analysis, the accounts were read with the question in mind: 'What kind of a story is this?' By paying close attention to the kind of plot-developments in the narratives, key aspects of their structure and of language, it was possible to analyse their genres. (See Appendix 17 for examples of this procedure). As in previous studies which have used this method, this enabled key contrasts to be made between some accounts, while similarities were noted with others. This allowed the researcher to highlight different pathways to recovery.

Analysis of language and meta-narratives

This aspect of the analysis focused on the use of cultural and social 'meta-narratives' or 'master narratives' and the use of language in order to examine how individuals used these in their stories of recovery. This included attending to imagery, as set out by Crossley (2000a). Jacobson (2001) has used this type of analysis in her study of recovery narratives, examining the various explanatory models which individuals draw on. The use of cultural meta-narratives has also been examined in studies of recovery from sexual abuse, in particular the 'therapeutic' and 'feminist/ political' meta-narratives (Davies, 1995; Harvey *et al.*, 2000).

It was not possible in this study to analyse each interview in its entirety using this method. Therefore, particular sections of a number of narratives were chosen which exemplified the use of the different meta-narratives. These were then analysed closely. Thus this part of the analysis is not meant to offer an all-encompassing analysis of language and meta-narratives across interviews, but rather to offer a more detailed examination of the ways language is used in selected places in the interviews. This narrowing of focus allows for some of the more intricate processes of meaning-making to be magnified and examined more closely. For an illustration of the process of analysis, see Appendix 18.

Analysis of turning points and stuck points

‘Turning points’ can be a key aspect of narrative accounts (Crossley, 2000a; Harvey et al, 2000). It was decided to focus on these in the analysis as it was considered these might be particularly relevant to narratives of recovery. Some individuals talked about crucial ‘turning points’ in their narratives and named them as such. In other narratives these were more implicit and embedded within the accounts.

Riessman (1993) emphasises that the methods of analysis may develop as the narrative study progresses. It was decided to focus in addition to ‘turning points’ on ‘stuck points’, to further explore key aspects emerging in these narrative moments. Again, this part of the analysis required attending to the detail of a number of sections of certain interviews and not to a comprehensive analysis of

every interview. Examples of ‘turning points’ and ‘stuck points’ were sought in each interview and selectively analysed. See Appendix 18 for a worked example of an analysis of a ‘turning point’.

Credibility checks and validity

One of the supervisors independently analysed aspects of the narratives, for example she read each interview and drew out a ‘core narrative’. This was compared with the researcher’s analysis of the core narratives and where there were discrepancies, a process of discussion ensued and interviews were re-read to identify the most accurate ‘core narrative’. One ‘correct answer’ was not being sought, nor that the process should be exactly replicable in terms of drawing out an identical ‘core narrative’. However it was important that the most salient aspects of each narrative could be agreed upon, even where this might be summarized in slightly different ways. In discussion, we came to a set of mutually agreed core narratives.

As narrative analysis is a developing methodology in the UK, it was important for the validity and credibility of the study to correspond closely with others undertaking this type of research. The methods used were discussed with other researchers who teach and use narrative analysis. They viewed the methods chosen as clear and appropriate (Squire, 2002, personal correspondence; Willig, 2002, personal correspondence). In addition, the researcher attended workshops on

narrative analysis (organised by the Centre for Narrative Research at the University of East London) throughout the study, where researchers compared methods and presented their work.

The narrative analytic section of the study was selected to be presented at a conference on 'Medical and Psychiatric Narratives', organised by the Medical Division of the Royal Anthropological Society. Feedback from those present indicated they seemed to find the presentation coherent, convincing and as constituting original and valuable research. It was requested that the paper be written up for publication.

A resume of the results of the narrative analysis were sent to participants. Two participants made comments in writing on the narrative analysis. Their comments are included in Appendix 20. The relevance of these for the credibility of the study will be addressed in the discussion.

The results were presented to a group of service users and workers in mental health. See Appendix 14 for their comments. The relevance of these for the narrative part of the study will be discussed subsequently.

'Owning one's perspective'

A further aspect of validity in qualitative research is the ability to be self-

reflexive and to own one's perspective. The perspective of this researcher is influenced by a number of factors and has been constantly changing and developing through the course of undertaking this research.

Firstly, the researcher's perspective as a psychologist is a crucial aspect of the study. The researcher is influenced by a number of psychological theories and models including cognitive, psychodynamic and systemic approaches. As is congruent with the aims of the study, the analysis will focus on psychological and emotional themes. However it is important to bear in mind that other factors which may receive less emphasis in this study may play a vital role in recovery, including biological or financial factors, for example. Where individuals have understood their recovery from psychosis as involving crucial biological factors, this has been drawn out in the analysis and should provide further evidence of reflexive validity.

The researcher is also influenced by personal experience of psychosis and recovery as a teenager. This, in part, has motivated the current study which seeks to highlight the experiences of those who have recovered from psychosis. Stiles (1993) states:

'Deep personal involvement and passionate commitment to a topic can bring enmeshment with risks of distortion, but they can also motivate more thorough investigation and a deeper understanding. Detachment and distance can distort too. Revealing an investigator's personal involvement and commitments to the process of investigation allows readers to incorporate the investigator's part in the story into their understanding and to adjust their understanding to compensate for the investigator's biases. The strategy of revealing rather than avoiding involvement is consistent with the broader shift in goals from the truth of the statements to the understanding by participants and readers. It is an approach that requires a degree of trust that the investigator and the research consumer will work responsibly toward understanding, even while pursuing personal commitments.' (p.614).

Certain aspects of the analysis reflect the researcher's particular interests. For example, the order of the themes may reflect the researcher's interest in the role of trauma in some psychotic presentations, as discussed in current psychological models of psychosis (see Garety *et al.*, 2001). Rather than representing an invalidation of the analysis, this is an indication of how the researcher's perspective will inevitably influence the presentation of the results. Likewise, it is interesting that the themes begin by focusing mainly on intrapersonal factors (in the first cluster), subsequently moving towards themes which include systemic and finally societal factors. This may reflect a bias in psychological thinking towards considering factors intrinsic to individuals, since psychology has traditionally offered interventions at that level, not at the level of societal change.

CHAPTER 3

RESULTS

Overview

The study sets out to explore two main questions in relation to recovery from psychosis:

1. What psychological and emotional themes emerge in the accounts of individuals who describe themselves as recovered or recovering from one or more psychotic episodes?
2. What kind of stories do individuals tell about their recovery from psychosis and what are the implications of this?

The study uses interpretative phenomenological analysis to explore the first question.

Narrative analysis is used to explore the second question. For the purposes of the narrative analysis, the second question is further subdivided into the following questions:

- i) Which genres of narrative, core narratives and tone emerge in individuals accounts of recovery from psychosis, and what does this tell us about the process of recovery?

- ii) What kinds of language and meta-narratives of psychosis and recovery do individuals draw on, and how are these used in the accounts?
- iii) What can an analysis of the ‘turning points’ and ‘stuck points’ in the narratives tell us about the process of recovery?

Interpretative Phenomenological Analysis

The first part of the analysis identifies four clusters of themes which are explored by individuals in their accounts:

A. *Making sense: How mad was I really?* –this cluster of themes refers mainly to the individuals’ accounts of their experiences of psychosis and the ways in which they have made sense of these experiences. It points towards a variety of ways of thinking about psychosis and recovery which include: understanding the social and psychological context of the experiences; understanding the psychosis as a response to previously experienced trauma; understanding psychosis as an opportunity as well as a danger. This cluster of themes also begins to address the implications of these understandings for recovery: the possibility of seeing the self in a new way; finding a ‘real me’ or ‘becoming more whole’; and psychotic experience as representing one of many realities, related to the many different aspects of being human.

B. *‘Beating up’ versus ‘tea and sympathy’: responses to psychosis* – this cluster of themes refers mainly to people’s responses to the experience of psychosis. This

includes whether individuals are able to accept themselves and their experiences or ‘knock themselves’; whether those close to them respond to their experiences in an understanding or rejecting and fearful way; whether the mental health system responds abusively and neglectfully or in a caring and helpful way.

C. *Telling stories* – the theme here is deception and silence versus honesty and openness. It examines what kinds of stories individuals are willing or able to tell in what kinds of context. It looks at how individuals behave within a system or a society which threatens to be punishing or silencing of certain kinds of story and the kinds of stories which the health system tells individuals, both in terms of deception and silence as well as honesty and openness. It also raises the importance of being able to ‘tell your story’ for recovery.

D . *Working out where you stand* – This refers to the theme of moving beyond the individual, interpersonal and the psychiatric system into broader issues of human rights and responsibility, including legal, political and societal aspects.

Narrative Analysis

Core narrative, tone and narrative genre

The first section sets out the results of the analysis of core narrative, tone and narrative genre and offers some further elucidation of these findings. The key findings are that the narratives can be categorised as narratives of 'escape', 'enlightenment' and 'endurance' and that the tone and core narrative are often related to the narrative genre.

Analysis of meta-narratives

This part of the analysis shows how individuals use the meta-narratives (e.g. medical, psychological, social, cultural) available to them to create their stories of recovery. It also suggests that individuals create their own 'meta-narrative' through the use of language which stands outside the traditional narratives of mental illness and recovery which enables individuals to 'reclaim their experience' (Dillon & May, in press). It also shows how within the dominant narratives, individuals create and negotiate their own space to manoeuvre and to exercise choice and control (agency), as well as to make meaning, and to develop their own sense of themselves (identity).

Turning points and stuck points

This part of the analysis turns to a brief examination of 'turning points' and 'stuck points' in the narratives. It suggests that key 'turning points' are related to the above analysis of language and meta-narratives and that they turn on issues of agency, meaning and identity. It is found that others or 'the other' play a crucial role in becoming stuck or being able to develop in terms of agency, meaning or identity and that recovery is thus found to be a fundamentally dialogic process.

Results of Interpretative Phenomenological Analysis

CLUSTER A Making sense: How mad was I really?

Theme 1: Going back

Some individuals describe their experience of psychosis as a kind of 'going back' and feeling as though they are reliving a previous time in their lives:

Well, I suppose what it was, was in my psychotic episodes the really...the one theme was about my own child abuse when I was younger...and in my psychosis I always went back like a detective... I was almost like a detective...trying to work out the riddles, the clues as to what happened (Suraya)

Suraya explains her 'psychotic' behaviour, looking for clues and seeing particular significance in everyday occurrences, as a search for an understanding of an experience which has never been articulated:

I think anything to do with sort of childhood experiences are quite...it's quite hard to put words to them anyway because they're so based on emotions. And also as a child you know you're not...there's a tendency for us to think of children in the sense of like an adult mind because we're always looking back at our childhoods. But it was I suppose, trying to find those emotions back rather than the words...or the experiences even.

For Indra, she found herself re-experiencing her childhood sexual abuse in the present but this was not recognised by the professionals treating her:

I was experiencing being raped, and being sexually abused [...] but there wasn't anybody there to say...They just said, 'paranoid schizophrenia' which means, I was imagining it. But there wasn't anybody there who said to me 'Well, have you in your childhood ever experienced these things? That might explain why at this point in time you're experiencing things happening like something outside of you...that you're being raped by something outside of you' or whatever

Donald also understands his experience of psychosis as linked to childhood sexual abuse and to his inability to think about it. He tells how he came from a church-going Catholic family and was sexually abused as a boy by a Catholic priest. He explains that when he heard voices he heard the voice of his abuser, blaming him for the abuse:

Again I think now on reflection that that was about my inability to resolve it by thinking it through. Because I refused to think about it. And I think if we refuse to think about things, if we refuse to sort of face things, then we suppress them and eventually the pressure gets too great and it's got to come out somehow.

For some individuals, then, there seems to be a connection between traumatic experiences in childhood (in these cases, childhood sexual abuse) and the experience of the psychosis, whether it is labelled as 'hallucinations', 'delusions', or 'paranoia'. Each of these individuals in their interviews describes the process of coming to an understanding of the underlying issues, either by working things through on their own or with a therapist, as central to their recovery.

Theme 2 : Living in fear

'Living in fear' was a recurrent theme in many of the interviews. Individuals described the attempt to disentangle experiences which had made them feel afraid, excluded or put down from the experience of feeling 'paranoid', as defined in psychiatric terms. Mary locates the beginnings of her psychosis at a moment in time when she was feeling excluded and rejected from her place of origin, having had a major conflict with a former boyfriend and his wife. She felt that '*they didn't accept me any more*' and she began to think people were talking about her behind her back:

'There might be builders in the house next door and I could hear them talking and I knew they were talking about me'

Looking back, she also sees herself and her experiences in the context of an abusive and undermining relationship:

When I look back on how I was then I can see how paranoid I was...but I had him telling me I was useless all the time [...] I'd go out to hang the washing out and he'd follow behind me and tell me I was hanging the washing up wrong

Meera describes growing up as an Asian woman in an area dominated by white British people, where she and her family experienced racial abuse and harrassment. She describes trying to fit in to two cultures and the difficulties she had making the transition to the different kinds of expectations and styles of communication in British culture, particularly in the work place. She found herself as a newly qualified professional feeling undermined and threatened at work and recognises that at times this tipped into a 'psychotic' perception of reality:

‘Just after I’d qualified and I was working for _____. So I was doing interviews. And I actually went to one interview where a girl was depressed and hiding under the covers and stuff and it was a little bit like what I’d gone through while I was a student. So um...I thought it was a set-up. Not thinking that it is quite common that people go through this. But it’s only now I’m sort of thinking that way. But at the time I thought, ‘Well, they know something. They know that I’ve had this and they’ve set this case up.’ [...] And the TV was covered in a sheet and I thought it was some sort of recording device and I was really so unaware of the interview situation but just looking at the environment and feeling really scared’.

There seems to be a sense amongst these individuals that ‘paranoia’ reflects an internal state of fear and terror which perhaps has made them perceive threat where other people might not. However it is recognised that at the time it is very difficult to disentangle what is a ‘realistic’ fear and what is ‘paranoia’.

Theme 3 – Looking at the experience from different angles and seeing the self in new ways

Psychotic?

*My world is the same world you inhabit
Turned to gold.
Meaning, richness: jewels
Encrust each freshly-discovered facet.*

*Inside my head I cover thousands of miles
In the time it takes you to stumble
Sleep-bleared*

From bed to bathroom.

I have outgrown sleep.

I have shed a skin.

[...]

*Layer upon layer of metaphor, meaning
Opens itself to me;
The life I thought was little
Is the one epic poem.*

*Outside
I stand sentinel of a static red sunrise.*

This is an excerpt from a poem written by Mary which she brought with her to the interview. She says that experiencing psychosis is '*not necessarily a bad thing*'.

She uses the analogy of the Chinese symbol for '*crisis*' which she tells me is the symbol for '*danger*' together with the symbol for '*opportunity*'. Her view is that psychosis can be an experience through which people can change and grow. She also views her psychosis as evidence of her sensitivity and '*you can't be sensitive without being vulnerable*'. Her view is that seeing psychosis only as an illness, or as a misfortune is limited:

'Instead of saying you're in a psychotic state you can say you're in a state of prophecy or you're in an imaginative state, you're in a poetic state.'

Her experience when she came out of hospital on one occasion was that she was bombarded with new ideas and the need to express herself:

It was quite difficult when I first came out of hospital. It was like this sort of you know...everything came together...I'd be up all night...writing and writing...just to handle all this new stuff that was coming in.[...] Just making sense of it all in a way that I hadn't done before.

So for Mary the psychosis seems to herald new kinds of creativity and understanding.

Other individuals comment on the positive aspect of psychosis. Suraya, whose diagnosis was 'manic depression' says she feels the psychosis marked a turning point for her:

Because if it hadn't been for the psychosis I think that possibly I would have carried on just like most people do...um...which is alright normally but tinges of paranoia, tinges of insecurity, which I think to be honest is what most people are like, really But [...] I think it was the psychosis that really sort of made me look at things just there...I had no choice but to look at them. And having looked at them I feel a lot more...calmer about myself and...probably that I actually like myself now as well which...which I think is quite rare, to be honest with you.

Rather than the 'onset' of an illness process, many of the individuals felt the psychosis marked '*the instigation of a healing process*' (Pete):

it is actually a positive thing. It's not a negative thing. The body is always designed to heal. The moment you don't heal, you're dead, so you won't have a problem (laughs). In the meantime, the breakdown is the instigation of a healing process which needs to be fed (Pete)

Pete's understanding of his 'breakdowns' are as a sign from the mind/body that it needs to be nurtured and he identifies sleep and a healthy diet as the first steps – '*basically you've just got to be rest, fed and watered and nurtured. And that is really what I'd say in the first instance*'.

Indra goes even further in her appraisal of experiences classed as 'psychotic'. She states that in the struggles she has in her life – with depression and suicidal thoughts, for example – she has found her voices have helped her at times:

Well, partly my voices have helped, I think, you know. It's been a heck of a journey, you know, but I think I've been taken care of along the way. That whenever I've really needed something that I've always found it [...] They're like a guide. [...]...there is both positive and negative...just as there are in most things. And in most people. And I realise that those that help me actually hold me to my highest ideals

Being able to view the experience of psychosis from different angles – as an opportunity as well as a danger; as evidence of sensitivity as well as vulnerability; as a meaningful part of experience; as the instigation of a healing process rather than the beginning of an interminable illness; as an experience which can be helpful as well as harmful - seems to characterise these accounts by individuals who feel they have recovered or are recovering from psychosis. Indeed the experience of Indra who finds some of her voices helpful raises the question of whether 'recovery' from psychosis is necessarily always an appropriate term or a sought after goal.

Seeing the psychosis in a new way also reflects onto how individuals see themselves. How the psychosis is viewed (by individuals, by their family, by professionals) makes an enormous impact on many individuals' identity as a person of value or a person '*to be consigned to the scrapheap*' (Cathy).

For Donald, he describes his ‘identity’ as changing dramatically once he was identified as ‘schizophrenic’ by the psychiatric system:

When I came off meds I was still hearing voices and I was on clozaril, methytryptaline, clomipramine, lithium and procycladine. So I was on quite a cocktail. And it was no surprise then that I spent most of my life really at that time in my bed. And in my room. I just didn't have the [...] will to live. I didn't have any will to do anything. I had no ambition any more. Um...and that was really from coming from a position in Thatcher's era from being um... I suppose the ideal of what Thatcher thought enterprise was. In London I was on a big salary even though I was young, I was a young man, because I was in the finance sector and I knew my stuff. So I was seen as a goer...I don't know I guess a bit of a whizzkid on finance at that time [...] Um...and to suddenly stop being that and become this large, dangerous, schizophrenic Scotsman was um...quite a shift.

Donald explains that it took the persistence of several people before he managed to start coming out of his room, going to the pub, and finally joining a ‘hearing voices group’ which put him on his ‘road to recovery’. The key to his shift he identifies as having ‘guides’ in the form of individuals who encouraged him and who pointed the way towards him starting to understand his experiences as connected to the events in his life (as a meaningful part of his identity), and then being able to work through those experiences and events. Thus for some individuals the psychosis is experienced as a stage on a journey towards integrating different parts of their experience or ‘*finding the real me*’ (Martha).

Theme 4 - Different realities/ different aspects of being human

There is a theme in many of the accounts that individuals feel that at the time when they experienced psychosis they needed help with '*a great many human problems*' (Miriam) which seem to be easily overlooked:

I was very distressed and disturbed when I was first admitted but it passed fairly quickly. I think I was only on and off psychotic for about 5 or 6 days [...] And I was very soon saying very... I was in a kind of very heightened emotional state but not deluded. What I was saying was [...] things like, 'Now I'm schizophrenic and all you can do is give me drugs'. When I had very passionate feeling that I needed help with a great many human problems, that I had never, ever received any help with (Miriam)

She describes her experience of psychosis as like '*a kind of explosion of emotion*' – '*as if all the trauma and anxiety of my family caught up with me when I was... in that year*' and as if it had '*been gradually building up over many, many years*' and '*eventually became more than I could contain*'. This theme of psychosis being some kind of an expression of emotional turmoil and the need for an approach which recognises the importance of emotions as part of being human, recurs. Pat explains her experience of hearing voices as:

I find it hard to acknowledge or express feelings... particularly anger... and sad feelings... those kind of feelings. And I think maybe sometimes I have strong emotions and I can't deal with them and they come out as voices, or whatever.

Martha in her account of having a 'manic psychosis' in a hospital set up as a therapeutic community says that in the psychosis she started to become angry and

say things about her background which as an obedient girl she had never dared to think or say. In contrast, Kate's experience is that in psychiatric hospital:

Nobody there wants any expression of emotions. That is the last thing. And of course you've got a whole ward full of very angry, very frightened, very hurt, very upset, emotional people. And they are not allowed to express any of that. Hence all the drugs.

Pat comments that her experience of being on high doses of anti-psychotic medication is that it stops her feeling very much –which may be helpful at times of crisis but is not how she wants to live her life all the time. She says

it's not listed in the BNF as side-effects or anything but...I'm less confident and less assertive...it affects my motivation [...] Not feeling [...] really sad or really happy or anything. And that sort of thing is not really taken into account, I think.

In addition to the emotional aspects of being human and in crisis, certain individuals mention other important factors they feel were not taken into account by those treating them. Pete (who has a medical training) says he feels important physical factors are ignored or not emphasised by the medical team in a way which prevents individuals helping themselves. For example, he found out himself how important developing a regular sleep pattern was for alleviating his psychosis, as well as the importance of a healthy diet and exercise. He also feels the mental health system did not take into account his 'thyroid deficiency' which exacerbated his psychosis, and he had to take action on that himself. Pete argues that by not considering multiple causal factors in the psychosis and communicating this to the patient, the system prevents individuals from taking action that could help themselves. Peter's understanding of his psychosis are that some aspects of it – and of his recovery – were '*unbelievably, stupidly simple*' (like monitoring his

sleep) and that other aspects are ‘*very complex*’ (like the connection with his thyroid, or some psychological aspects). Thus he argues that people need help to understand both the simplicity and complexity of recovery from psychosis.

Indra states she wants to be treated as a whole human being, and have her personal history as well as cultural and religious factors taken into account when she is being treated in hospital. She says people need to take into account:

‘the physical, mental but also my spiritual aspects of who I am. You can’t split them. I can’t split my experiences as a child from my experiences as an adult human being [...] And therefore if there are things in my past which have been traumatic, then they’re going to come through, and they came through [...] And there’s a lot of misunderstanding, for example [...] I started talking about karma and things like that and they’d think I was bonkers because they’ve got a western sort of...and they’ve got this medical model as well. So either they’re ignorant of the fact that...you know, cultural backgrounds, and/ or the medical model they’ve studied and/ or they’re frightened. And I’ve seen many medical doctors who are frightened and they can’t cope so they put up a barrier. And [...] you need to have a certain kind of training in order to be able to work with that [...] And part of that training has to be I think to understand the person in the context from which they’re from and if you don’t understand that context, then you’re going to label them paranoid, you’re going to label them stupid.’

Indra’s view then, is that for a professional to be able to help someone experiencing psychosis they need to be able to take into account all aspects of that person, including the person’s history, their physical health, emotional as well as mental life, and their cultural and religious background.

Cluster B- ‘Beating up’ versus ‘tea and sympathy’ : responses to psychosis

Theme 5 – ‘Knocking yourself’ versus ‘Looking at things/ liking yourself’

The first aspect of this cluster refers to how individuals themselves respond to their experience of psychosis. Hugh says *‘I think a lot of people are knocked back because they have an illness and they don’t believe it’s ever possible [...] to focus on a life any different’*. Most of the individuals describe a point in time in their stories of recovery when recovery did not seem possible and they contemplated or attempted suicide, which seemed the only way out of their situation:

‘By the time I came out that time I was convinced as everybody else, ‘Yeh, OK, I’m mentally ill, I’ve got to take drugs for the rest of my life’ [...] And in the end I decided, OK, if that’s the choice, hospital or drugs, there’s one other choice. And the other choice is – OK if I’ve got to take drugs for the rest of my life, I will make this life a short one. So I took the lot, of the anti-depressants.’ (Mary)

Meera explains she has felt embarrassed about her experiences of psychosis and blamed herself, feeling it must have been somehow *‘self-inflicted’*. On the other hand, she doubts this and feels that an important part of her recovery has been about *‘accepting myself’* and trying to find ways of understanding her experience.

Donald says that by beginning to understand the voices in the context of his own life experience, he was able to work through their implications and accept himself better:

That certainly was my experience in recovery, was it was about working. In terms of working through the issues; working through the fears was more important than

controlling them. Because once I worked through the fact...of the abuse...and the biggest issue of abuse for me was finding myself innocent um...and once I'd found myself innocent then the whole reason that the voice had power was gone. The voice's power was rooted in the fact that I was guilty. But once I'm innocent, where's the power of the voice? The voice can still be there, but it has no power. And if it has no power, then that's OK. And I guess then again that to me would also be part of the recovery process would be the idea that voices only have power until you take it away from them. And the only way you take it away from them, again, is by exploring it and dealing with it.

Thus for these individuals developing an understanding and accepting approach towards themselves and their psychosis marked an important stage in their recoveries. Further important aspects of individuals' responses are identified as being able to feel in control, take responsibility and make choices. Donald describes how when he found a way to '*be in control of the voice-hearing experience*' he also began '*accepting that I was responsible for my recovery, not the services*'. In addition, he states,

I think choice is really important in terms of recovery. I think people need to be allowed to make choices. And not choices that we present them. Those choices are not choices at all. They're what we think you need. So choices for themselves.

These aspects of individuals' responses to psychosis are crucially influenced by the responses of the people and the systems around them, as illustrated in the subsequent themes in this cluster.

Theme 6—'It is not actually the breakdowns which are the problem – it is the ways you are treated which are the problems' (Pete)

One dominant theme in individuals' accounts of how they have been treated by those close to them following their experiences of psychosis is that 'nobody wants

to know'. Individuals have felt excluded and ignored by family members and former friends:

I haven't got any friends. I have not got any friends. I have got one...I have got one girlfriend who is also manic-depressive. Who's been, you know...long story, but...Nobody wants to know. Nobody wants to know when you've got mental illness' (Kate)

_____ *[...] was my best friend at...primary school [...] He was my buddy, really. We would go cycling round everywhere, you know. And we got on well. But I since met up with him again at _____ university, when I got to university. But I'd lost everything then. He didn't seem to want to know me. [...] My mother never rings me now. My mother hardly rings me. She doesn't want to talk on the phone. My sister never rings me. None of my family ring me. My cousins or anyone. Noone rings me* (Richard)

For some individuals, breaking off certain relationships marks a key turning point in their recovery – sometimes with family members, sometimes with partners:

That ended up in a two year relationship where he was like totally abusive and exploitative of me [...] And I [...] was just drowning in lack of 'me' [...] and that took me two years to break away from and made me very ill for a long time' (Kate)

For others, they identify helpful relating as a key aspect of their recovery. Mary says it is important to find people to talk to who are '*not afraid*' of the experience of psychosis and who will help you to find out more about yourself as a person, rather than just see you as someone who is '*mentally ill*'. Pat says that '*there is a way of just being with people which helps*' and that friends and partners can help people experiencing psychosis if they are able to do this. Cathy says she cannot imagine surviving her psychosis without the support of her partner:

I would never have recovered as much if it wasn't for _____. She has pushed me and pushed me and pushed me. And if I'm down she's pushed me and pushed me and she supports me. She's been through hell and back. She's lived through

everything and she's stood by me. And that's a big plus to recovery if you've got someone, someone to be there at the end of it all.'

Theme 7– 'it's a crazy system'

Most individuals spent a considerable proportion of their interviews talking about the role of mental health services in their recovery – either in terms of how it helped or hindered them. One aspect of this is the ‘craziness’ of the system, which is experienced by some individuals as exacerbating their difficulties, rather than helping them. The fear which many individuals are experiencing as part of their ‘paranoia’ is responded to with fear by the system, which further terrifies them –

'and if you've really been to hospital and been beaten up and sort of strapped down and injected then you're probably paranoid for the rest of your life' (George)

Indra describes how in her psychosis she was having delusions that she was being raped, reliving the sexual abuse she had experienced as a child. She told the medical staff what she felt she needed but

instead of taking me seriously they said, 'Oh...' they sectioned me. You know. They threatened to forcibly hold me down and give me injections if I didn't take my medication. Which actually perpetuated the inner violence I was experiencing because it became a reality in my outer world [...] What the medical profession and the doctors were saying [...] was 'Don't talk about the voices'. The consultant, quote, unquote, 'Put a lid on it'. And I got diagnosed first time in hospital. Went in voluntarily. Ended up being sectioned and being told I had paranoid schizophrenia and I should 'put a lid on it', not talk about it.

Compulsory treatment with depot medication (injections) is one aspect of treatment which individuals feel particularly undermines any helpful, collaborative care. Instead it magnifies the effects of an experience in which the individual already feels terrified, confused and not in control. Rather than offering an environment which helps the individual to feel safe and cared for (and provides a qualitatively different experience to that of their psychosis), hospital treatment is experienced by some individuals as '*such a dehumanising process*' (Indra). For Indra, '*a hospital isn't a place of safety...it's a place of violence. I think I can't really say any more than that.*'

For others (Martha and Miriam for example), the type of care they feel has helped them has been 'therapeutic' environments where they have felt listened to where they were encouraged to try and understand the meaning of their experiences for them as individuals:

'The good things about this hospital – this therapeutic community – was just the whole caring, accepting atmosphere. You were allowed to get your feelings out, you were allowed to cry, be angry, and there wasn't any sense of punishment. It wasn't, 'Oh, you'll have to go to the quiet room', you know, or 'We'll have to do this to you.' [...] You were never patronised, never patronised. And you just felt as if you were in...you were in a vibrant place [...] there was an enthusiasm about the whole place'.

Martha also cites the fortnightly family therapy meetings as being important in her recovery as well as the attitude of her psychiatrist who she felt was very supportive and 'always there for me'. Thus individuals seem to feel that an understanding approach where the person and their views and concerns are taken seriously helps recovery. An approach where individuals are treated as though their thoughts and feelings are not important and where they may be forcibly medicated against their

will and diagnosed in line with a medical model without taking into account all the aspects of their experiences is felt to hinder recovery.

Cluster C ‘Telling stories’

Theme 8– Deception and silence versus honesty and openness

In the context of environments where individuals feel they will be ‘punished’ or ‘controlled’ if they are honest, there is a theme of having to use one’s cunning, lie or keep quiet about certain things to survive. Peter tells how:

‘It was an active aspect of discussion amongst my team whether I was schizophrenic or manic-depressive [...] And I took myself off to Mind [...] read all the papers on schizophrenia , read all the papers on manic-depression and decided that I preferred the symptoms of manic-depression to those of schizophrenia, and rehearsed the symptoms of manic-depression. So when I was asked, ‘Did I hear voices?’ I just kept emphatically saying, ‘No, no, no, no, no, no.’

Particularly after experiencing some time in hospital, individuals describe coming to their own conclusions as to whether hospital is helpful for them and if it is not, realising what they need to do to be discharged:

‘I had to lie to get out of hospital [...] the doctor reminded me of somebody [...] – one of the Hindu gods. And the other doctor was like Archangel Gabriel, the angel. So I thought these two people were here to help me [...] [but] the first time I told the doctor [about my thoughts] they gave me medication and I went to hospital. So I thought, ‘Well, this isn’t working, so I’ve got to tell them that I am OK and I am fine.’ So that’s what I did.

Mary and George come to similar conclusions:

'you have to lie to them. [...] If you keep telling them you're fine, you know, and make a bit of effort with your appearance or whatever, they'll let you out' (Mary)

'the only way you can get out of hospital and get off treatment is to say 'No, I haven't got any hallucinations, doctor, you've done a wonderful job. I feel much better now'. And out you go. But you've still got it there. And then it comes back' (George)

The system (and the professionals within it) are also experienced by many individuals as dishonest and lacking in openness:

'I was put on a trial [...] and I remember my results did not fit any category...and I remember the individual rubbing out different results of mine to put me in the mainstream of 'manic depression' [...] and she did that in front of me. And that was, um, 'clinical research'. (Peter)

Suraya describes the duplicity of her psychiatrist when she asked for help with trying to come off her medication:

'she just said, 'Oh but Suraya you know you do have to be on this medication for the rest of your life, you know.' And then I turned around and said to her, 'Well, you...you told me I was going to be on it for 5 years'. And then she said, 'Yes I know, but...'. Obviously that's not what she was thinking.'

Individuals also talk about the difficulties of not being given information:

'[my father] hasn't really been honest about what went on in the referral interview [...] he hasn't given me any information. It's all been from my father's point of view [...] and I want things in my interest not in his interest, you know.'

'they never gave me any paper-work or any clinical details to say what electric shocks I was having, so I don't know the details of the...the clinical details of it...' (Richard)

There seems to be an assumption that if a person is experiencing psychosis, it is not helpful or necessary to give them any information about their condition or their treatment, or to take their wishes or point of view seriously. At times this 'not taking the patient seriously' is taken to extremes:

I remember one thing [...] they said, 'Will you sign this form for ECT?' And I said, 'What's ECT?' And they said, 'It's Extra Clothes [...] and Towels'. And I said, 'Oh, alright, I'll sign that'. (George)

The relationship between some individuals and some mental health professionals is thus characterised by mutual distrust and suspicion. Rather than being characterised by any kind of 'therapeutic alliance', it resembles much more relationships between a 'judge' and an 'accused' or 'prison warder' and 'prisoner'.

A word that recurs in the narratives when individuals describe talking about psychosis and mental health problems is 'taboo'. Miriam describes how her father's mental health problems were '*taboo*' in her family and Suraya says that if it had not been for her therapy she thinks that talking about her psychosis *would 'still feel like something of a taboo'*. Miriam describes how it has taken 19 years for her to begin to talk openly about her admission to psychiatric hospital:

'I'm going through a...what I feel...describe to myself as a 'coming out phase' where I want to speak about it and feel even a sense of pride, that I have recovered.'

For Suraya, her therapy marked the first stage in being able to talk about her psychosis openly. She now runs workshops for users and mental health professionals with a colleague where they talk about their experiences and what

they feel helped them to recover. For Suraya, being able to talk openly about these experiences in a safe atmosphere is a crucial part of the recovery process:

I also think that telling a story is very much part of the recovery process [...] if you consider that the more you tell your story the more you get familiar with it, so the more you understand it for a start and also the more you accept it'.

Suraya emphasises the importance of where and with whom a person tells their story so that it is a positive and affirming experience in which the person feels in control. If done in the right setting, she says, each time she tells her story '*there is more depth to it*', it feels '*therapeutic*' and it becomes '*a constant dialogue that's ever changing and growing*'.

Thus individuals describe being able to talk openly about their experiences of mental and emotional distress as a crucial part of the recovery process. In environments where individuals feel they will not be listened to or where there is a lack of trust or collaboration between patients and professionals, open dialogue is not possible and this is seen to hinder the recovery process.

Cluster D – Working out where you stand

Theme 9 – Human rights and responsibilities

For a number of the individuals in this study their experiences of psychosis and of how they have been treated by mental health services have led them to ask

questions about human rights and responsibility – within legal, social, or political frameworks:

'I joined Amnesty [...] And then you think, 'Well, hang on, human rights, what's happened to them in the mental health system?' [...] And I can remember saying to a nurse in hospital [...] that time when they were holding me and [...] they had no business to keep me there [...] And I said to a nurse, 'I should be writing to Amnesty International about this. [...] I sort of thought [...] 'Why aren't people protesting about this?' ' (Mary)

Peter complains that his treatment by mental health services has been beset by incompetence, beginning with a diagnosis of 'cocaine-addict' (he does not use illegal drugs) by a psychiatrist who he says was an alcoholic:

'there is no accountability in psychiatry [...] I need answers. My life has been destroyed. [...] It's a lack of accountability...who's going to...where's my life going to go?'

As with a number of the participants, he is trying to take legal action to force the system to be accountable.

Donald explains how his 'battle' with the psychiatric system over his voice-hearing being meaningful and medication not being effective led to a context in which '*they felt totally justified in doing whatever they wanted to you in the name of the mental health act.*' He has come to the conclusion that the only way forward for mental health services is to make a clear distinction between treatment (which must have the consent of the patient) and detention which should be within the power of the legal system:

'Within a legal framework you have recourse to the law and you have much more rights within law and a right of going through a system which is clearly defined. [...] So I think for a kick-off compulsory admission shouldn't be allowed by the

system. I think if anybody's got a legal admission it should be a magistrate's court. And then the job of the psychiatrist is to get the person out.'

Donald is disillusioned at the apparent lack of commitment of the legal profession to fight for clients' rights even where laws have been breached:

'I've been more fed up than anything else in recent years at the lack of any real commitment shown by the legal profession to fight...they're frightened [...] to advocate properly for clients [...] People that have been through the system could do law now and show them what a real fight is. If we could change our energy in that direction...'

A number of the participants raise the issue of society needing to be educated about mental distress. There was a view that discrimination in the workplace and sensationalist reporting in the media should become as unacceptable for people who have experienced mental health problems as it is for ethnic minorities or people who have had physical health problems or have a disability:

'at the end of the day we're all here to try and educate those outside...that people with schizophrenia and manic depression aren't all murderers and psychopaths [...] I think there will always be a stigma...it's like racism...there's always going to be some racists, and racism. It's not going to go away. But I would hope that in another ten years that we have educated society so that they're not frightened of us. Anybody who's diagnosed with such an illness, you know, who starts then putting themselves in that category, that people will be treated with compassion [...] and [...] accepted' (Hugh)

Suraya shares the view that it is people's attitudes that need to change:

'It's mostly attitudes I suppose and I suppose society (laughs). Society must be changed – a bit, even a little bit, that would really help. Because at the end of the day we've all got to go out into society, haven't we? And there are the sort of damaging things like the hurtful remarks that people give once they know you've got a history. That's very damaging and it's very hard to get past that. You know [...] like the government tends to want to see huge changes um and they want the reshuffling, you know, the changing of services [...] but it is the sort of little sort of attitude shifts that would help the most.'

Their experiences of psychosis and recovery have raised questions for individuals about the law, human rights, and society's attitudes towards people who have experienced mental distress. Thus the recovery journeys of some individuals have taken them beyond the realms of the individual and of health care and into thinking about and being active within the realms of politics, the law, and societal change.

Results of narrative analysis

Core narratives, tone and narrative genre

The following table offers an overview of how the 'core narratives' 'tone' and 'narrative genres' were characterised for each interview.

Table 2: Core narrative, tone and narrative genre for each interview

	Core narrative	Tone	Genre
Int 1 Peter	'battling a corrupt system'	educating/ protesting	enlightenment
Int 2 George	'getting shut of schiz'	educating/ protesting	escape
Int 3 Mary	'fighting for survival'	protesting/ angry	escape
Int 4 Martha	'getting the healing'	educating/ thoughtful	enlightenment
Int 5 Patricia	'an ongoing journey'	educating/ resigned	endurance
Int 6 Kate	'going it alone'	angry/ resigned	endurance
Int 7 Suraya	'getting control of my story'	educating/ protesting	enlightenment
Int 8 Simon	'seeing my way in the world And exploring new places'	educating/ thoughtful	enlightenment
Int 9 Hugh	'getting on with my life'	educating/ monotone	endurance
Int 10 Richard	'looking for an identity'	disenfranchised/ resigned	endurance
Int 11 Donald	'living a recovered life'	educating/ protesting	enlightenment
Int 12 Indra	'achieving integration'	angry/ educating	enlightenment
Int 13 Cathy	'coming full circle'	disbelieving/ shocked	endurance
Int 14 Miriam	'making a narrow escape'	thoughtful/ protesting	escape
Int 15 Meera	'finding my identity and fitting into two cultures'	thoughtful	enlightenment

Narratives of escape

A number of the narratives have been categorised predominantly as ‘narratives of escape’ although this theme appears in many of the other narratives also. These narratives have all the drama associated with this genre, which would include war novels and films about escapes from enemy prison camps (e.g. *The Great Escape*), for example. The key elements of such narratives are: figuring out who the enemy are and carefully building up a picture of their methods and movements; being able to dissemble; using one’s cunning; finding points of ‘least resistance’, often in the form of a sympathetic individual who facilitates finding a ‘way out’; and finally the element of ‘luck’ or ‘chance’.

A fundamental backdrop to this type of narrative is imagery of imprisonment which is linked to psychiatric care – Mary talks about being ‘*convicted of*’ five psychotic episodes and says of one of the hospitals she was in: ‘*It was just a prison. It was somewhere where they just locked you up and threw away the key*’. In order to deal with this you get ‘*survival skills*’: according to Mary,

'one of them is: if they do attack you – passive resistance. Very important. And, you know, you have to lie to them. If you keep telling them you're fine, you know, and make a bit of effort with your appearance or whatever, they'll let you out'.

Mary gives an example of an 'attack', when she was threatened with compulsory medication as a voluntary patient when she said she was going to leave:

'And I walked to the door. You know, goon squad jump on me...They didn't actually jab me in the bum because again I did passive resistance, I just lay there, didn't struggle. I just said calmly, 'Let me up please. Leave me alone. You don't have to drug me.' They said, 'No, you've got to take it.' And they um...they actually showed me the needle...they held it in front of my eyes...said, 'Here it is. This is what you'll get if you don't take your tablets.'

Mary says '*you have to lie to them*' to achieve a successful 'escape from psychiatry' and then develop strategies for managing on your own with your own networks, to prevent further 'imprisonment'.

For Miriam, she describes her experiences of having two admissions to hospital in her twenties and then no contact with psychiatric services as a '*miraculous escape*'. This is particularly in the context of having a father who had a breakdown in his youth, '*took medication for the rest of his life*', and '*was never really free of the role of the psychiatric patient*'. Miriam identifies one important element of her 'escape' as being her own certainty that there was more than one way of understanding her psychosis and rejecting the 'biological model' - '*I had a very passionate feeling that I needed help with a great many human problems*'. However her experience on her first admission was that the attitude of the staff was '*all that is irrelevant. You are now schizophrenic and we treat you with medication*'. Yet she maintained her stance and on her second admission she felt that one of the

junior doctors was sympathetic to her and perhaps '*pulled some strings*' so that she was admitted to a different setting which was a therapeutic environment. Here she was encouraged to talk about her problems and her family were also invited so that she gained a clearer picture of her father's problems, rather than them being a '*terrifying taboo*'. Her fight to have her point of view recognised was for her a '*life and death*' issue, because it meant the difference between her developing as a person, or being classed as the same as her father which meant for her '*the end of my life*'. She says her life since has not been some sort of '*triumphant progression*' but that:

'I do feel very proud at times that I have come back from this thing that people say they fear so much. Apparently in the surveys, they say 'death' and 'madness'. So you have to consider it an achievement to have come back, to have recovered from madness.'

For Miriam, her escape is not only from a certain kind of hospital care but also from some of her own distress – through being helped in a therapeutic milieu – and from an identity as a chronic psychiatric patient.

For George, the oldest of the interviewees, his 'escape' came after twenty years of being in and out of mental hospitals with a diagnosis of 'paranoid schizophrenia' in the 1950s and 1960s. His motivation in being interviewed is to bear witness to his recovery as he felt unable to disclose his past history during his working life (in broadcasting) but now feels guilty that others do not know it is possible to recover from 'schizophrenia' and to 'escape' from the psychiatric system. He describes one

hospital he was in as '*terrible...an old, walled...enormous, walled hospital*'. He says

'they had an outside reception ward, that was quite nice, but I kept going into the padded cell there. And then after that you were transferred to the Old Hospital and everyone said if you go in there, you never come out, you know. I had a tremendous fight trying to prevent my going in there.'

Within the hospital, as George describes it, there are levels of imprisonment and coercion, including the padded cell, use of straitjackets, and compulsory injections. George has two 'accomplices' in his escape: one is a man who gives him a method of getting rid of 'schizophrenia' which involves relaxing and allowing his voices to become part of him. Another is a doctor, who is sympathetic to George's hatred of medication and allows him to leave the hospital after an admission without drugs, provided he is closely monitored. George uses the technique he has learned until within a year the psychosis (particularly hearing voices) has almost disappeared, he holds down a job without medication and is never admitted again. This constitutes his escape from 'schizophrenia', life on medication and psychiatric hospital.

In these narratives, then, the overarching theme of 'escape' is linked to a type of psychiatric care which is experienced and described as a kind of 'imprisonment' or 'torture'. It is also linked to an 'escape' from an identity – of the 'chronic psychiatric patient' – which seems to threaten to deprive these individuals of any sense of a hopeful future where they would be free to make meaningful choices in their life. It is also linked to finding ways of managing or 'curing' distressing psychotic experiences – escaping from the experience of psychosis itself.

The tone of these narratives is predominantly one of anger and protest at experiencing what was termed ‘health care’ but felt to be incarceration and torture. However at times the tone is also thoughtful and educating as individuals recount what has helped them in their struggles to escape from their mental and emotional distress. For George, the escape is both from the experience of hearing persecutory voices (*‘getting shot of schiz’*) as well as from having to take medication and being in hospital. For Mary, her escape from the psychiatric system is what she seems to see as most important, with the actual experience of the psychosis felt to be less damaging. This is a sense shared by Miriam for whom escaping from the identity of a ‘chronic psychiatric patient’ and the hopelessness of her psychiatrists’ prognosis felt like a matter of life and death.

Narratives of enlightenment

The genre of the ‘enlightenment narrative’, also called ‘quest narrative’ or ‘conversion/ growth’ narrative, is one that is common to religious texts, particularly conversion stories and medieval tales (such as knights’ quest for the ‘Holy Grail’). It is also the genre of many scientific narratives (hence the label ‘The Enlightenment’ for the historical period in which rational thought and positivist science began to take over from religion as the primary means of understanding the world and experience). A group of the narratives have been categorised as primarily ‘narratives of enlightenment’ which refers to the key role of understanding (which can be sudden or gradual) in the development of the person’s narrative of recovery. In some ‘enlightenment narratives’, spirituality and religion

form an important part of the narrative. In others, 'enlightenment' refers to coming to a gradual understanding of the self and the experience of psychosis, and the word 'enlightenment' is not always used. Terms such as 'understanding', 'knowledge', and 'insight' (used quite differently to its psychiatric sense) are also used to describe this process which has been termed 'enlightenment'.

'Enlightenment' takes many forms in the narratives. It is usually presented as following on from periods of extreme distress or confusion ('dark' times) – hence perhaps the rather bold term 'enlightenment'. It refers to a sense of extreme relief and renewed vision in contrast to previous experience of extreme despair and hopelessness. Simon's narrative, for example, uses the term 'enlightenment' to describe a range of experiences, starting with the experience of taking drugs such as LSD at a point in his life when he felt he had reached a '*dead-end*'. He says '*something kind of clicked [...] it was like enlightenment for me*'. He describes suddenly feeling confident and that '*it was just like stepping into someone else, another reality*'. Following on from this he says he '*just went into this deep sort of depression*'. In order to try and escape from this he describes trying to find a different kind of 'enlightenment' through :

'a cultish thing that was going around in ____ at the time' – 'sort of 'enlightenment forums and 'insight' and so on...and basically it's a sort of mish-mash of [...] kind of American ideas, therapy with sort of like Zen'.

This, he says, '*drove me completely kind of mad*' although at the time it sounds as if he experienced it as a kind of 'enlightenment':

'I remember [...] believing I had died, and I was a ghost, no-one could see me, for instance. Kind of hitch-hiking or something, I'd died and passed into this other sort

of world [...] I had special powers of communication with animals or things like this. Or with people...telepathy...’.

Thus experiences while taking drugs and in this ‘spiritual forum’ and ‘madness’ itself seem to offer some kind of ‘enlightenment’ which seems to have frightening as well as elating aspects and is perhaps afterwards felt to have been a kind of ‘pseudo-enlightenment’.

Some time after this Simon agrees to being admitted to a hospital where he continues to ‘act strange’ and refuses medication. He is not compulsorily detained but at one point he describes that something ‘dawned’ on him and he ‘let go [...] of being that mad’. This seems to be another kind of ‘enlightenment’ which is quite sudden and is hard to describe:

‘It was like ‘serendipity’...it was like a moment of, you know,...religious language would be kind of ‘grace’ or something, you know. It would be like...something changed. And I was aware that something changed and I let go of something. And it was a bit unbelievable how it could just let go. Because I hadn’t taken this drug or I hadn’t...[...] And I felt kind of quite...sort of ‘battle-weary’ kind of feeling.’

This moment of realising the dangerousness of his behaviour and ‘taking responsibility’ is followed by a very gradual piecing together of parts of his life – moving back in with his girlfriend, signing on, doing some ‘menial’ work. Four years later he says he began to look into therapy and has since explored various kinds of therapy, as well as martial arts, and other approaches to physical and mental well-being. He has trained as a therapist and worked in various capacities in mental health. This phase of his life seems to be characterised by a kind of

‘enlightenment’ too, but this time in the sense of a gradual development of understanding, both intellectual and emotional.

As in Simon’s case, the psychosis itself is experienced by some people at the time as a kind of ‘enlightenment’ after dark times. For Suraya,

‘what I hated most was the depression, and the suicidal ideas. That was really disturbing. But the mania wasn’t disturbing. The mania was fantastic, really. It was exhilarating. You were suddenly someone really powerful. You could have all...[...] these talents and [...] connections with people [...] I was more approachable and funnier and I suppose I had more character and was more creative as well [...] it brought home to me how much of our brains we don’t use’.

Peter understands his ‘manic psychosis’ as

‘what I call the ‘holiday syndrome’, you know. How many times have we been low and depressed and fed up, broke, you know, dead-end job, got no money, and we take off on holiday. You know, it really is exactly the same dynamic’.

For him, psychosis is when part of the brain goes on holiday –

‘when you have a breakdown [...] the conscious is cognitively, kinaesthetically, emotionally...it’s just overloaded, it’s exhausted. And it switches off. And the [...] subconscious [...] takes over, so you say, do...crazy things. It’s like living in a dream.’

Meera, Mary, Martha and Kate describe an aspect of psychosis which they feel has enabled them to have new understandings and new ‘insights’, intellectually and emotionally, into certain aspects of their experience. However Meera, Mary, and Kate also stress that there is a ‘dark side’ to the psychosis also which can feel dangerous, terrifying and confusing. Their stories of ‘enlightenment’ are not simply

about viewing the psychosis in part as positive, but also about gaining a gradual understanding of the experience in their life-contexts and of learning how to be able to have more control over and manage their mental and emotional states. Thus narratives of 'enlightenment' seem to be characterised by understanding the psychosis as meaningful in some way – as a sign that you need to take a break, for example, (Peter) or that there are aspects of your experience you need to attend more to (in Suraya's case the effects of her childhood sexual abuse). From this initial step, narrators of enlightenment narratives describe a journey in which their understanding of themselves and others seems to broaden and deepen the further they travel and there is a sense of becoming progressively more 'enlightened' or 'healed' (to use Martha and Peter's word).

The core narratives can reflect a battle with a system which does not share the same kind of 'enlightenment', for example I have characterised Peter's account as 'battling a corrupt system' and his tone is both protesting and educating. Donald's tone shares both these characteristics also so there seems to be something about enlightenment narratives which open up possibilities for becoming angry as well as thoughtful about what the person begins to see and understand: for example, what constitutes help in psychosis and what stops individuals from recovering (Donald/Peter). An educating/ thoughtful tone is most common in enlightenment narratives because individuals feel they have important insights to share with others. 'Getting control' seems to be also part of these narratives, as suggested by Suraya's core narrative 'getting control of my story'. The theme of exploring new territory and

making new discoveries is also evident in Simon's core narrative 'seeing my way in the world and exploring new places' and in Meera's 'Finding my identity and fitting into two cultures'.

Narratives of endurance

'Endurance' narratives are characterised by a kind of 'acceptance' of life as a struggle which may have achievable goals and share some aspects of 'enlightenment' or 'escape narratives' but which are perhaps less 'optimistic' in tone. For some individuals this is because they characterise their experience of psychosis as suffering from a health condition, like diabetes, which they have to monitor and which constitutes an obstacle – if not an insuperable one – to their progress (Hugh). For Pat, recovery is '*a good word*' but '*it's a process[...] for me, anyway*' rather than '*an 'end thing'*'. For Pat it is a journey and '*bits of it are quite positive*' but much of it is also a struggle. Richard also likes the word '*recovery*' – '*because it's positive isn't it?*' but for him also he is not sure he knows '*what recovery means*' and struggles with thinking that to be labelled '*disabled*' might be more useful for him in terms of knowing his rights and his position in society. For Cathy, she feels she has had to endure not only the experience of psychosis which she found terrifying and exhausting, but also brutal treatment at the hands of the police, stigmatisation by her neighbours and being '*turned inside out for six weeks at the hospital*' to try and find the reasons behind her sudden paranoia at the age of

42. She longs to be able to find work again and stop taking medication but she is finding both a struggle, partly because of others' attitudes. For her, it is a daily process of retaining self-belief and determination, picking herself up and getting through the bad days.

These narratives have most in common with the traditional medical notion of recovery from psychosis or 'schizophrenia' – that a person is unlikely to make a 'full recovery' and will need to try to manage as best they can with an ongoing 'condition'. Indeed, in all of the endurance narratives the medical approach holds an important place, particularly in the realm of medication. For Cathy, this raises a dilemma because on the one hand she says she accepts what the doctors tell her, that she must take medication for the rest of her life. On the other hand, she tells me later in the interview that she does not see why she should need to do this, having experienced only two psychotic episodes in her life-time, and she tells confides that she has secretly cut down her dose and plans to come off medication completely if she can. She expresses her internal conflict about not wanting to disobey her doctor and yet being unhappy with taking the medication indefinitely as she has read up on some of the longer-term effects of taking the drugs. She also wants to know about other people who have been interviewed – whether they have recovered without medication, whether they have been able to find work again and lead fulfilling lives. This seems to point towards a search for a different kind of story which is hard to come by – a story which moves beyond acceptance and maintenance towards hope, ambition and fulfillment.

Analysis of use of language and meta-narratives

Medical narratives

A number of the accounts made extensive use of a medical meta-narrative to describe the experience of psychosis and recovery. The analysis examines what characterises the way the medical narrative is used by individuals who describe themselves as recovered or recovering from psychosis.

Firstly, there is an emphasis on the individual's power to affect the course of the illness. The narratives do not offer a deterministic account of diagnosis equals illness equals powerlessness and decline. Instead, the individuals' understanding of the physical aspects of their illness informs them about the kind of action they need to take to promote their own recovery:

'when making diagnoses such as this illness, you must accept that illness. But you must accept it in a way that it's only an obstacle [...] Just like people with diabetes' (Hugh).

Hugh emphasises that an important part of his recovery has been setting himself goals to achieve, as well as using strategies for managing his difficulties, such as setting aside time each day to communicate with his voices. For him:

'self-management is a big issue, taking control for yourself. I often discuss with my GP and my psychiatrist what...how much medication I think I should be on. If I'm

doing well, I might say, could you cut it down a bit... [...] Or if I'm more anxious we look at increasing the medication'

Having a sense of being in control of his own life and his own illness is a vital component to Hugh's recovery as he describes it.

Peter uses several meta-narratives, including a medical narrative, to describe his experience of psychosis and recovery. However, he takes a more critical stance towards his experience of psychiatric care, and he contrasts psychiatric treatment with what he would expect of general medical treatment:

'the system is never geared to healing. It is talking about 'containment', 'maintenance of symptoms', you know. You're talking about, 'This is a problem – what are you going to do about it?' [...] You know, it's like a patient being wheeled into theatre: 'You've got secondary cancer, here's the scalpel...'

Peter feels he has had to develop his own treatment programme, beginning with '*the identification that by watching my sleep-pattern I could watch my psychosis*'.

He has developed his own '*self-assessment*' tool to help him notice if he is becoming manic. He has arranged to have his thyroid function monitored because he has recognised that this is also a contributory factor in his psychosis. He complains that the lack of communication between psychiatry and general medicine fails patients because '*many things cause psychosis*' – '*the thyroid*' which '*governs metabolism*', '*dehydration*', '*diabetic comas*', '*overheating*'. He suggests that a proportion of patients could benefit if they were given information about important aspects of looking after themselves physically (e.g. not taking illicit drugs, sleeping regularly, eating well, taking exercise). As with Hugh, an important aspect of this

narrative is that the individual is in control of his own treatment and feels knowledgeable and informed about his condition.

Psychological/ psychotherapeutic narratives

Some of the individuals in this study made use of narratives derived from psychology or psychotherapy. The key aspects of these narratives in people who describe themselves as recovered from psychosis seems to be:

- having an understanding of the psychosis which is consistent with them as unique individuals and their life-trajectories;
- having the experience of talking with a sympathetic other who can enable the individual to make sense of experience and view it from different angles;
- developing a sense of a self who has had the experience of psychosis but who is not defined solely by this experience.

For Martha and Indra , therapy offers a kind of 'validation' of their personal experience and understanding of their psychosis. Indra contrasts her experience in hospital where she was told not to talk about her voices and '*Put a lid on it*', with her experience when she first contacted her therapist: '*who when I said, 'Well, actually I want to talk about the content of my voices'* [...] *she said, 'Well, of course you do*'. Indra also identifies being listened to and taken seriously as crucial parts of

the process which, she says, does not mean agreeing with everything the person says:

'You don't have to collude with the person [...] If they thought the world wasn't square, I don't mind them saying 'I don't think the world is square'. But what I want is the dignity of somebody believing me and saying, 'I understand you have these experiences. I don't experience the world that way but it must be very frightening for you...' For the first time, I feel I'm being taken seriously, you know.'

For Pat, therapy has helped her to '*understand some of the meanings of my experiences*'. However Pat's narrative of therapy is not altogether positive. She describes how her first breakdown was precipitated partly by her relationship with a therapist who suddenly broke off the therapy as Pat was becoming increasingly 'paranoid'. After this Pat began to hear voices, in particular the voice of this therapist. She contrasts this experience of a therapy she felt was badly managed with her more recent experience of a therapy she feels has helped her.

Both Suraya and Simon feel that therapy has '*equipped [them] with the tools to be here now*' (Suraya). Simon says '*I personally can't imagine finding my way here without that sort of thing*'. Suraya says of her 4 year, once fortnightly, humanistic therapy: '*it gave me the space [...] to reflect on my life and to sort of think about the themes and to sort of accept a lot of my experiences*'. In particular she identifies the Gestalt 'empty chair exercise' as giving her perspective and enabling her to recognise different aspects of herself:

'at one time I had about seven different chairs and then I'd talk to the different parts of myself. And just realising that there were different parts gave me encouragement, you know so that when I was feeling really low I knew...I took that outside and I knew that even when I was feeling really low there was still a part of me that was positive as well [...] it made me sort of be objective, sort of go...look

down and see...the whole thing...rather than just being caught up with the emotion, not knowing how to deal with it.'

For Simon, the therapeutic narrative is also about having someone who can

'just be someone else as well...and to reflect on it...from another sort of point of view [...] 'it gave me tools and different ways of thinking and like I say, different ways of inhabiting...my life...or states of mind and stuff and reflecting on them.'

These individuals describe finding a wide variety of psychotherapies helpful.

However the common elements of these narratives seems to be about being treated and respected as a unique individual; the co-creation of a meaningful account of the person's experience; being helped to gain some distance from distressing emotional experiences and view and understand them in different ways. In addition there are two other important common elements to these therapeutic narratives.

Firstly, the time-frame – these individuals describe a therapeutic relationship which typically lasts for several years (2-7 years). Secondly, the individual concerned has chosen the therapist and is in control of the therapy, to the extent that they normally decide how often to meet and for how long, since they are paying for it (albeit in most cases at reduced rates).

There are some stories of psychotherapeutic help within the NHS which describe psychotherapeutically oriented wards in which group and family therapy were key elements. For Martha and Miriam these fulfilled some of the same functions as the stories of private therapy discussed above, in particular validation and being able to begin to make sense of their experiences within the context of their individual lives.

Cultural/ religious/ social narratives

Some individuals tell a story about their psychosis and recovery within a religious or cultural or social frame of reference. For Indra, it makes her angry when this aspect of her experience is neglected or rejected:

'I think I'm angry about the lack of interdisciplinary [...] relating to what constitutes a human being and the imposition of the medical model without any thought of applying it to the cultural context the person comes from. [...] For example, I make sense of my experiences in terms of the fact that I was born in India. I came here as a small child but I grew up in a Hindu background. Which isn't just a religion. It's a cultural background as well. And the fact that over the years Buddhism has helped me quite a lot. So if I look at it in [...] the cultural context of where I'm coming from if I want [...] someone else to understand me, I want them to take that into account because they would explain why I see things the way they are.'

Indra gives an example of what happens when the medical narrative is used to dominate her cultural narrative:

'for example [...] I started talking about karma and things like that and they'd think I was bonkers because they've got a western sort of...and they've got this medical model as well. [...] if you don't understand that context, then you're going to label [people] paranoid, you're going to label them stupid.'

One explanation Donald has of his experience of voice-hearing is linked to a cultural and religious narrative:

'I come from a Celtic culture which is another thing the system didn't seem to take on board, that I come from a culture that is different from...the Anglo-Saxon, the ...[?] culture we have in medicine or certainly in psychiatry. I come from a culture where we're much more likely to believe in the psychic experience or second sight or even hearing voices. Bearing in mind 20% of my population in Scotland come from a Catholic background and we're actually encouraged to hear voices – call it

conscience – we're encouraged to do that as children. So we must through that encouragement almost be open to evolving difficulties to do with voices. So I think in a sense I was trained to hear voices at an early stage in my life and then unfortunately within the church I was abused and when I heard voices I heard the voice of my abuser, who was a catholic priest'

Donald suggests here that certain cultures value the experience of voice-hearing and do not view it necessarily as pathological. In fact, he jokes:

'My mother thought I was schizophrenic. She didn't know the problem I had was hearing voices until many years later. And when I told her [...] she said to me, 'But everybody hears voices'. [...] I don't think I've ever told her yet that everyone doesn't [...] So I think, well obviously my mother's lived her whole life hearing voices and just assumed it's a perfectly normal thing to do.'

Thus, for Indra and Donald, the different values attributed to their beliefs or experiences in different cultures (belief in 'karma' or 'hearing voices', for example) reflects onto the individual, and how they are valued within that culture or society – whether they are regarded as 'bonkers' (Indra) or 'perfectly normal' (Donald).

Using everyday language and narratives

A further type of language and narrative which is used to describe the experience of psychosis and recovery is taken from the vernacular- the 'man on the street's' language of madness. Kate talks about 'pretty weird times', 'getting kind of high', 'flying a good six feet off the ground', going 'completely off the rails', 'going completely out of control and being all over the place'. Simon similarly uses the terms 'difficult times' and that 'I sort of lost my footing where I was going'. In this type of narrative, recovery is talked about as a journey in which the individual tries to find their way back onto a road which makes sense for them. Recovery is

described as a '*like a sort of journey*' (Patricia) and Meera also describes '*the clouds lifting*' and starting to be able to see her way. Mary talks about being '*on the road to recovery*'. Kate says:

'it's taken me...you know three years of being away from hospital, two years of being drug-free and you know a good four months I've actually...of being able to kind of be...a small part of who I am. It's been a really long, long journey.'

Donald states that he has had key people who he describes as '*guides*' or '*map-makers*' who have helped him make the journey from '*chronic schizophrenic*' to where he is today - successful businessman and father, amongst other things. For most individuals who describe recovery in these terms, the journey has no clear end-point because it is as much about their life-trajectories as individuals as it is about '*recovery*' from a particular experience. Simon says

*I do find sort of '*recovery*' sort of a strange kind of term in some ways for me. Because it does suggest in some ways getting back to where you were and I find that sort of...like with health...like you get flu and then you recover. Whereas to me the whole sort of thing of...it's kind of actually exploring completely...you know becoming kind of quite different...growing...and going into completely different places.'*

Peter talks of his '*first breakdown*' and subsequent '*breakdowns*'. He describes life as '*like a very strong rope*' and '*a breakdown is when all the strands are frayed and snapped*'. His recovery strategies are a way of attending to the condition of

each strand of the rope to make sure they are all in good order, and to take action if any seem to be fraying.

For Donald, his definition of recovery is about being able to function in society. He uses a narrative about fixing something which is not functioning adequately in his analogy about recovery:

'my problem with mental health services is a simple one. If you give people a screwdriver and tell them to put a nail in a wall, they won't succeed. And what we have is a whole host of mental health professionals that have got the wrong tools for the job. Or they have too few tools to do the job. So because our system is dominated by this...this maintenance, biological model, what they get as a toolkit is a drugs cabinet. Or...or psychosocial interventions or...What they don't get is an integrated toolkit that allows them to apply what's right for the individual'

What is the function of this kind of narrative for these individuals? One aspect of using everyday language to describe experiences of psychosis is that it is normalising and allows the experience to be talked about with anyone, outside specialist contexts. Anyone can understand the term 'breakdown' or 'going off the rails'. These terms do not have any explanatory value in themselves (they do not imply how a person might go about 'getting back on the rails' for example) but neither do they carry the sense of mystery or stigma which can be attached to clinical terms such as 'schizophrenia' or 'bi-polar disorder'. They also describe isolated incidents, or brief periods of time. They are not as easily turned into a label which threatens to stick to the individual for life. In addition, these terms and images have been chosen by these individuals from their vocabulary and knowledge of the world before their 'breakdowns'. There is no sense that these terms have been forced onto them unwillingly, as there is often with psychiatric

diagnosis. There is a sense of being able to define themselves and having power to describe their experiences in their own ways.

Analysis of 'turning points' and 'stuck points'

Key 'turning points' and 'stuck points' in the narratives were analysed. Change or lack of change in identity, meaning and agency were found to be crucial aspects of these narrative moments.

'Turning points' and 'stuck points': Identity

Mary identifies key turning points as being when '*I started to find out who I was...who I am*'. She describes this as happening when she joined certain important groups. Firstly, she joined 'AlAnon', for the partners and relatives of alcoholics, her partner being a recovering alcoholic. Through this she came across the revolutionary idea that '*you are the expert*'. The fact that they '*let me join*' felt revolutionary for her in itself but then she gradually developed her own expertise, volunteering on the telephones and sharing experiences with others. Following from this positive experience of joining an organisation, she joined Amnesty International, where she began to see her experience of the mental health system in Britain in the context of issues about human rights: '*so you can see yourself in this different way – as the victim of an unjust system*'. This gives her the confidence to take action against her treatment, by making a formal complaint to the hospital

once she is outside it, even though her experience inside is of being ultimately quite powerless in the face of the system. Thus a sense of belonging and developing a new sense of her own identity seem key aspects of this turning point for Mary.

On the other hand, Kate describes a scene in which her identity as a 'manic-depressive' is like a box from which she as a person cannot make herself heard. She describes a meeting with her sister :

'who was being her usual obnoxious self [...] I was saying oh how well I am and how pleased I am that I've been making so much progress with the change of diet and homeopathic drops and all the rest of it. And she said, 'Yes, but you are a bit high'.

Kate feels this is:

'the most undermining thing that anyone can say to you. Especially when it's not true. Especially when I'm just expressing myself in the way that is me.'

Suraya describes a meeting with her psychiatrist in which she is addressed in a similarly patronising tone when she says she wants to try and come off her medication (lithium) : *'Oh, but Suraya, you know you do have to be on this medication for the rest of your life, you know'*. For Suraya this means that she is being asked to identify herself as a 'manic-depressive' for the rest of her life. However she finds the courage to make the experiment on her own when she is travelling abroad and meeting other people who *'were sort of treating me as if I was the same as them'* and *'could not believe'* her story about needing to be on medication. Clearly, the creation of identity is a dialogic process and conversations

and other kinds of interactions with others are key ways that ideas about identity can shift or remain stuck.

Turning points and stuck points: agency

Agency is about having and not having choices, control and power. The most extreme example of losing agency is where individuals have their freedom to make choices taken away as when an individual is detained in hospital under a section of the mental health act and compulsorily treated with medication against their will. This is part of what Indra considers to be the 'dehumanising' nature of psychiatric care, since being able to exercise choice over one's life and body is a fundamental aspect of what it means to be human. Donald says

'I do not think treatment should ever be compulsory. I think human beings have the right to make decisions. I think there's an argument for compulsory treatment when [...] you don't know [a person's] wishes.'

For Donald, the practice of compulsory treatment meant that he spent six out of nine years under section in hospital because he refused to take medication outside of hospital: *'And for me it wasn't about compliance with a therapy that was working. It was non-compliance with a therapy that wasn't working. So I became seen as very challenging to the system because I wouldn't take medication.'*

According to Donald this turned his treatment by the psychiatric system into a battle of wills where *'it was almost as if you had to accept that you were ill according to their interpretation of illness before they would say there was any'*

chance of you even slightly getting better.’ By this time, he had lost any sense of power or agency:

‘I just didn’t have the will to live. I didn’t have the will to do anything. I had no ambition any more [...] it was almost as if what the system said was, ‘you have no ability left.’’

Donald describes the ‘turning points’ in his recovery as being to do with individual people who were ‘guides’ or ‘map-makers’ on his journey, helping him to find his way. The first ‘guides’ are people who help him to re-find his sense of agency: the first time he agrees to go to the pub, the first time he picks up the phone and initiates contact with someone, the first time he decides to attend a hearing voices group. Closely linked to ‘agency’ is the sense of exerting ‘control’ and taking ‘responsibility’. By exploring his life-experiences Donald says he could:

‘be in control of the voice-hearing experience, by very much accepting ownership of my own experience, accepting that I was responsible for my recovery, not the services. And then, living it.’

Donald says that in the workshops he runs now he tries to get this idea across, that the power and the responsibility to recover ultimately lies with the individual:

‘I sort of tell them that I don’t do the work, they do, and then I give them loads of work to do. And people...a lot of people said they won’t do it. That’s not what I’ve found. I’ve found that people do the work. They do want to recover. They do want their lives back. And if they know this is going to cost them three or four hours a day or what for six months then they’re going to do it.’

There is a sense in the narratives that helping people to make choices, take difficult decisions, and take responsibility is fundamental to the recovery process.

Individuals want to have choices about the kinds of treatment they receive: *‘People should have a choice as to what sort of treatment they want and not be imposed and*

they should have advocacy right throughout everything’ (Richard). Donald takes this idea of ‘choice’ further:

‘I think choice is really important in terms of recovery. I think people need to be allowed to make choices. And not choices that we present them. Those choices are not choices at all. They’re what we think you need. So choices for themselves. So sometimes the best planning tool for the future for somebody would be a blank sheet of paper. That gives them the ultimate choice.’

Turning points and stuck points : meaning

As has emerged in the thematic analysis, finding a sense of meaning in the experience of psychosis is crucially linked for some people with their recovery. For Miriam, it is very important *what* meaning is given to her psychosis. On her first admission to hospital she is given a diagnosis of ‘schizophrenia’ and prescribed anti-psychotic medication. The meaning this holds for her is that she is being told she will have a life like her father’s, as a chronic psychiatric patient. She tries to tell the staff in the hospital that she is not ‘schizophrenic’ but that she needs help with ‘*a great many problems I had never received any help with*’. Her experience is that the staff’s view is ‘*all that is irrelevant. You are now schizophrenic and we treat you with medication*’.

She describes becoming very ‘stuck’ after this admission, ‘*almost paralysed with depression*’. She returns to the hospital saying they have to do something or she will kill herself. She is then admitted to a different ward with a ‘therapeutic approach’. Here, what she says of her life experiences is taken seriously and her

feeling that this is important is validated. The meaning of her psychosis is transformed: it is not indicative of a biological fault which she has to accept but is a sign of a psychological disturbance which she can receive help with. Within the space of six weeks, Miriam feels she has come to a better understanding of herself and her family, and she never needs hospital treatment again.

CHAPTER 4

DISCUSSION

Overview

This was a qualitative study which set out to examine two main questions in relation to recovery from psychosis

1. What psychological and emotional themes emerge in accounts of individuals who describe themselves as recovered or recovering from one or more psychotic episodes?
2. What kind of stories do individuals tell about their recovery from psychosis and what are the implications of this?

The first question was addressed using Interpretative Phenomenological Analysis. The second question was addressed using narrative analysis. The second question was further sub-divided into 3 parts:

- i) Which genres of narrative, core narratives and tone emerge in individuals accounts and what does this tell us about the process of recovery?

- ii) What language and meta-narratives of psychosis and recovery do individuals draw on and how are these used within the accounts?
- iii) What can an analysis of ‘turning points’ and ‘stuck points’ tell us about the process of recovery?

This was one of a few attempts in psychology to research individuals’ subjective experience of psychosis and recovery through detailed interviews analyzed qualitatively and to explore how people make sense of and construct an account of their experiences.

It was also one of a few studies which focuses on the experience of psychosis and recovery in a population not recruited through clinical sources. The use of qualitative methods in clinical psychology research is still relatively rare and as such this study also makes a contribution to this developing area.

Fifteen individuals were interviewed following a semi-structured format. Interviews were transcribed and the participants were invited to comment on the transcripts. The transcripts were first analyzed thematically using Interpretative Phenomenological Analysis. Secondly, narrative analysis was used to explore further aspects of each account. An analysis of genre, tone and core narratives was undertaken for each interview. Particular sections of narratives were analyzed in depth to examine language, meta-narratives, ‘turning points’ and ‘stuck points’. Participants were sent a summary of an initial analysis of their transcripts for comments to further extend the collaborative nature of the research enterprise. Other researchers in the fields of IPA and narrative

analysis were consulted to discuss the use of methods and to cross-check and validate the analysis.

The discussion will first focus on the results of the IPA analysis, setting these in the context of current psychological theories of psychosis and recovery and discussing their implications. Secondly it will discuss some of the issues raised by the analysis of narrative genre. Thirdly, it will examine the analysis of language, meta-narratives, turning points and stuck points. It will be discussed how key concepts, for example to do with making meaning, developing identity and agency, recur in different parts of the analysis. Following this, the discussion will reflect on the process of doing the research, address questions of validity and limitations, and set out implications for services.

Psychological and emotional themes

The importance of ‘making sense’ for recovery from psychosis

The interpretative phenomenological analysis drew out firstly the importance of making sense of the experience of psychosis as an important part of recovery. In this study individuals had made sense of their experiences in a variety of different ways: some understood their experiences as primarily a biological illness which they had to come to terms with and manage; others understood their experiences in religious or cultural terms; others viewed their psychosis as a psychological response to certain life

experiences. Many held several hypotheses simultaneously, while their emphasis on one aspect or another varied. Perhaps most importantly, individuals had developed an understanding of their experiences which made sense to them in the context of their lives and which carried implications for how their recovery process could best be facilitated. This provides further evidence for the importance of a holistic approach to psychosis treatment which goes beyond a symptom-based approach (Alanen, 2000; McGrory, 2000). It fits with previous studies which have found individuals to use a variety of frameworks for understanding mental illness and developing their own recovery strategies (Jacobson, 2001; Lapsley, Nikora & Black, 2002). It suggests that exploring how the person is making sense of their experiences and helping to facilitate an understanding which is convincing and useful to the individual can best promote that person's recovery and may motivate them to mobilize their own recovery and coping strategies. This is in line with theories of cognitive therapy for psychosis which suggest that appraisals of symptoms and of the illness itself have an impact on outcome (Garety *et al.*, 2001; Morrison, 1998; Slade & Bentall, 1988). The results of this study include individuals rejecting 'the externalizing hypothesis' (Garety *et al.*, 2001) and understanding their symptoms as self-generated; however they go beyond this and suggest how different ways of making sense of the psychosis have implications for the self-concept. For example, if the psychosis is viewed as one aspect of sensitivity or creativity this can reflect positively on the sense of self. If, however, it is viewed as a deficit, this can reflect negatively on the self. Where psychotic symptoms are understood to be related to life experiences, this offers another kind of appraisal of symptoms which frames the experiences within a meaningful context where they can be

integrated into the person's identity. This could be seen to form part of an 'integration' style approach (McGlashan, 1987; McGlashan & Carpenter, 1981) which has been found to be associated with better recovery from psychosis.

The theme of 'Going back' in particular provides an interesting seam of evidence about one aspect of psychosis. It suggests that psychotic symptoms are perceived in some cases to be related to experiences of childhood trauma. This is important for a number of reasons. Firstly, it suggests the importance at least in some cases of paying attention to the content of hallucinations or delusions. This has traditionally been ignored in psychiatry with symptoms being viewed as meaningless 'white noise' which merely point to the existence of an underlying brain pathology (McKenna, 1994). Secondly, these results offer qualitative evidence which corroborates a number of quantitative studies and theoretical papers which suggest there may be a relationship between traumatic experiences and psychosis. Garety *et al.* (2001) suggest there may be more than one route to developing psychosis. It is possible that psychosis as a psychological response to previously experienced trauma may constitute one particular route. It has been found that severe trauma histories are more common in individuals with first episode psychosis whose symptoms do not respond to medication (Fowler, 1999). Thus it is suggested that traumatic experiences may contribute to treatment resistance (Garety *et al.*, 2001), perhaps suggesting that this group require different or additional treatments to anti-psychotic medications. Further studies investigating this area have found that individuals often relate hearing voices to traumatic life experiences (Romme & Escher, 1993); that there is a high correlation between life-time experiences of

trauma and severe mental illness (Mueser *et al.*, 1998); that there is a similarly high correlation between reported childhood abuse and first-episode psychosis (Greenfield *et al.*, 1994); and that there is a relationship between symptoms of schizophrenia, childhood abuse and other dissociative symptom clusters (Ross, Anderson & Clark, 1994). This is clearly an important area in psychosis research which warrants further investigation.

The theme of 'Living in fear' also has a number of theoretical and practical implications for psychosis research and treatment. Firstly, it stresses the importance of the emotional experience of 'paranoia', implying that it is not just the cognitive aspect that is relevant. Information and emotion processing are characterized by the perception of others and events as threatening. Developmental theories of psychopathology stress the importance of early relationships for the individual's healthy psychological and emotional development. Recent studies which have examined schemas (beliefs and patterns of thought which develop through childhood via early experiences) in individuals who experience paranoia have suggested these may play a role in the etiology or maintenance of paranoid delusions (Bentall *et al.*, 2001). In this study, some individuals associated the experience of being paranoid with experiences they had had, or were currently having, of being put down, excluded, bullied, or racially abused. Garety *et al.* (2001) point to the possible role of core beliefs in perpetuating psychosis and it may be that these individuals have not been able to reject an 'intrusive thought' such as 'they all hate me' because it has matched beliefs about the self which have

developed over their life-time and that this has contributed to a vicious cycle of psychopathology. This suggests the role of therapy in challenging these perceptions of the self, others and the world. It also highlights the need for further research to explore the connections between self-schemas, psychosis and recovery.

Responses to psychosis: intrapersonal, interpersonal and systemic

This aspect of the analysis brought together the themes across the interviews which highlighted how the person themselves, those close to them, and the systems with which they became involved, responded to the experience of psychosis. There was a spectrum of responses represented at one end by a caring and understanding approach ('tea and sympathy') and at the other end an approach characterized by violence or control ('beating up'). For some individuals psychotherapy had offered an understanding approach, for others it had been an in-patient setting run along therapeutic lines. For others, it was an attitude they adopted to themselves along with the role of key friendships and other supportive relationships. It was this kind of approach which was associated with being able to pursue a road to recovery. A further important aspect of this lack of coercion and control was that individuals described being able to make their own decisions and take responsibility for themselves. This also seems to be key in recovery. Jackson and Iqbal (1999) have stressed the importance of increasing a person's sense of control in the early stages of recovery from psychosis and reducing the sense of entrapment and humiliation which can lead to depression and suicide

(Birchwood & Iqbal, 1998). In this context, approaches and practices which limit people's choices, ability to make their own decisions and responsibility are not associated with recovery. This further corroborates the evidence from early intervention programs one of whose 'top priorities' is to reduce involuntary admissions, since this is viewed as having a significant negative impact on sense of control in psychotic illness, and on recovery (Jackson & Iqbal, 1999). Having said this, there was a view expressed in the study that the 'containment' of hospital could be important at times when individuals felt they could be a risk to themselves or other people. This warrants further research as it is a complex yet crucial aspect of mental health care. It might benefit from a study exploring both staff and patients perceptions of the role and effects of compulsory admission.

Telling stories: communication and 'finding a voice'

The theme of silence and deceit versus openness and honesty in relation to individuals' and professionals' communication within mental health, as well as the kinds of stories about mental health heard in society reflects a neglected topic. Differences between the accounts of individuals who have experienced mental health difficulties and mental health care at particular points this century have been analysed and discussed by Crossley and Crossley (2001). They discuss how the document *The Plea for the Silent* (Mc.I. Johnson & Dodds, 1957), which is a collection of accounts of individuals who have been in mental institutions in the 1940s or 50s, sets a very different tone from, for example, *Speaking our Minds* (Read & Reynolds, 1996), a more recent collection of

personal accounts by users and former users of mental health services, and that 'the voice' of the psychiatric survivor is qualitatively different now, to what it was a few decades ago. For example, they discuss the apologetic tone of the 1957 text and contrast it with the more demanding, oppositional tone of the 1990s text. As well as noting a tendency for the later accounts to 'turn inwards' and use language about emotions and internal experience, they also note a 'turn outwards', towards political engagement, both of which reflect themes found in this study.

Hyden (1995) has pointed out the importance of constructing a 'platform' from which to speak, and finding a 'voice' in which to talk about experiences of mental health difficulties. This 'finding of a voice' could potentially have far-reaching implications. Similarly 'silenced' stories in the past have been stories of sexual abuse, for example (Herman, 1992). The telling of such stories has implications for society's response to the individuals affected by such trauma and it is possible that as survivors of mental and emotional distress find ways of telling their stories, some of the stigma and taboo surrounding these experiences will change. As these experiences are talked about openly, and understood better, the fear of the unknown and apparently inexplicable which presently affects attitudes towards mental health problems may dissipate. As Crossley and Crossley (2001) have noted, changes in the 'personal' voice of the 'mental patient' develop in close relationship with wider movements and with changes and developments in the social, economic and health fields.

On the other hand, some researchers who have studied the narratives of trauma survivors argue that maintaining an ‘incoherence’ can be a survival strategy, arguing that aspects of the experience may remain ‘incoherent’, unable to be made sense of or unable to be talked about, and that this need not be seen as being an obstacle to recovering a meaningful life (Harvey *et al.*, 2000). In view of the stigma attached to mental health problems individuals have also described how they have deliberately not talked about their experiences (e.g. George, who began to talk about having been treated for schizophrenia only after retiring from his career in broadcasting). This may then constitute a necessary survival strategy in some contexts. It begins to suggest the importance of context in terms of recovery strategies. In terms of concepts such as ‘sealing over’ and ‘integration’ recovery styles (McGlashan, 1987), it also suggests that these may require refinement both in terms of individuals and their social contexts.

‘Working out where you stand’ : social and political aspects

The theme of ‘telling stories’ is also associated with the theme of ‘working out where you stand’, since for both social and political context is crucial. As in the analysis of some illness narratives (Frank, 1993) or in the accounts of parents coming to terms with a child’s disability (Gray, 2001), activism can be one way in which recovery, or coming to terms with a condition, can manifest itself. This theme highlights the importance of society and culture for attitudes towards and recovery from psychosis, reflecting those studies which have shown that recovery rates vary between societies (Warner, 1994, 2000; Waxler, 1979; WHO, 1979) and recent qualitative studies which have also drawn

out the importance of societal factors in recovery, for example the effects of stigma as a barrier to recovery (Baker & Strong, 2001). For further exploration of how cultural and societal factors influence recovery, this discussion now turns to the narrative analytic part of the study.

Narrative analysis

What does the analysis of narrative genre tell us about recovery from psychosis?

The analysis of narrative genre identified three types of narrative: narratives of 'escape', 'enlightenment' and 'endurance'. As Frank (1993) discusses, the identification of narrative genre allows the narratives to be read with attention to particular similarities and differences between individual narratives. It is not to suggest that this is the *only* way in which the narratives could be categorised, nor that elements of more than one genre cannot appear in the same narrative.

Narratives of escape

The narratives of escape described recovery as an escape from the psychiatric system, the distress of the psychosis and the life-long identity of a psychiatric patient.

Some individuals describe an ideological battle with a system which is felt to be totalitarian in its insistence that individuals adopt the belief that they are mentally ill, that this has biological causes, and that they must agree to take medication for the rest

of their lives. Any doubts about these beliefs or dissent can be treated as 'lack of insight' and set in motion a readiness in the psychiatric system to use compulsory powers to force individuals to comply with this system of beliefs regardless. In those narratives in which the system is experienced in this way, recovery for the individual means finding ways of escaping from the system in order to preserve an identity which allows for hope, agency and meaning. Escape from the dominant medical ideology also enables the individual to hold on to his or her personal beliefs about the nature of their distress, its causes, and the implications for how best to recover. Thus the narratives of 'escape' include both physical aspects (such as getting out of hospital) and also psychological or ideological aspects – escaping from the enforcement of a particular belief system about the self, the psychosis and the implications for recovery, where the assumptions are that recovery is unlikely or impossible.

These narratives thus have more in common with those of survivors of imprisonment, for example political imprisonment, than with illness narratives (e.g. Langer, 1991; 1996; Young, 1988). This raises important issues about some individuals' experience of mental health care. It raises philosophical and political questions about the conflicting roles of the mental health system in terms of social control and the aim of helping to care for and act in the interests of the individual with mental health problems. At times these roles seem to contradict one another and perhaps this points towards the need for a system in which these roles can be made distinct and defined more clearly. At the least, it warrants further thought and investigation if best practice is to be furthered.

Narratives of enlightenment

The narratives of enlightenment share much in common with 'quest' narratives as discussed in studies of illness narratives, in particular the aspects of a search for meaning, and a sense of being part of an ongoing journey (Crossley, 2000a; Kleinman, 1989). They also share key aspects of 'restitution' narratives (Frank, 1993) in the way in which their recovery journeys often take on an element of activism in an attempt to 'repair', for others if not themselves, elements of their damaging experiences. In their emphasis on gradually making sense of their experiences and use of a therapeutic meta-narrative they also have much in common with narratives of recovery from trauma such as sexual abuse (Davies, 1995; Harvey, Mishler, Koenen & Harney, 2000).

One way in which the narratives differ from illness narratives is that the psychosis itself is experienced as a kind of 'enlightenment' for some individuals. Some accounts describe the psychosis as to do with being in a 'heightened emotional state' in which the individual is brought face-to-face with aspects of their life-experience which they had previously neglected, or held out of conscious awareness. Psychodynamic terminology is used by some to describe a process whereby what has been 'unconscious' is brought into 'consciousness' in a psychotic form. For some individuals the psychosis marks the beginning of a period of self-discovery in which they seek help to make sense of their psychosis in the context of their life-experiences. The psychotic contents of their thinking rather than being dismissed as empty signifiers of a biological illness are taken up as offering clues to important psychological and emotional conflicts. Thus for some individuals the psychodynamic model of psychosis (see Alanen, 1997; Jackson, 2002)

seems to offer a useful way of understanding their experience and pointing towards strategies for recovery, through therapy for example.

‘Enlightenment’ narratives see recovery as a process, starting from the initial experience of psychosis. Whereas the psychiatric term ‘insight’ is used to describe the extent to which the person accepts they have a biological illness which requires medical treatment, the notion of ‘enlightenment’ is multi-faceted and does not assume the kind of understanding which individuals need to develop to help them to recover.

Individuals describe developing their understanding over years. The enlightenment narratives do not suggest there is one way of recovering. Rather the individuality of each person’s recovery is emphasised along with the need for people to be treated as unique human beings.

The aspect of time is also crucial in these narratives. Individuals emphasize that different things have helped them at different times. One element of these recovery stories in which time plays a key role is with the issue of medication. Individuals have a sophisticated understanding of the effects of taking different medications –both in terms of their subjective experience of being on various medications and in terms of having read about the theories of how the drugs work and the associated risks or ‘side-effects’. Some individuals feel that medication has been helpful to them at particular times. Interestingly, what some describe as helpful is the sedative component of the drugs more often than any supposed direct effect on the psychosis. This fits with theories about one of the primary effects of anti-psychotic medication being to enable patients to

avoid sleep-deprivation (Charlton, 2000). For these individuals, it is important that they are able to stop taking medication when they no longer need help to regulate their sleeping pattern. Others describe finding it helpful to take anti-psychotic medication in the longer-term and this is perceived to help to regulate distressing aspects of the experience of the psychosis. However, for these individuals, being able to negotiate about how much medication they take at any time is crucial, and being prescribed higher doses of medication is experienced as actively hindering their recovery. These accounts offer subjective evidence of how medication can help or hinder recovery, depending on how it is prescribed. This finding ties in with previous studies which have found that being able to have choice and control in treatments is important in coping with and recovering from mental illness (Baker & Strong, 2001; Faulkner & Layzell, 2000; Martyn, 2002). Time is crucial in terms of diagnosis, with individuals wanting it to be recognized that they should not be defined all their lives by a diagnosis they have received at one point in time. Time also plays a vital role in terms of recovering emotionally from psychosis, various treatments and sometimes also earlier trauma associated with the psychosis. This is a process that in these narratives is recognized to have taken years, often requiring the ongoing help and support of partners, family or therapists.

Narratives of endurance

The 'narratives of endurance' come closest to the dominant medical paradigm of how one might 'live with psychosis'. They also reflect aspects of some of the illness narratives of 'acceptance' (Frank, 1993). However even within these narratives there is

a strand of protest running through them about wanting to be treated differently by professionals and by society. Individuals want to have more choices about which types of treatments they are offered and how they use these, as found in previous studies (e.g. Faulkner & Layzell, 2001; Martyn, 2002). One participant wanted to come off her medication but feared telling her psychiatrist in case she was regarded as difficult or disobedient. Individuals wanted action to be taken so that the stigma of having mental health problems is reduced in society and employers are prevented from discriminating against individuals who have had mental health problems in the past. This is in line with other recent studies which have examined 'barriers to recovery' (e.g. Baker & Strong, 2001; Jacobson, 2001) and also reflects themes in the interpretative phenomenological analysis part of this study, in particular the societal aspects of the theme 'Working out where you stand', as discussed above.

Recovery as a process of 'doing meaning', 'doing identity', and 'doing agency'

In the analysis of language and meta-narratives as well as of 'turning points' and 'stuck points', the role of the transformation of meaning, and the development of identity and agency were highlighted as key. This also reflects themes from the interpretative phenomenological analysis, including the importance of 'making sense' of the psychosis, and being able to see the self in new ways, as well as retaining the capacity to make choices and exercise control within a framework of understanding. The

‘problem of the psychosis’ or, to put it in a more neutral way, the ‘experience of the psychosis’ causes the participants to ask themselves the same questions:

- How can I make sense of this experience? (Meaning)
- What does this mean about who I am as a person ? (Identity)
- What actions can I take, given this information/ understanding? (Agency).

The way individuals used the narratives of psychosis available to them in order to promote their recovery seemed to suggest that it was vital within these narratives to be able to find the space to manoeuvre and create opportunities for developing meaning, identity and agency. This is consistent with previous studies which have highlighted the role of identity and agency in recovery from schizophrenia – *‘the rediscovery and reconstruction of an enduring sense of self as an active and responsible agent’* (Davidson & Strauss, 1992). Other studies have highlighted the role of changes in identity in recovery from severe mental health problems more broadly – *‘transforming the self’* (Jacobson, 2001) and *‘reclaiming a positive sense of self’* (Ridgeway, 2001). The importance of agency has also been identified in a number of studies – *‘moving from withdrawal to engagement and active participation in life’* and *‘active coping rather than passive adjustment’* (Ridgeway, 2001); *‘a sense of control and independence’* (Smith, 2000); *‘taking control’* and *‘having choices’* (Faulkner & Layzell, 2000). The importance of a sense of meaning has also been highlighted in relation to recovery from severe mental illness broadly : *‘moving from alienation to a sense of meaning and purpose’* (Ridgeway, 2001); and in relation to managing life with

schizophrenia: '*Maintaining morale, finding meaning*' (Martyn, 2002). There follows a brief discussion of how the analysis of language and meta-narratives as well as turning points and stuck points highlighted the way that changes in a sense of meaning, identity or agency influenced recovery.

The medical meta-narrative

A variety of meta-narratives are employed by individuals when talking about their recovery. Thus it is not simply the choice of meta-narrative itself which promotes or hinders recovery, but the way that narrative is used. In the meta-narratives which use a medical discourse, it is crucial for recovery that the narrative allows the individual agency, and possibilities for a socially acceptable and hopeful identity, as well as making sense to the individual in terms of their own experience. At present this is a vastly neglected area in clinical research. For example, research into medication focuses almost exclusively on objective measures, without considering that 'taking a pill' or 'being given depot medication' has a meaning for individuals which affects how they think, feel and act (a notable exception to this is work applying a discourse analytic approach to conversations about medication with professionals and users e.g. Harper , 1999). The 'placebo' effect has been studied extensively, showing how taking any pill can have a positive effect if the person believes it will work (see e.g. Andrews, 2001). However the opposite effect has been neglected: the psychological impact on individuals forced to take medication which they believe has no positive effect or is

harmful to them. Individuals in this study describe a complex set of reflections on their understanding of their difficulties and their experiences (positive and negative) of taking different medications, for example. One report (Cobb, 1993) and one study (Rogers *et al.*, 1998) have explored the views of individuals on taking medication, showing in particular that the reality is more differentiated and complex than a simple 'compliance' versus 'non-compliance' model. This could be an important area for further research.

The psychological/ psychotherapeutic narrative and meaning, agency and identity

A number of therapists and researchers have examined how therapy can be a dialogic exchange which opens up possibilities for creating new ways of thinking about the self, the other and the world, in terms of meaning, identity and agency (Georgaca ,2001 ; Davies, Thomas & Leudar, 1999). Some of the difficulties of maintaining dialogue with a person experiencing psychosis have also been discussed, viewing psychosis as the disintegration of dialogic self-structure (Lysaker & Lysaker, 2001). The notion of 'resilience' has been linked with the concept of 'reflective self-function' where an individual is more resilient to psychological problems if he/ she is able to view themselves, others and the world from different standpoints (Fonagy, Steele, Steele, Higgit & Target, 1994). It could be argued that developing this ability is a key aspect of all psychological therapies – be it cognitive-behavioural, psychodynamic, or systemic, for example. In this vein Brewin and Power (1999) have suggested that psychological therapies can be viewed in an integrated way by understanding them as facilitating a process of meaning transformation focusing particularly on themes to do with the self

and the other (the self as powerless, inferior, non-existent, or futureless; the other as abandoning, betraying, or hostile). Thus within a psychological framework, being able to 'play with reality' (Fonagy & Target, 1996; Target & Fonagy, 1996; Fonagy & Target, 2000), whether this takes place in therapeutic encounters or outside of them, may be key in developing our understanding of how we can best promote recovery from psychosis. This study found individuals experienced crucial 'turning points' or 'stuck points' in a dialogical manner. That is, it was in interactions and conversations with others that individuals found they could create meaning, have opportunities for agency and develop their ideas about who they were - or that the freedom to act, make meaning or identify themselves in certain ways were denied them. It may be that the importance of 'others' in recovery which has been identified in previous research (e.g. Faulkner & Layzell, 2000; Martyn, 2002; Ridgeway, 2001) has to do with the fundamentally dialogic nature of the recovery process in negotiating and creating meaning, identity and agency.

The societal/ cultural approach and meaning, identity and agency

Several strands of narrative about society and culture emerged in the analysis. One strand was where individuals used cultural beliefs about hearing voices, for example, to normalise or value their experiences. One participant (Donald) talked about how he came from a culture in which individuals were encouraged to hear voices from an early age (within the Catholic church) and this links up historically with the value attributed to people who heard voices in a religious context in the past as being revered as saints

or prophets (Porter, 2002; Romme & Escher, 1992). Similarly another (Indra), viewed her experience as part of her spiritual life as a Buddhist-Hindu and not as evidence of a pathology.

Another strand is where a society or culture is viewed as an obstacle to the recovery process, for example through the stigmatisation of psychotic experiences or the difficulties of finding employment. The role which systems within society play in facilitating or hindering recovery from mental distress has been examined at length (Warner, 1994; Smail, 1995). Anti-stigma campaigns have tried to tackle this at one level (e.g. the British Department of Health's 'mind out for mental illness' campaign, or the '1 in 100' billboard posters paid for by Janssen-Cilag, manufacturers of the newer anti-psychotic medication, which refer to the ratio of the general population who will receive a diagnosis of schizophrenia). Public health campaigns would seem to have a role to play in destigmatising mental health problems. However the identification of the self as 'ill' can be both liberating and problematic in terms of developing identity, meaning, and agency, and this warrants further research.

Another interesting aspect of 'identity' in the narratives is that in their recoveries individuals describe rediscovering important aspects of their pre-psychosis identities (as found by Hyden, 1995). For example, Mary takes up art again, having trained as an artist; Donald runs a very successful business in mental health, having worked in the city as an accountant; Peter gets involved in scientific research, having had a medical training. This raises important implications for early intervention services, where

individuals may not yet have had a chance to develop a sense of their strengths or work-identity. It suggests that services need to focus on people's strengths and on providing them with opportunities to explore and develop their potentials, talents and skills as individuals, thus creating the possibility of an alternative to being socialised into an identity as a chronically ill person. As Ho *et al.* (1997) observed in a study in the USA of people with a diagnosis of schizophrenia, over half of patients are primarily supported by social service agencies an average of 7 months after first hospitalisation and once this disability status is taken on, it is rarely terminated. It may be important that the social security benefits system can be flexible enough to encourage people to study or work if they feel able to, without the fear of losing their financial support altogether if they experience further difficulties. This dilemma in those coping with or recovering from mental health problems has been discussed in relation to a recent outcome study of a supported education initiative (Isenwater, Lanham & Thornhill, 2002).

As a whole, this aspect of the analysis highlights the need to consider societal aspects – the economy, the role of poverty and deprivation, employment and education opportunities, prejudice, and legal aspects such as employment rights and human rights in order to do justice to the nature of the difficulties faced by people with psychotic diagnoses.

The role of reclaiming language and experience in recovery

The analysis of meta-narratives suggests that one way of talking about psychosis and recovery is to use language and imagery which exist outside of medical or psychological discourses, such as talking about ‘a journey’, ‘going off the rails’, ‘starting to see my way’, ‘flying six foot off the ground’, ‘swinging from the chandeliers’, ‘things were going a bit strange’. Dillon and May (*in press*) have termed this kind of process ‘reclaiming language and experience’, where individuals wrest their experience from what can be felt to be a colonisation by a pathologising discourse and ‘make it their own’. They argue that this allows the experience to be felt and understood in all its complexity: *‘Instead of being a list of symptoms with side-effects on top, we are people who hear voices and see visions, have unusual thoughts, passionate feelings, intense experiences.’* Stories about psychosis and recovery in the user-literature (e.g. Baker & Strong, 2001) and in literature more broadly (Hornstein, 2002) are seen to offer diverse ways of understanding the experience of ‘madness’ as offering a window onto an aspect of human experience that need not be pushed to the margins of society and of what it is acceptable to talk openly about. Thus, individuals draw also on language which refers to the earlier struggles of groups in society who have been marginalised and discriminated against, such as the feminist movement, the gay rights movement, and disability rights, hoping to follow in their footsteps of increased acceptance and recourse to the law on issues of discrimination. Harvey *et al.* (2000) discuss how not just individual narratives but also cultural narratives can change over

time. They give the example of native Americans, once cast as the aggressors with the settlers as 'heroes', but later identified as victims and oppressed peoples. A similar shift in role may be heralded by new narratives in mental health, for example the shift from 'victim' to 'survivor' (Crossley & Crossley, 2001). Developments in narrative therapy also address centrally how individuals talk about their experiences, how they cast themselves and are cast by others in their narratives, and how far they are enabled or disabled by their stories (White, 1987; 1995; 1996). This study suggests that one aspect of facilitating recovery may be to allow individuals the scope to describe their experiences in their own words, rather than expecting them to adopt exclusively medical or psychological terminology. This may facilitate not only their own understanding of their experiences, but it may also help them to talk about their experiences with others outside of mental health settings, thus decreasing stigmatisation.

What did individuals mean by 'recovery'?

Individuals identified themselves as recovered or recovering from psychosis according to a variety of criteria including whether or not they are taking medication and whether or not they are working. The analyses of the interviews suggested other factors such as the relative importance to individuals of whether or not they continue to have 'psychotic' symptoms and how confident they feel about their emotional and psychological well-being. This suggests that recovery means different things to different people and that professionals should discuss with users what the goals of recovery are for them. Some people, for example, may want to take medication if it means they can function more easily in a work environment. For others it may be important to be

supported to come off medication if they see this as a key aspect of their recovery, even if it means risking a return of some of their psychotic experiences. For some, they expressed doubts about the word 'recovery'. One person said for them it was not about getting something back which they had lost but about exploring completely new places – more a process of 'discovery'. This notion of 'discovery' is echoed in other users' stories of recovery (e.g. Leibrich, 1999) where stories have titles such as 'It's a privilege, not a disability'; 'I think it's just about being real'; 'Looking for my self'; 'It's all about managing my life'; 'Control the illness, don't let it control you'; 'I gradually found a place in the world'; 'Discovering the life you want'. Interestingly these titles (which are from a New Zealand publication), reflect to a large extent some of the different themes which emerged in this study – for example, the emphasis on control and managing in some accounts, or on finding an identity, different realities, or discovery in others.

Another individual in this study also queried the word 'recovery' and wondered whether the notion of 'disability' might be more appropriate for him and have helped him to find an identity in society and to know his rights. He associated recovery with working (he undertook voluntary work) and not being in hospital, but he still felt socially excluded and alienated, identified himself as a 'typical schizophrenic' and continued to take medication. Recovery is a multi-dimensional concept with each dimension on a broad spectrum. The notion of recovery is not incompatible with that of disability, as is stressed particularly by Anthony (1993). An individual with a disability can recover if they can come to terms with their disability and find meaning and value in life. As

Zetlin and Turner (1985) discuss in the context of mild learning disabilities, individuals talk about being able to outgrow their disability through their life-style, such as living independently, working, and having a partner. Effectively, in terms of social identity and status, they are no longer disabled. There are a variety of ways, then, in which recovery can be formulated, according to the experiences of different groups of individuals.

Pathways to recovery

The group of participants which were recruited for this study had a wide-range of different experiences of psychosis. They had received a variety of different diagnoses (with some individuals having received a number of diagnoses over time), and their difficulties had persisted for varying lengths of time. It is possible that the narrative genres of 'escape' 'enlightenment' and 'endurance' may reflect some of the differences between the different accounts. For example, an 'endurance' narrative may reflect an experience of ongoing psychotic difficulties such as in schizophrenia, where the individual's definition of recovery is to be able to manage his/ her symptoms and regain meaning and purpose in life despite these. 'Enlightenment' or 'escape' narratives may at times reflect a different pathway to recovery, where the psychosis has perhaps been limited to a small number of episodes and individuals sense they have 'escaped' longer-term difficulties, or have come to understand the context of their psychotic experiences. However this is over-simplified since individuals with longer-term problems and diagnoses such as schizophrenia describe a variety of pathways to recovery and also tell 'escape' and 'enlightenment' narratives. For example, one

participant (George) told how he 'escaped' schizophrenia and further hospital treatment after twenty years of recurrent episodes by a technique taught him by a fellow patient ('timesharing'). Another participant (Donald) explained how after being treated for ten years for schizophrenia, he came to understand his voices as connected to his life experiences and by working through these, was able to recover a meaningful and functioning life. These may represent exceptional cases, or even cases of misdiagnosis. However their existence warrants further research.

The study demonstrates that there are different pathways to recovery in that some individuals felt they had recovered through long-term psychotherapy, or self-help groups, others with the help of medication, others through meaningful work, others through changes in diet and life-style, others through the use of particular strategies. For some individuals in the study recovery meant that they continued to hear voices (for example) but this did not impede their lives significantly any longer. This would be termed 'social recovery' (Birchwood & Jackson, 2001). Others might no longer have any symptoms, nor take medication, but they still struggled to participate in social activities that were meaningful to them. This is an example of symptomatic or clinical recovery. For others, they described having no symptoms, taking no medication, working and being without psychological difficulties. These would be examples of 'complete recovery' and 'psychological recovery' (Birchwood & Jackson, 2001). It is known that a proportion of people recover after one psychotic episode and that in the longer term the outcome for individuals with a diagnosis of schizophrenia, for example, can improve over time (Harding *et al.*, 1987). It has broadly been assumed that this can

be explained biologically – for example, Breier *et al.* (1991) suggest that improvement in the longer term may be due to the reduction of dopamine function in the brain which occurs with ageing. However, this study contributes to the evidence that psychological factors can also affect whether and when a person recovers from psychosis. Many of the individuals in this study associated their recovery with strategies they had undertaken themselves. There may be important biological factors which make it more or less likely that an individual will experience recurrent psychotic episodes (Nuechterlein & Subotnik, 1998). However, equally, psychological factors may play a crucial role as in Simon's account, where he describes a key moment when he made a decision to let go of his 'madness' and gradually worked to explore and learn from his psychological difficulties. This study opens up possibilities for exploring further the role of the individual and psychological factors in recovery from psychosis.

Critical Reflection

Recruitment

The recruitment of participants was done through advertisements and word-of-mouth , as is often the case in qualitative studies. The participants recruited were ideal for this qualitative study in that they represented '*key informants who have a profound and central grasping of a particular cultural world*' (Plummer, 1993, p.104). That is, those individuals who came forward for the study had reflected at length on their experiences, had often read extensively around the area, and were often involved in

groups or organisations with others where relevant issues were discussed and thought about. Blumer (1979) makes a similar point, stating that:

'A half dozen individuals with such knowledge constitute a far better representative sample' than a thousand individuals who may be involved in the action that is being formed but who are not knowledgeable about that formation' (p.xxi).

However it is important to reflect on the particular characteristics of these individuals in discussing the results of this study. These were largely a group of highly motivated individuals, who were articulate and who had highly developed ideas about mental health. As they were recruited through user-groups which generally take a critical stance towards mental health care, it was likely that critical opinions would be over-represented. However additional advertising at conferences ensured that a range of views was represented. Another interesting aspect of the recruitment was that a number of the individuals worked in mental health. Perhaps their involvement in the study was a reflection of their ability to think through their difficulties and then try to channel their experiences positively, in terms of working or taking part in the study, for example. Obviously in some cases this meant that individuals talked about their experiences in quite theoretical terms and drew on a range of personal and professional expertise in their responses in the interview. In any case it meant that, in accordance with Blumer (1979), they were knowledgeable about a number of aspects of the topic.

Everyone who responded and who fitted the criteria was interviewed without selection. In one case, practicalities meant that an interview with one person did not go ahead. A

number of people volunteered for the study after enough participants had been recruited, so they were not included in the study.

One salient aspect of recruitment was that it was difficult to recruit from minority ethnic populations, despite specifically contacting user organizations run by and for ethnic minority groups. One of the two Asian participants in the study commented that if a person has experienced racism or abuse (for example in the psychiatric system) it is hard to differentiate where it might come from. Thus it may be doubly difficult for individuals who have been discriminated against because of their race and their mental health problems, to speak about their experiences, particularly with a white mental health professional.

Interviewing

The interviewing process itself was straightforward. Individuals generally came ready to talk. Some had clearly talked about their experiences at length before (for example in counselling or therapy, or in support-groups, or through running workshops on understanding psychosis). Some had already written about their experiences, either for themselves, or for publications such as users' magazines. For others, this was one of the first times they had talked at length to someone else about their experiences of psychosis and recovery. This required some flexibility in procedure. For example, one participant chose to pause repeatedly to gather her thoughts and it was suggested that she take control of the tape-recorder and press 'pause' as and when she wanted time to think.

Analysis

As the results of the analysis emerged I found that assumptions I had held previously were at times confirmed and at times challenged by the findings. Some of the assumptions which were confirmed were: that people found the mental health system at times not unhelpful in the process of recovery; that some individuals understood their psychosis as linked to experiences of trauma (though I was surprised at the number of people who made direct links between their particular experience of psychosis and childhood sexual abuse); that some individuals had found talking about their difficulties (e.g. in therapy) an important part of the process of recovery. Results which challenged my assumptions were, for example, that one individual described himself as 'a prime example of recovery actually happening', though he accepted the diagnosis of 'schizophrenia', and planned to take medication indefinitely. He made me realize that individuals hold different definitions of 'recovery' and that for him being able to achieve the goals he set himself which were to raise his daughter and work in the voluntary sector meant for him that he was 'recovered', regardless of his diagnosis or medication. The individual who described how he had learned that his psychosis was connected with a 'thyroid condition' opened my eyes to an aspect of psychosis I was previously unaware of. Individuals who described how the mental health system had helped them, for example where hospitals or wards were run as therapeutic communities, or where they had experienced sympathetic psychiatrists who listened to their concerns and acted on them (for example, with regard to medication or changing a

diagnosis) highlighted ways in which the system can be experienced as helpful and responsive to users' needs. The results also suggested how many diverse ways individuals had found for recovering from psychosis, with or without the help of the mental health system. This challenged me as a psychologist to realise the limitations of a psychological approach to intervention which might only be sought out and used by a proportion of individuals.

I was also challenged to think about the term 'recovery' in the context of the research. Some individuals felt it accurately reflected their experience. Others found it too simplistic a description of a process which could take years, with times of discovery and times of further difficulty. In part, this reflects a diversity of experiences in the sample. However it is an issue which is common in this area. O'Hagan (2002) discusses how recovery has been defined within a New Zealand context, where all mental health services are required to use a 'recovery approach'. She highlights similar debates about recovery to those found in this study, quoting individuals as saying, *'Recovery takes you back to where you were, but my experiences transformed me'*; *'I'll always have mental health problems, so I'll never recover'*; *'I don't believe I had an illness but recovery implies I did have one'*; *'I don't see my madness as undesirable, so what is it I need to recover from?'* (p.16). Despite these debates about the term 'recovery', it remains useful if it can be defined along different dimensions and in the context of the individual. In New Zealand, recovery has been loosely defined as *'living well in the presence or absence of one's mental illness'* and particular emphasis is placed on the role of society, cultural factors, and communities in enabling recovery. In contrast, the American model

has been criticised for being overly individualistic and monocultural (O'Hagan, 2002).

As is the nature of qualitative research, this study opened up areas for further research, revealing a diversity in both what is termed 'mental illness' and what is termed 'recovery'. In particular, it showed that individuals define their own recovery subjectively, according to the factors that are most meaningful to them.

Addressing questions of validity

According to Elliot, Fischer and Rennie (1999), qualitative research can be evaluated by examining

1. Whether the researcher has owned his or her perspective in the research
2. Whether the sample has been situated adequately
3. Whether the results are grounded in examples
4. Whether credibility checks have been provided
5. Whether the research is presented coherently
6. Whether the research tasks have been accomplished, especially with regard to general versus specific questions
7. Whether the research as it is presented resonates with readers.

Yardley (2000) has suggested the following as criteria to evaluate good qualitative research:

1. Sensitivity to context
2. Commitment and rigour
3. Transparency and coherence
4. Impact and importance.

These overlap to some extent with Elliot et al (2001). However I will take their points in turn.

Firstly, I have discussed my own perspective when I came to this research and have also described how my assumptions were both upheld and challenged at times by the process of analysis. My perspective as a researcher with my own views of psychosis, drawn from personal and professional experience as a psychologist, have undoubtedly informed the research process and the way in which I have discussed the results. Clearly the interviews were a dialogue to which I contributed, and interviewees could be seen to be giving me responses they thought I wanted to hear. On the other hand, it could be argued that a context was created in which stories about trauma, or about treatment which was experienced as abusive, for example, could be told. I tried not to influence participants in their responses; for example, this extract from the interview with Cathy shows how she is attempting to construct the research process in a particular way. In the exchange I try to leave open the question of recovery and how it is defined by different individuals:

C: That's my aim. [...] I'm sure once I've got a job and I don't think about things as much...that'd be...that'd be the drug, going back to work and be happy and it would just be over. Because I'd have done a full circle...it would just be over. Gone through 2 years of hell and that would be it. [...] I'd like a job. And that's my aim, if I could get a job. And not to be taking these blooming [...] tablets. Um...and I can do it without medical advice. If I do get signs I'll just kick it back in – step it back up. So...[...?]. Are you a great believer that you can go...go it alone? Is this what you're trying to prove?

HT: Um...I suppose this research is quite broad research about recovery and recovery means different things to different people. But I know that for some people that I have spoken to recovery to them means not taking drugs and doing what they want to do; for other people it means that they still do take medication but they feel they are achieving what they want [?], so I think it's different for different people.

Interestingly, though the interview context is one in which individuals seem to feel able to be open about their experiences. For example, in this same interview Cathy tells me a 'secret':

P13: [...] And I'm sitting there in the drop-in thinking, this is what these drugs have done to these people, you know all the twitching and slurred speech. And I'm thinking 'What's risperidone doing to me?' You know, it's messed up all my periods. That's gone out the window. So you know you've got to think how...I've put 2 stone in weight on, I was your size. That's another thing that brings you down. You just don't know what these drugs are doing to you but you have to take them....You don't think that? Do you not think we need to take them?

HT: Well, people have got different views on this, haven't they? Like, some people think you have to be on these drugs for the rest of your life, and some people think it is possible to recover and not have to take the drugs. [...]

P13: Shall I let you into a secret? I stopped taking mine. I could feel the psychosis coming back. I put myself back on. But recently in the last month I've cut it down to 2mgs, without anybody's guidance, because I'm determined to...not to take them. And instead of having a whole risperidone now, I'm just taking half a one and I'm watching myself. Because what the Maudsley roadshow said about what these drugs do to you and what can happen, [...] but if I have to be on them for the rest of my life, I was quite shocked. Because my doctor before that in _____ said I wouldn't be on them for very long. So what do we do, Hermione? What do we do? Do we take them because the psychiatrist is saying or do we wean ourselves off them?

Perhaps through the researcher showing she is open to different viewpoints, this secret or hidden material comes to light. It is important information in the context of recovery

because it illustrates a process of decision-making in which the individual takes responsibility for her health even where she fears others may not approve. It also illustrates the dilemmas individuals face when exposed to apparently contradictory advice or information (her 'psychiatrist' and 'The Maudsley roadshow') and suggests some of the complexity around issues of 'non-compliance', as discussed previously.

Secondly, I have situated the sample in the chapter on 'method', discussing both how I recruited the participants and giving information on demographics and diagnosis. The participants could be seen to represent people with a particularly critical view of mental health services, since user-groups are normally involved in advocating for better services. This may well be one characteristic of this sample. Another characteristic is that they were articulate and it may be that they have been able to give an account of experiences shared by others who are less vocal. One participant described how, having her first experience of psychosis in her thirties as a trained social worker, she had a certain 'naus' e.g. she knew what kind of letters her GP should write so that she could do work under the 'therapeutic earnings' scheme. In some instances, then, these participants have developed psychosis and recovered later in life and have drawn on their life-experience and expertise prior to the psychosis to help them in recovering.

Thirdly, I have endeavored to ground all my statements in examples, particularly in the 'results' chapter. Where I have discussed findings in the discussion without reference to examples, the reader is referred to the relevant sections of the 'results'.

Fourthly, I have set out in the ‘method’ section the credibility checks which were used e.g. cross-analysis of the data by my college supervisor and by two colleagues; validation of the results by presenting them to a group of mental health workers and users with whom they resonated and seeking validation from the participants for the analysis. The way in which participants’ comments were used to validate the analysis can be seen in Appendix 13, for example, where Mary states that she believes that her ‘paranoia’ and ‘ideas of reference’ ‘*are actually based on real life experiences*’. She details how her experience of psychosis has been a reflection of previous experiences of exclusion, providing some credibility for the theme of ‘living in fear’. Similarly, Meera’s comment about her psychosis that ‘*I think I was concerned about private investigators at this time as I had started seeing someone else and was very fearful of how this would be viewed by my family*’ also suggests a link between ‘paranoid’ thoughts and real experiences of feeling afraid. Simon’s comments provided further validation for the importance of making sense of the psychosis, and particularly for the theme of ‘Different realities, different aspects of being human’, while Kate’s comment about the alternatives to medical treatment being ‘*a political issue*’ suggest the credibility of ‘Working out where you stand’ as a theme. It is not possible to know about the views of those participants who did not respond to the resume of the analysis. However Mary’s comment that ‘*I think it’s a really important study and hope the people who need to hear, hear what you’re saying*’ suggests that the analysis resonates with her experience and that she views the research as worthwhile.

In validation of the narrative analysis, Mary agrees that her narrative could be categorised as a 'narrative of escape' and elaborates on how she sees this (Appendix 20). She further comments on the notion of 'turning points', suggesting that the most important 'turning point' for her was 'ideological' (concerned with the meaning of the psychosis). Simon comments on the use of the term 'enlightenment' to characterise his narrative. He raises the concern that it could be understood in a 'romantic' or will be addressed in the discussion. 'simplistic' way, when the reality for him felt very 'complex'. On the other hand, he encloses an extract from a book which seems to elaborate on the idea of the 'enlightenment narrative', suggesting that it may be an accurate reflection of his construction of his experiences. Thus this gives the analysis of genres some 'testimonial validity' (Stiles, 1993).

When a resume of the results was presented to a group of users, ex-users and professionals in mental health, a variety of comments were recorded (see Appendix 14). A professional present said he thought it was a 'very important' study. One of the former users suggested that there should be a greater focus on what hinders recovery. Another stated that the study should make clear the time-scale of recovery and that it takes place over years. Another former user raised the concern that the study would have little impact on how individuals were treated within the mental health system. She wanted to know how it would be disseminated. Another person said she did not know what was meant by 'agency'. Each of these points was considered in turn. It was decided not to change the format of the results to focus more on what hinders recovery, since it was felt that some of the themes already addressed this, such as 'Knocking

yourself' versus 'Looking at things/ Liking yourself'; 'It is not actually the breakdowns which are the problem – it is the ways you are treated which are the problems'; and 'It's a crazy system'. The point about the time-scale of recovery was noted for inclusion in the discussion. The question of the impact of the study and dissemination was noted and measures were taken to disseminate the study as widely as possible e.g. proposals were sent for conference presentations; thought was given to preparing the study for publication. The question raised about 'agency' highlighted the need for thought to be given to the language used in the study and that it should be tailored to particular audiences.

Feedback from the presentation of the results at a national conference is presented in Appendix 16. The comments suggest, firstly, that individuals consider studies of recovery to be important and are eager to hear them and for them to be disseminated. They further suggest that this study was well received. Kate's comment indicates that the research process itself can be experienced as helpful in terms of recovery and this is a valuable aspect of the study. This has been termed 'catalytic validity' (Stiles, 1993) and is defined as '*the degree to which the research process reorients, focuses and energizes participants*', and addressing '*the empowerment of research participants*' (p.611). One audience member raised the question of how to make the recovery concept relevant to all of those experiencing longer-term severe mental health difficulties. It was noted that this would be included as an important aspect of the discussion, with reference to key literature in the field (e.g. Anthony, 1993; O'Hagan, 2002).

Coherence and resonance must be judged by individual readers. As Stiles (1993) discusses, resonance may vary depending on the orientation and experiences of individual researchers and readers; likewise particular aspects of a study may resonate more with some readers than others. This was borne out in the comments on the analysis by the participants, where aspects relating to their own experiences seemed to resonate most strongly for them (see Appendix 13).

In response to Yardley (2000), further criteria for assessing this piece of qualitative research will be set out:

Sensitivity to context: This piece of research has been set out in the context of previous work in this field, both quantitative and qualitative. The sociocultural context has been discussed in terms of the characteristics of the participants and the researcher. It could be added here that while most of the interviews took place at University College London, two were conducted at participants' homes at their request. This did not result in detectable differences in the nature of the interviews, although this possibility cannot be ruled out. Perhaps more importantly, individuals knew they were talking to a psychologist and may well therefore have over-emphasized the psychological aspects of their psychosis or recovery. In addition, in the analysis, specifically emotional and psychological themes were drawn out, so that other aspects of recovery which individuals mentioned, like having somewhere decent to live or eating well were not dominant in the final account. Peter, for example, said that to some extent '*you cut the cloth to suit the fit*', in response to a question from me about the relative influence, as he

saw it, of his thyroid problems and other factors in his psychosis. He was thereby perhaps intimating that he would emphasize psychological factors to me, which he might not in another context. Thus the contextual nature of this study must be borne in mind when considering the importance of psychological factors in recovery.

Sociocultural context has also been discussed in relation to the themes of 'Telling stories', for example. It has been shown that the disclosure of certain kinds of stories are only possible in certain sociocultural contexts and in others these stories are silenced. There has been a discussion of a dialectical relationship between individuals' stories and socio-cultural conditions. This research has taken place in a societal, as well as a scientific, context in which it may be becoming more possible for such stories to be told and heard.

In addressing ethical issues, the participants were fully informed about the study and it was stressed that they were free to withdraw their consent at any time. Each participant who requested it (fourteen out of fifteen) was sent a copy of the initial transcript and was to send any additions or corrections. A number did so. They were later sent a resume of the results for their comments. As Riessman (1993) discusses, it is a good idea to ask for participants' views on interpretations to be sought, however their views should not erode the analysis if on reflection the researcher considers his or her interpretation valid. For example, George commented on his disappointment that his specific technique of 'time-sharing' was not mentioned in the resume of the results. This point was taken on board and a note was made to mention specific techniques such

as this in the discussion and in future presentations but it was not thought appropriate to alter the analysis to include this in a more dominant way, since the analysis focused on psychological and emotional themes rather than particular strategies. Themes relating to 'time-sharing' such as developing understanding in relation to the psychosis and viewing it as relating to different aspects of being human, were included in the analysis.

Commitment and rigour: According to Yardley, '*the concept of commitment encompasses prolonged engagement with the topic (not necessarily just as a researcher, but also in the capacity of sufferer, carer, etc), the development of competence and skills in the methods used, and immersion in the relevant data (whether theoretical or empirical)*' (p.221). My engagement with the topic has been ongoing for over a decade. I have worked with people experiencing and recovering from psychosis for a number of years. I also began using qualitative methodologies in my first degree in psychology and have subsequently published a paper, part of which was a qualitative study which I undertook exploring individuals' experiences in a supported education project for adults with longer-term mental health needs (Isenwater, Lanham & Thornhill, 2002).

In terms of the rigour of the analysis which '*refers to the resulting completeness of the data collection and analysis*' (Yardley, 2000, p.221), the data was collected from a wide-range of participants which, as well as being a potential disadvantage in the study, could also be viewed as an advantage in that it encompassed the views on recovery from psychosis of individuals with a great variety of experiences. The initial IPA analysis was conducted rigorously, achieving both a depth and breadth of analysis across the

interviews. This procedure has been set out in full in the appendices. The narrative analysis was subsequently undertaken to give further breadth to the analysis and to offer another level of interpretation, including further social and cultural aspects. This part of the analysis also allowed the accounts to be studied holistically, and to draw comparisons between the narratives (in the analysis of genres). The means by which this was done has also been set out in the appendices. The analysis of narrative tone, genre and core narratives was undertaken across all interviews. The analysis of language and meta-narratives as well as of turning points and stuck points was conducted on discrete sections of the narratives which were judged to be representative of the use of particular 'meta-narratives', or represented particular kinds of 'turning points' or 'stuck points' . Different aspects of analysis require attention to different amounts of text (Yardley, 2000) and the researcher is constantly engaged in the task of balancing the desire for as full an analysis as possible with the practicalities of bringing a project to completion (Miller & Crabtree, 2000).

Transparency and coherence: The write-up of this study has aimed for transparency in that it has given a detailed account of how the participants were recruited, and provided an audit trail through examples of each stage of the data analysis in the appendices. In addition, I have attempted to be 'reflexive' in considering how my assumptions and beliefs might have influenced the research process. In view of this, it is perhaps interesting to consider a study which was ongoing at the same time as this one on 'Self-management in schizophrenia' , undertaken by David Martyn (Martyn, 2002) and funded by the National Schizophrenia Fellowship (now renamed 'Rethink Serious

Mental Illness '). Even the titles of the studies betray assumptions of the researchers – that I choose to focus on 'recovery' while Martyn uses the word 'self-management', implying the management of an ongoing condition. Martyn recruited his participants through the NSF, whereas the participants in this study were recruited mainly through user-groups, whose members tend towards an emphasis on the psychological and social aspects of mental health difficulties. Interestingly, some of the themes which emerged were similar, such as the importance of 'making sense' in this study and Martyn's 'Maintaining morale, finding meaning' (2002). Others diverged, such as 'Managing 'having schizophrenia'' in Martyn's study and 'Working out where you stand' in this study. This reflects differences within the two groups, for example in political orientation. Both studies make important contributions to an understanding of coping with and recovering from psychosis across a range of experiences. It is hoped that this study can provide valuable insights into the experiences of certain individuals who have recovered from psychosis, while indicating that these are not intended to be representative of the population of people who receive treatment for psychosis as a whole.

The criterion of coherence refers to the '*clarity and cogency - and hence rhetorical power or persuasiveness - of the description and argumentation*' in the research project (Yardley, 2000, p.222). It also '*describes the 'fit' between the research question and the philosophical perspective adopted, and the method of investigation and analysis undertaken*' (p.222). As discussed previously, the aim of this research was to explore the subjective experience of individuals who described themselves as recovered or

recovering from psychosis and to examine the kinds of stories individuals told about recovery. The methods chosen for this study were IPA and narrative analysis. As the study of this area using qualitative methodologies is in an early phase, the study was designed to be broad in scope. Thus individuals were not subdivided according to diagnosis, or length of time recovered, or other factors. This is in line with similar studies to date (e.g Jacobson, 2001; Ridgeway, 2001; Smith, 2000; Young & Ensing, 1999). However the wide range of experiences of psychosis and recovery had disadvantages for the study. For example, in IPA analysis, it is assumed that the researcher is comparing themes across individuals whose experiences are fundamentally similar in some way. In this study, all the participants had experienced psychosis and described themselves as recovered or recovering, and in this respect their experiences were similar. However it could be argued that the diversity within the group (for example, with regard to the nature and duration of the psychosis, or the diagnosis received) placed limitations on how far themes between interviews could be meaningfully drawn together. It might be helpful for future research to focus only on individuals who had received a diagnosis of schizophrenia, or only on individuals who had had one psychotic episode, or who experienced psychosis with a diagnosis of bipolar disorder. It might also be useful to categorise and select individuals according to different types of recovery, as set out in the literature, for example using the typology of 'symptomatic', 'social', 'complete' and 'psychological' recovery (Birchwood & Jackson, 2001). Studies could further subdivide participants according to age-group, gender, or ethnicity, for example, in order to explore key themes and aspects of recovery in diverse groups. As qualitative studies in this area become more numerous, it

is likely that studies will emerge which focus on discrete groups and particular aspects of the experience of psychosis and recovery and which will be better able to provide a coherent account of individual phenomena. It is hoped that this study has paved the way for further research by opening up the field and indicating the range of experiences which it is possible to explore under the rubric of recovery from psychosis.

Impact and Importance: It may be too early to judge the impact and importance of this study. However, it has been received with interest at a number of conferences and comments from colleagues and peers suggested it was an important study. Written versions have also been requested for publication by an academic and a user publication. It provides a valuable adjunct to the many quantitative studies being undertaken in psychosis research and to illuminating aspects of newly proposed psychological models of psychosis (e.g. Garety *et al.*, 2001).

Areas for further research

The question of accomplishing general versus specific research tasks is an important point which relates to the issue of the limitations of the research. The aim of this research was to open up and explore questions about psychosis and recovery, not to answer them categorically, nor to be able to generalize from the findings. This research has opened up a number of areas which warrant further investigation. For example, further exploratory studies (which could be user-led or undertaken jointly with users) could look in more detail at issues such as responsibility and recovery; choices and

recovery; the experience of medication and recovery; hospital treatment and its helpfulness or unhelpfulness in recovery from psychosis; the experience of cognitive-behavioural therapy and factors helping or hindering recovery from psychosis; the experience of psychosis in individuals who have never come in contact with mental health services (as in Romme & Escher, 1993); and barriers to recovery in individuals who do not identify themselves as recovered or recovering.

Certain hypotheses could be tested using quantitative methods, for example

- Hypotheses about the role of agency in the recovery process could be tested by giving individuals choices about their treatment, or not, in in-patient settings.
- Studies could examine the uses and effects of compulsory treatments (a European study across 12 countries on the use of coercive measures in psychiatry is currently underway funded by the European Commission. It focuses on an evaluation of coercive measures and the human rights of patients, see www.eunomia-study.net).
- Studies could examine further the role of traumatic experiences in psychosis.

Longitudinal studies using quantitative and qualitative measures could explore further:

- The pattern of episodes of psychosis and recovery over time and how this relates to recovery strategies the individual may be using;
- The pattern of diagnosis over time and whether this has any implications for understanding the nature or role of diagnosis

Process research in psychotherapy could, quantitatively or qualitatively, examine:

- What aspects of psychological therapy for psychosis seem to be most effective in the moment-to-moment interaction between client and therapist?

The limitations of the study have been addressed above. In particular, it must be emphasized that the participants were drawn mainly from organizations which are usually critical of traditional practices in mental health. They were mainly white, mainly in their middle-years, and most had pursued some form of higher education. Their experiences of psychosis and recovery may only be relevant to a proportion of people who experience psychosis. Other groups, for example those who are younger, or poorly educated, or from more socially disadvantaged backgrounds could form the focus of future research. On the other hand, it may be that some of the results from this research may have wider applicability and that these participants have been able to articulate experiences which are shared by different groups. Further research will be needed to confirm or disconfirm these findings across diverse groups.

Implications for psychology, psychiatry and mental health services

It is important to stress that this study on its own cannot set out implications for mental health services, since it is based on a very small number of individuals who, it could be argued, may be exceptional cases. However it can raise questions and highlights areas which need further investigation. In conjunction with evidence from other studies it can also begin to make some suggestions for promoting recovery from psychosis in mental health services.

Individuals' accounts suggested a number of pathways to psychosis and recovery. In particular the study raised the question of whether one route to psychosis may be via childhood trauma and whether this may require different interventions from those traditionally given to individuals. It also requires consideration to be given to the content of psychosis and possible links with life-experience, and the provision of more than one treatment to individuals which could include a psychotherapeutic approach (as in the Finnish model; Alanen, 2000). This represents an additional rationale for the provision of psychological therapy for psychosis, already set out in guidelines for good practice in the United Kingdom (DOH, 1999; BPS, 2000).

The study raised questions about the compatibility of coercion and care within the mental health system. Coercion was not associated with recovery for the participants in this study. This suggests that services and the professionals within them may need to consider carefully the implications of extending powers of compulsion (currently under consideration by the Department of Health) on the possibility for individuals to make

full recoveries. This is echoed by early intervention services who endeavour to avoid compulsory admission wherever possible (Jackson & Iqbal, 1999). Nonetheless, conflicts between the goals of providing protection and promoting care must be acknowledged.

The study suggested that a collaborative approach between mental health service users and professionals is optimal for promoting recovery. Where this is not deemed possible, frameworks could be implemented which ensure that communication is maintained with the patient as far as possible and that they are informed of the reasons for their detention or treatment, and their rights within the system.

The study suggested that assessment of individuals could pay close attention to the person's story and their understanding of their experiences. As suggested by previous studies (e.g. Knudson & Coyle, 2002), the development of coping or recovery strategies may be enhanced if the person's framework of understanding is taken into account and worked alongside. This includes taking into account cultural and religious factors.

The study suggested that users of services could be given information and choices about their treatments wherever possible. It further suggested that some individuals could benefit from information about the nature of psychosis and its possible aetiologies, as well as recovery strategies which others have found useful. For example, some individuals could be encouraged to take an active role in their recovery, for example by

watching their sleep-pattern, not taking illicit drugs, or building up a supportive network.

The study suggested that it might be helpful to encourage patients to talk about their experiences in their own way and to make sense of their experiences in terms of who they are as individuals. It also suggested that important therapeutic work could focus on the person's strengths, not just their difficulties.

In order to promote recovery, individuals could be offered a broad range of alternatives both in hospital and at discharge. This could include: the option of further education (as in supported education projects, for example); employment opportunities (for example, supported employment); psychological therapy; information about creative groups e.g. art, drama or writing groups; self-help groups. As increasing numbers of people have access to the internet, patients could be given a leaflet at discharge with a number of website addresses where they can obtain information about coping with mental and emotional distress. Alternatively, access to the internet could be facilitated within hospital in order to help service users access such information.

A number of the participants held the view that 'hospitals' were not helpful environments for someone experiencing psychosis. They suggested environments which were smaller and less like institutions, such as 'crisis houses', and could be run or co-run by users or ex-users of mental health services who could be role-models for

recovery. A number of such initiatives are already in existence and it has been suggested that they should become universally available (BPS, 2000).

As it is increasingly recognised that stigma and discrimination within society and within the domain of employment, for example, can hinder recovery, there needs to be campaigns and legislation to tackle these wider issues in order to maximise the potential for recovery in those who have experienced mental distress. The need for such action has also been recognised in previous studies (e.g. Baker & Strong, 2001).

Conclusion: A whole person approach – a whole systems approach

The notion of a ‘whole person’ and a ‘whole systems’ approach is taken from Johnstone (2000). It seems to sum up well the overall findings of this study which are participants felt that many factors need to be taken into account in terms of both themselves and of the systems in which they find themselves if recovery is to be made a reality for more people who experience psychosis (or indeed other kinds of mental distress or disability). Included in ‘systems’ are the systems of language – psychiatric, psychological, and lay – which have been discussed in this study. Researchers and clinicians in the field of mental health have a dual responsibility to those with whom they work, firstly, to think about them carefully, taking into account many diverse aspects of their lived

experience, and secondly, to talk with and about them carefully, using language and stories which create rather than limit their potentials and possibilities.

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APPENDIX 1: ADVERTISEMENT FOR THE STUDY

ADVERT

Are you over 18 ?

Have you ever heard voices, experienced paranoia or held unusual beliefs for a time?

Do you feel you have recovered or are in the process of recovering from these experiences? Perhaps you think recovery is the wrong word?

Did mental health services help you? If not, why not?

We want to hear from users or ex-users of mental health services about what they think has helped them in their recovery process. We hope this will generate some ideas about how mental health services can be improved.

If you are interested and have an hour to spare for an interview please contact Hermione Thornhill on

Tel: 0208 503 7286

or e-mail: hermionethornhill@yahoo.co.uk before 27th October, 2001, if possible.

Individuals will be offered £10 as a thank-you gesture for their time.

All aspects of the study including inquiries are strictly confidential. This research has been approved by the Joint UCL/UCLH Committees on the Ethics of Human Research.

APPENDIX 2- ETHICAL APPROVAL



The Joint UCL/UCLH Committees on the Ethics of Human Research

Committee Alpha Chairman: Professor A McLean

Please address all correspondence to:

Iwona Nowicka

Research & Development Directorate

UCLH NHS Trust

1st floor, Vezey Strong Wing

112 Hampstead Road, LONDON NW1 2LT

Tel. 020 7380 9579 Fax 020 7380 9937

e-mail: iwona.nowicka@uclh.org

Dr L Clare
Lecturer in Clinical Psychology
UCL
Department of Psychology
Gower Street

May 23, 2001

Dear Dr Clare

Study No: 01/0053 (*Please quote in any correspondence*)

Title: A study of recovery from psychosis using narrative analysis

Thank you very much for your letter addressing the points raised by the ethics committee. There are no further objections on ethical grounds to this study going ahead.

Please note that it is important that you notify the Committee of any adverse events or changes (name of investigator etc) relating to this project. You should also notify the Committee on completion of the project, or indeed if the project is abandoned. Please remember to quote the above number in any correspondence.

Yours sincerely

Iwona Nowicka
pp- Professor André McLean, BM BCh PhD FRC Path
Chairman



UNIVERSITY COLLEGE LONDON

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General Enquiries: 020 7679 1897
Clinical Tutor Team: 020 7679 1258
Senior Secretary: 020 7679 5699
UCL Switchboard: 020 7679 2000
Code from overseas: +44 20
Fax: 020 7916 1989

CONFIDENTIAL**INFORMATION SHEET FOR VOLUNTEERS****Study Title: Recovery from psychosis**

**Researchers: Linda Clare, Sub-Dept of Clinical Health Psychology, UCL,
Gower St, London WC1E 6BT. Tel: 0207 679 1844**

**Dr Rufus May, Isle of Dogs CMHT, 3rd Floor, Jack Dash House,
2 Lawn Close, London E14 9YQ Tel: 0207 364 6097**

**Hermione Thornhill, Sub-Dept of Clinical Health Psychology, UCL,
Gower St, London WC1E 6BT. Tel: 0207 679 7897**

You are invited to participate in a research project which asks individuals about their experiences of psychosis (experiences like hearing voices, holding unusual beliefs, and paranoia) and recovery from these experiences. We think this research is important because to date only a few studies have asked people how they have coped personally with these kind of life experiences. We are hoping that this study may contribute to ideas about what is important and helpful in recovering from psychosis so that mental health services can learn if and how they can best fulfill a role in facilitating the recovery process.

You will be invited to explore with the researcher topics such as how you understood your psychotic experiences at the time, how you understand them now and the positive and negative aspects of such experiences. You will also be invited to discuss how you or your circumstances might have changed or not changed since having these experiences. You are free to raise any topic which you feel is important in the discussion and to refuse to discuss any topic which you do not wish to explore.

The study comprises one interview which lasts approximately one hour and one follow-up where you will be asked to comment briefly in writing on an initial analysis of the interview. The interview will be tape-recorded, written out in full by the researcher and then studied and compared with other people's accounts of their experiences, looking for similarities and differences in the experience of recovery. The tapes are strictly confidential and will be kept in locked conditions for the duration of the study. Quotations from the interviews may be used in subsequent reports or articles but will always remain anonymous and every effort will be made to protect confidentiality by changing any potentially identifying information. Although we believe it is unlikely,

should you feel distressed after the interview, please let the researcher know and she will arrange for you to be able to speak further with one of the clinicians involved in the study.

You will receive £10 for taking part which is a 'thank you' gesture from us.

You do not have to take part in this study if you do not want to. If you decide to take part, you may withdraw at any time without having to give a reason.

All proposals for research using human subjects are reviewed by an ethics committee before they can proceed. This proposal was reviewed by the Joint UCL/UCLH Committees on the Ethics of Human Research.



Sub-Department of Clinical Health Psychology

UNIVERSITY COLLEGE LONDON

GOWER STREET LONDON WC1E 6BT

APPENDIX 4- CONSENT FORM

General Enquiries: 020 7679 1897
Clinical Tutor Team: 020 7679 1258
Senior Secretary: 020 7679 5699
UCL Switchboard: 020 7679 2000
Code from overseas: +44 20
Fax: 020 7916 1989

CONFIDENTIAL

CONSENT FORM FOR VOLUNTEERS

Study Title: Recovery from psychosis

Researchers: Linda Clare, Sub-Dept of Clinical Health Psychology, UCL,
Gower St, London WC1E 6BT. **Tel:** 020 7679 1844

Dr Rufus May, Isle of Dogs CMHT, 3rd Floor, Jack Dash House,
2 Lawn Close, London E14 9YQ. **Tel:** 020 7364 6097

Hermione Thornhill, Sub- Dept of Clinical Health Psychology, UCL,
Gower St, London WC1E 6BT. **Tel:** 020 7679 7897

I have read the information sheet about this study

I have had the opportunity to ask questions and discuss this study

I have received satisfactory answers to all my questions

I have received enough information about this study

I have spoken to Hermione Thornhill about this study

I understand that I am free to withdraw from this study:

- at any time
- without giving a reason for withdrawing

I agree to take part in this study

Signed..... (Volunteer) Date

Signed..... (Hermione Thornhill, researcher). Date.....

APPENDIX 5 – INTERVIEW PROTOCOL

As you know, the conversation we are about to have is part of a study to try and help understand what enables people to recover from – or perhaps live meaningfully with – psychotic experiences.

1. Perhaps to begin with you could tell me something about yourself and what has brought you to the point of sitting here talking to me about ‘recovery’ ?

2. One thing I was wondering was about the word ‘recovery’. Is that a word you would use, or what would you talk about ? What does it mean to you ?
3.
 - a) Can you say something about what you feel you have ‘recovered from’ ?
 - b) Could you say a bit about what things were like when you were in hospital/ experiencing psychotic symptoms ?
 - c) How did you make sense of your experiences at the time ? How do you see it now? If your views have changed, can you describe how these changes developed ?
4. I wonder if you have thoughts about what sort of things led up to the psychosis? (Maybe external events, or things going on within you ? Did you have an idea of how things fitted together at the time ? Do you now ? Do you think this is important ?)
5. I wonder if you could say something about the kinds of things that you feel helped you in the ‘recovery process’ and the kinds of things which were not helpful, or maybe actively made things worse for you ? Are you aware whether there were certain things which were helpful at one point in time, which were no longer helpful at a different stage ?
6. When you look back, can you see particular points in time or events which you think marked some kind of crucial turning point or turning points for you ? What did these involve ? Particular people ? External events? Internal events eg changes of attitude/ belief ? (try to get a ‘story’ for each point)
7. How do you think other people’s views about psychosis have affected you ? Whose views have been important for you, either positively or negatively ?
8. How do you think your experience of psychosis has affected you as a person ? Do you think it has played an important part in your life or is irrelevant overall ? Do you think there have been both good and bad aspects to these experiences ? How might you have been different without them ? Have you valued these experiences ?
9. Can you think of any one or two things which you think might have helped you in your recovery process which you did not find at the time you needed them? Things, for example, which might help other people experiencing psychosis now ?

Thank you.

APPENDIX 6 – SAMPLE SECTION OF TRANSCRIPT

Sample section of interview transcript:

HT: So when you came out of hospital this last time that you describe and you sort of said to the doctors , 'Yes, everything...you've done a wonderful job. Everything's fine thank you very much.' And actually you still had...what ? heard voices, or whatever...but then you started this 'timesharing' ...

P2: Well, there was another factor. In the last hospital there was a Dr _____ in _____. And he knew how I sort of was paranoid about compulsory treatment. And he said, 'It's alright if you can manage to um stay sober for a whole month and you'll be under observation the whole time, we'll let you go without a pill...without um...neuroleptics'. And that was fine. That worked. You see other times you had the terrible sort of 'revolving door' where you go in, you're put on drugs, and it's terrible. Nothing can be worse than trying to work on drugs. On neuroleptics. It sort of...it really sort of...well it's a miserable thing...your mind can't cope but you feel you have to cope, and you're struggling. And trying to hold down a job in that thing and especially with everyone saying you've got to get everyone back to work and how marvellous it is. You just feel suicidal. It's the only time I really wanted to sort of...go. And in fact I nearly did. I nearly jumped off a high building. I was working for _____ at the time and they had this amazing high walkway from one building to the other. And I nearly went over several times.

HT: What's _____ ?

P2: _____...they make um central heating controls...thermostats and all that nonsense. And they made rather lousy computers.

HT: So you were trying to hold down this job while you were coming in and out of hospital?

P2: Oh no, it was when I'd come out I got this job. Yes, I think I came back. They allowed me back. Then I was fired shortly afterwards. But um...no, I'm getting so confused..that was...that was the time before last... After my first breakdown I went about 13 years before getting caught again. Then the next one, it was 4 years, then the next one it was 2 years...and then I really thought, you know, it was getting shorter and shorter...I'd be in for life. And I would have been, I'm sure. If I hadn't found this other way out.

HT: And do you think there were any other factors which helped you other than the 'timesharing'? Was there anything else that was important at that time ?

P2: Well, one thing they did take on was relaxation. And just relaxing...letting your mind go blank. And that's helped. Tensing the body and every time release your...But we got that fairly early on, I think after... I went to...The first one was _____ Hospital near _____. That was terrible. An old, walled...enormous, walled hospital. That was about 1950....probably about 1959 I think...no, 1950. And they had an outside reception ward, that was quite nice, but I kept going into the padded cell there. And then after that you were transferred to the Old Hospital and everyone said if you go in there, you never come out, you know. I had a tremendous fight trying to prevent my going in there. Because I'm quite big and you need quite a big nurse...male nurse to restrain me.

HT: Because you were desperate to get out...

P2: Well, I thought, once in I'd never be out.

HT: So do you think there was something about you as a very determined person, or with a fighting spirit which helped you to recover in the longer term?

P2: I think it was just luck, meeting this other man. I think there were a lot of people, probably like me, who were in there for life. And, you see, once I got better, I didn't say anything about it until I got...I

went...On my last recovery, I got the only job I could get was teaching in _____. And after that I went to _____ which is a sort of secondary education college and then I got a very good job [in broadcasting]. None of which...I mean I never told anything about my previous experience. So I couldn't tell them I'd been a nut. So then when I was retired, I really started writing up about it quite a bit. And um...because I'd had a terrible conscience, you see. How is it you've got so many people sort of stuck wherever I am [?]. Why haven't they met Fred who's told them how to get out of it? And so I've tried to write about it. But it doesn't seem to work. You know, the number of people who've heard about 'timesharing' is abysmally small. The number of people who try it even less.

[...]

P2: Well, for a long time, you see you had the voice going on and with the voice goes urges to do certain things and also to shout back at the voice. You can see people who talk to themselves all the time. And um you've got to suppress all that so you look, behave as if you're normal. Especially if you've been to a mental hospital and had compulsory treatment. You just realise you've got to do everything to avoid appearing a nutter. And it's a nightmare experience, that...And however clever you are you still...it gets you down.

HT: So lots of pressure comes, I suppose from the stigma attached to mental health problems...having to try and hide it...

P2: It's not so much the stigma. It's the fear of going back to hospital where you're going to get beaten up. And getting beaten up is terrible. I mean, when you get...It's alright, two male nurses can't cope...you can say 'No, I don't want an injection'. If they try, they will break their needle. I'm full of broken needles. And um, if you have a broken needle, you then have to go off to an outside hospital. You've got to get an x-ray to see if it's near an artery and they don't like it at all. So generally, minimum thing is you get...you don't go to the Institute of Psychiatry lectures, do you?

HT: I haven't been, no.

P2: Yes..um...three nurses is the worst. Three male nurses. I call it 'a gathering of three'. Each one would hold an arm and the other would slap and punch you until you agreed to be injected. And four or five is alright, because they would just pin you down, but it's the three is the menace... And going through that nightmare...and this happened every time you need an injection, you know...you're paranoid about having injections because you think they're trying to whittle your brain down...and when you go to a mental hospital you see in the next ward where there are people strapped to wheelchairs with their tongues popping in and out of their mouths and you say, 'That's what they're trying to turn me into'. Life's a nightmare with schizophrenia. It really is. And they don't realise it. One thing I'm trying to do [?] is to get rid of compulsory treatment. Because I mean that is so damaging, not only to the patient, but it's also so expensive, because especially in countries other than this the statistics on the recovery rate from schizophrenia is 50% within about 3 years. And if you've really been into hospital and been beaten up and sort of strapped down and injected, you're then probably paranoid for the rest of your life. And it's just such a stupid system. But in the olden days, they'd just take you in and say 'If you take these injections there's a good chance you'll be allowed out'. 'If you don't take the treatment, you'll be here until you recover. You might never recover. It's a chance you might take.'

HT: So if you could do it differently, what would you do, what would your suggestions be for...?

P2: I would say the next act has to abolish compulsory treatment to anyone who has the capacity that he doesn't want treatment. And if they could put that wording in, it would save a hell of a lot of bother.

HT: And then how would you judge 'having capacity'?

P2: Having capacity to say, just to say. If they say, 'Look, I don't want treatment', you have the capacity to say you don't want treatment. There are some people who come in who just don't know what you're talking about, they're so far gone. That you don't know whether they want it or not. Or they come in...that

debate about ECT. Where people come in in a coma and they're flat out. And they say the only way they can revive them is giving them ECT, if not they'll die. And people say, 'Ah yes, but you shouldn't give it to them'. And that's crazy, I think. If you are incapable of saying you don't want treatment...There's a snag here in that...this is a danger...you go in and you're high and they give you a knock out injection, and when you're completely knocked out and you can't think, they say, 'Now we're going to give you a course of treatment'. I remember one thing when I was absolutely blated (?) out...they said, 'Will you sign this form for ECT ?' And I said, 'What's ECT ?' And they said, 'It's Extra Clothes and Ties...and Towels'. And I said, 'Oh alright, I'll sign that.' Now that was silly. Now why did they get me to sign that. Because at that stage you didn't...you got it compulsorily anyway, you didn't need a signature. [pause]

HT: So would you say that people should be allowed to be retained in a hospital if they are a risk to themselves or other people but they shouldn't be forced to have treatment...would that be...?

P2: That's right. If they're a risk to themselves and others you can contain them.

APPENDIX 7

Interpretative Phenomenological Analysis: Stages 1 and 2 of analysis

Extract from George's interview: pp.20-22

Initial notes in left margin (Stage 1)

Suppress all that	P2: Well, for a long time, you see you had the voice going on and with the voice goes urges to do certain things and also to shout back at the voice. You can see people who talk to themselves all the time. And um you've got to suppress all that so you look, behave as if you're normal. Especially if you've been to a mental hospital and had compulsory treatment. You just realise you've got to do everything to avoid appearing a nutter. And it's a nightmare experience, that...And however clever you are you still...it gets you down.
Look, behave as if you're normal	
Compulsory treatment	
Do everything to avoid appearing a nutter	
A nightmare experience	
It gets you down	

Themes in right margin (Stage 2)

P2: Well, for a long time, you see you had the voice going on and with the voice goes urges to do certain things and also to shout back at the voice. You can see people who talk to themselves all the time. And um you've got to suppress all that so you look, behave as if you're normal. Especially if you've been to a mental hospital and had compulsory treatment. You just realise you've got to do everything to avoid appearing a nutter. And it's a nightmare experience, that...And however clever you are you still...it gets you down.	Looking normal Compulsion Looking normal nightmare
---	---

Example 2: second extract from George's interview

Notes in left margin (Stage 1)

Fear of going back to hospital	HT: So lots of pressure comes, I suppose from the stigma attached to mental health problems...having to try and hide it... P2: It's not so much the stigma. It's the fear of going back to hospital where you're going to get beaten up. And getting beaten up is terrible. I mean, when you get...It's alright, two male nurses can't cope...you can say 'No, I don't want an injection'. If they try, they will break their needle. I'm full of broken needles. And um, if you have a broken needle, you then have to go off to an outside hospital. You've got to get an x-ray to see if it's near an artery and they don't like it at all. So generally, minimum thing is you get...you don't go to the Institute of Psychiatry lectures, do you?
Getting beaten up	
You can say 'no'	
I'm full of broken needles	

Themes in right margin (Stage 2)

HT: So lots of pressure comes, I suppose from the stigma attached to mental health problems...having to try and hide it... P2: It's not so much the stigma. It's the fear of going back to hospital where you're going to get beaten up. And getting beaten up is terrible. I mean, when you get...It's alright, two male nurses can't cope...you can say 'No, I don't want an injection'. If they try, they will break their needle. I'm full of broken needles. And um, if you have a broken needle, you then have to go off to an outside hospital. You've got to get an x-ray to see if it's near an artery and they don't like it at all. So generally, minimum thing is you get...you don't go to the Institute of Psychiatry lectures, do you?	fear violence/ getting beaten up 'saying no' damage
--	--

APPENDIX 8

Interpretative Phenomenological Analysis (Stage 3): Analysis of themes within interviews

Example 1: Peter

'simple but complex'

explaining causes of psychosis- biological, psychological

explaining recovery – simple and complex

explaining 'the human organism' – simple and complex

'it's a crazy system'- 'Beating up' v 'tea and sympathy'

'the concept of healing'

Understanding

Advances in medicine

Not being understood

The 'joke' of diagnosis

Being treated as a criminal

Exclusion

Not being wanted

Lying and secrecy v openness and truth

Deceit – by patient

Deceit – by clinician

Deceit – by police

'Changing the story'

Openness/ telling the story

Example 2: George

Power- control & obedience v disobedience & punishment

A tremendous fight

Disobeying authority

Threat of punishment

Guilt

Holding on/ Control

The Fear Element

'Just because I'm paranoid doesn't mean they're not out to get me'

Integration

Balance/ cooperation

Communication

Deceit v openness

Pretending to doctors

Secrecy

Partial truths

Keeping quiet (at work, in public)

Deceit of medical staff

Deceit in personal relationships

Openness by 'patients'

Openness by staff

Self and other

Telling the difference

Achieving integration

Life's a nightmare with schizophrenia

Thoughts of suicide

Losing hope

Damage

Handicap

Trauma

Knowledge/ understanding

Useless knowledge

Resistance to new knowledge

Learning experiences

Importance of thinking

Life after recovery

More alive than before

Integration

Rights

Political/ campaigning for change

Context of recovery

Rights/choice/ control

Dreaming

'pie in the sky'

Luck

'the baked beans effect'

Example 3: Mary

Managing on my own
'you're the expert'

Crime and punishment

Being cared for in hospital v not being cared for

Not being understood

'Paradigm shift'
culture shock
identity crisis

Exclusion

Not being accepted any more

Trying to make sense

Fear

Fear of relapse
Others' fear of psychosis
Fear/ paranoia

Survival and recovery

Helpful relationships v unhelpful relationships

Helpful organisations v unhelpful organisations

Life on drugs

Turning points

Reaching a dead end

Education/ learning/ growth

Human rights/ activism

Identity
'seeing yourself in a different way'
'being a full person'

Deceit

Luck

'It would be nice if...'

APPENDIX 9

Interpretative Phenomenological Analysis (Stage 3, contd.): Clustering themes across interviews

Below is a comprehensive list of themes from all the interviews, showing how they clustered in the final analysis

Cluster A Making sense: How mad was I really?

Theme 1: Going back

Int 6 – Abuse/ exploitation
Connection between past and present

Int 7 – Trying to make sense
Going back
Abuse

Int 11- Making sense
Abuse
Loss

Int 12- Abuse
Past reality...present reality

Theme 2: Living in fear

Int 2- ‘the fear element’
‘just because I’m paranoid doesn’t mean they’re not out to get me’

Int 3- Fear
Fear of relapse
Others’ fear of psychosis
Fear/ paranoia

Int 4- Fear

Int 5- Persecution

Int 8- Fear
Anxiety

Alienation

Int 13- paranoia...reality

Int 15- Fear- 'scared by everybody, really'
Paranoia...reality?

Theme 3: Looking at the experience from different angles and seeing the self in new ways

Int 2- Life's a nightmare with schizophrenia
Thoughts of suicide
Losing hope
Damage
Handicap
Trauma
Knowledge/ understanding
Useless knowledge
Resistance to new knowledge
Learning experiences
Importance of thinking

Int3- Managing on my own
'you're the expert'
Trying to make sense
Reaching a dead end
Identity
'seeing yourself in a different way'
'being a full person'

Int 4- Systems of belief
Healing
Labeling
Illness or not?
Looking at things in different ways

Seeing things from others' viewpoints
Awareness

Int 5- Learning
Understanding
Being aware
Valuing experiences

Int 6- Illness versus a certain kind of experience/insight/ understanding

Int 7- Valuing it
Getting perspective, seeing different viewpoints

Int 8 – Naming things differently
Having different explanations, other viewpoints

Int 9 - How you view illness
Identity, naming

Int 10- Being positive versus being negative

Int 11- Calling things by different names
Different interpretations
Identity shift
Making connections
'being a victim'

Int 12- Imposition of one way of thinking
Different labels
Many aspects
'sane in the middle of it all'

Int 13- 'for the scrapheap' versus 'my old self'
Staying positive

Int 14- Thinking different things about the experience
Different ways of talking about it

Int 15- Changing perspective within a delusion
Finding my identity

Theme 4: Different realities/ different aspects of being human

Int 1- ‘simple but complex’
explaining causes of psychosis- biological, psychological
explaining recovery – simple and complex
explaining ‘the human organism’ – simple and complex

Int 3- ‘Paradigm shift’
‘culture shock’
‘identity crisis’

Int 4- Finding the person that I really was
Feeling versus not feeling
What is ‘normal’?

Int 5- Expressing feelings
Fear of closeness and separation

Int 6 – Emotional isolation versus understanding , connecting with people
Drowning in lack of me versus becoming more myself

Int 7- Highs and lows as part of being human

Int 8- Different realities
Protection
Becoming different/ growing

Int 9- Living a normal life

Int 11- Normal experience?
Guilt versus innocence

Int 12- Being treated as ‘unique...whole human beings’
Becoming a whole human being
Different aspects of being human

Int 14- ‘explosion of emotion’
‘human problems’
finding my real self

Int 15- juggling self between cultures

Cluster B ‘Beating up’ versus ‘tea and sympathy’: responses to psychosis

Theme 5: ‘Knocking yourself’ versus ‘Looking at things/ liking yourself’

Int 2- Integration
Balance/ cooperation

Int 3- Education/ learning/ growth

Int 4- Wanting it to end
Acceptance
Taking care of self
Choice
Control

Int 5- Choice
Understanding

Int 7- Taking control
Looking at things/ liking yourself

Int 8- Control
Responsibility
Being embattled versus letting go
Learning to look after myself

Int 9 Everyone is different
‘knocking yourself’
taking control

Int 11 Being able to think things through
Control
Responsibility
Exploring and dealing with things
Choice

Int 12 Knowing your experiences relate to you

Int 13 ‘bad days’ and ‘good days’

Int 14 responsibility

Trusting own feelings

Int 15 acceptance
'it's OK to be the way I am'

Theme 6: 'It is not actually the breakdowns which are the problem - it is the ways you are treated which are the problems'

Int1- Exclusion
Not being wanted

Int2- Communication

Int 3- Exclusion
Not being accepted any more
Helpful relationships v unhelpful relationships

Int 4- Shame
Others' expectations
Abandonment
Support
Affirmation

Int 5- making friends
Support

Int 6- abuse/ exploitation
People 'don't want to know'
Ending exploitation

Int 7- Breaking off relationships
Support

Int 8- Importance of being with people
Being looked after

Int 10- being considered 'a deviant'
Others not wanting to know

Int 11- guides/ map-makers

Support

Being accepted

Int 12- being taken seriously

Sympathy

Int 13- harrassment

Exclusion

hopeless messages versus hopeful messages

Theme 7: It's a crazy system

Int 1- 'the concept of healing'

Understanding

Advances in medicine

Not being understood

The 'joke' of diagnosis

Being treated as a criminal

Int 2- Power: conflict between control & obedience v disobedience & punishment

A tremendous fight

Disobeying authority

Threat of punishment

Guilt

Holding on/ Control

Int 3- Crime and punishment

Being cared for in hospital v not being cared for

Not being understood

Helpful organisations v unhelpful organisations

Int 4- care in hospital

Being understood

Control

Int 5- care versus neglect and abuse

A nice way of being with someone

Imprisonment

Threats/ violence

Safety

Harassment

Int 6- responsibility/ protection versus being unsupported, uncared for
Healing versus 'torture to the point of conformity'

Int 7- being supported versus not being supported

Int 8- left to take responsibility

Int 10- Devastation

Brutal treatment

Compulsion

Lack of entitlements

Punishment

Denial of rights and privileges

Being treated like a prisoner

Int 11- Compliance versus resistance

Getting into a battle

System says 'You have no ability left'

'wrong tools for the job'

compulsion versus choice/ being able to make decisions

Int 12- being threatened

Compulsion

'dehumanising process'

being understood versus not being understood

violence/ inner violence

Int 13- Intrusion/ violence

Int 14- Being ignored versus being taken seriously

Hopelessness versus hopefulness

Int 15- 'soap opera'

Cluster C Telling stories

Theme 8: Deception and silence versus honesty and openness

Int 1- Lying and secrecy versus openness and truth

Int 2- Deceit versus openness

Int 3- Deceit

Int 5- Being believed

Int 7- Talking openly/ breaking taboos

 Hiding/ deceit versus openness

 Telling your story

Int 8- Being closed versus being open/ sharing the experience

Int 10- Dishonesty/ lack of information

Int 1- 'Put a lid on it'

Int 13- Openness versus deceit

Int 14- 'taboo'

 'coming out'

Int 15- Lying versus opening up

Cluster D – Working out where you stand

Theme 9: Human rights and responsibilities

Int 2- Political/ campaigning for change

 Context of recovery

 Rights/choice/ control

Int 3- Human rights/ activism

Int 4- society as ill/ mad/ unhealthy

Int 5- using the illness as an excuse

Int 7- 'society must be changed'

Int 9- campaigning
'educating society'

Int 10- exclusion/ alienation versus rights, role in society

Int 11- 'using biology to cover up society'

Rights
The law

Int 12- the right to be believed

The right to be treated as a 'sentient human being'

APPENDIX 10

Interpretative Phenomenological Analysis: Master List of Themes

Cluster A: Making sense: How mad was I really?

Theme 1: Going back

Theme 2: Living in Fear

*Theme 3: Looking at the experience from different angles and seeing the self in
new ways*

Theme 4: Different realities/ different aspects of being human

Cluster B: ‘Beating up’ versus ‘tea and sympathy’: responses to psychosis

Theme 5: ‘Knocking yourself’ versus ‘Looking at things/ liking yourself’

*Theme 6: ‘It is not actually the breakdowns which are the problem – it is the ways
you are treated which are the problems’*

Theme 7: ‘it’s a crazy system’

Cluster C: Telling stories

Theme 8: Deception and silence versus honesty and openness

Cluster D: Working out where you stand

Theme 9: Human rights and responsibilities

APPENDIX 11

Interpretative Phenomenological Analysis: showing initial themes and recategorization according to master list

Extracts from George's interview: pp.20-22

Initial Themes

<p>P2: Well, for a long time, you see you had the voice going on and with the voice goes urges to do certain things and also to shout back at the voice. You can see people who talk to themselves all the time. And um you've got to suppress all that so you look, behave as if you're normal. Especially if you've been to a mental hospital and had compulsory treatment. You just realise you've got to do everything to avoid appearing a nutter. And it's a nightmare experience, that...And however clever you are you still...it gets you down.</p>	<p>Looking normal Compulsion Looking normal nightmare</p>
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Recategorization

<p>Well, for a long time, you see you had the voice going on and with the voice goes urges to do certain things and also to shout back at the voice. You can see people who talk to themselves all the time. And um you've got to suppress all that so you look, behave as if you're normal. Especially if you've been to a mental hospital and had compulsory treatment. You just realise you've got to do everything to avoid appearing a nutter. And it's a nightmare experience, that...And however clever you are you still...it gets you down</p>	<p>Deception and silence versus honesty and openness (Cluster: Telling stories)</p>
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Example 2

Initial themes

<p>HT: So lots of pressure comes, I suppose from the stigma attached to mental health problems...having to try and hide it...</p> <p>P2: It's not so much the stigma. It's the fear of going back to hospital where you're going to get beaten up. And getting beaten up is terrible. I mean, when you get...It's alright, two male nurses can't cope...you can say 'No, I don't want an injection'. If they try, they will break their needle. I'm full of broken needles. And um, if you have a broken needle, you then have to go off to an outside hospital. You've got to get an x-ray to see if it's near an artery and they don't like it at all. So generally, minimum thing is you get...you don't go to the Institute of Psychiatry lectures, do you?</p>	<p>Fear</p> <p>violence/ getting beaten up</p> <p>'saying no'</p> <p>damage</p>
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Recategorization

<p>So lots of pressure comes, I suppose from the stigma attached to mental health problems...having to try and hide it...</p> <p>P2: It's not so much the stigma. It's the fear of going back to hospital where you're going to get beaten up. And getting beaten up is terrible. I mean, when you get...It's alright, two male nurses can't cope...you can say 'No, I don't want an injection'. If they try, they will break their needle. I'm full of broken needles. And um, if you have a broken needle, you then have to go off to an outside hospital. You've got to get an x-ray to see if it's near an artery and they don't like it at all. So generally, minimum thing is you get...you don't go to the Institute of Psychiatry lectures, do you</p>	<p>'it's a crazy system'</p> <p>(Cluster: 'Beating up' versus 'tea and sympathy': responses to psychosis)</p>
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APPENDIX 12

Interpretative phenomenological analysis: complete set of quotations for Cluster A

Cluster A- Making sense: How mad was I really?

Theme 1: Going back

'I was sexually abused between the ages of about 3 and 6, I would say. By older children, really [...] But that leads on to being...sexually disinhibited when manic...a classic manic thing and if you're put in a vulnerable state in a mixed ward with patients...male patients, ex-patients, trying to cruise the ward to find the next vulnerable, psychotic female to prey on [...] then you're going to get taken advantage of [...] ; 'when I slowly come to myself again I realise that I'm in some sort of bizarre sexual relationship with this guy who is attempting to have intercourse with me at the top of the fire-escape. [...] and he's saying 'Drop your pants and bend over' and I'm going, 'Oh, OK, how far?' You know...because I have no real...I...I suppose I'm back in that bicycle shed being told to drop my pants, you know. You do what you're told by someone that's older than you, I don't know. I don't understand it. But there's something very deeply connected between the abuse that I suffered as a young child and the exploitation that I was put through in the hospital' (Interview 6: p16)

Well, I suppose what it was, was in my psychotic episodes the really...the one theme was about my own child abuse and when I was younger...and in my psychosis I always went back like a detective...I was almost like a detective...trying to work out the riddles, the clues as to what happened. (Interview 7 p2)

'I think anything to do with sort of childhood experiences are quite...it's quite hard to put words to them anyway because they're so based on emotions. And also as a child you know you're not...there's a tendency for us to think of children in the sense of like an adult mind because we're always looking back at our childhoods. But it was I suppose trying to find those emotions back rather than the words...or the experiences, even. Because I think what I was caught up in was trying to sort of pinpoint every detail as to what did happen to me as a child and I've since realised there is no way that I'm ever able to do that' (Interview 7 p6)

'and then unfortunately within the church I was abused and when I heard voices I heard the voice of my abuser, who was a catholic priest.' (Interview 11 p4)

'there was the abuse, there was my...the death of my first partner which really drove me from ____ and that's why I ended up in England. But the whole thing of hearing those voices of those two people now for me is clearly rooted in my inability to resolve those issues' (Interview 11: p5)

'Where if we look at abuse...I mean abuse is so prevalent in psychosis, especially sex abuse. And yet people cannot, for some strange reason, put cause and effect together.' (Interview 11: p5)

'I was hearing voices that were meaningful within my life experience. And people don't look at life-experience enough.' (Interview 11: p6)

'I was experiencing being raped, and being sexually abused and being [...] but there wasn't anybody there to say...they just said 'paranoid schizophrenia' which means, I was imagining it. But there wasn't anybody there who said to me, 'Well, have you in your childhood ever experienced these things? That might explain why at this point in time you're experiencing things happening like something outside of you...that you're being raped by something outside of you' or whatever' (Interview 12: p7)

'my therapist, my GP, and the consultant who I ended up with all happened to link in together and they talked to each other. [...] and my therapist said, this is the kind of thing, talked about my child-abuse and he said 'Well' you know 'Depressive psychosis as a result of childhood trauma' (Interview 12: p9)

'I guess the best I can explain it is to say that I believe in karma [...] what karma says is you sow what you reap, I mean you reap what you sow, and you also, you sow in the current moment, and so depending on how you sow, you will reap in the future. And also, what that does, it gives me a cyclical understanding of experience in my life.' (Interview 12: p16)

Theme 2: Living in fear

'if you believe that's it's a conspiracy against you, which you do, and people are using telepathic force, and what they want to do is get you back into mental hospital where you would have your...more of your brain taken off to reduce your awareness. I mean...that's a total nightmare.' (Interview 2:p6)

'the person daren't let it out otherwise they're going to get clobbered' (Interview 2: p18)

'the fear element had gone' (Interview 2: p16)

'fear of going back into hospital' (Interview 2: p21)

'getting beaten up is terrible' (Interview 2: p21)

'if you've really been to hospital and been beaten up and sort of strapped down and injected, then you're probably paranoid for the rest of your life' (Interview 2: p22)

'That's what they're trying to turn me into ' (p22)

'you're paranoid about having injections because you think they're trying to whittle your brain down' (p22)

'the marriage was very, very difficult... with abuse and violence...not much actual violence and certainly not you know breaking arms and things but there was a certain amount of physical violence and there was lots of other...verbal and psychological abuse [...]when I look back on how I was then I can see how paranoid I was...but I had him telling me I was useless all the time [...] I'd go out to hang the washing out and he'd follow behind me and tell me I was hanging the washing up wrong' (Interview 3: p8-9)

'but while I was at home I suddenly felt...very...really fearful of my mother...absolutely...very fearful...and I thought there was a look of evil in her face...and I wouldn't be left alone in the house...[...] I thought she was going to harm me or kill me or something like that...' (Interview 4: p2)

'she was very, very domineering and although she was a loving mother in a lot of ways, she was also, I was afraid of her, I cow-towed to her and instead of 'How do I feel today?' it was 'How is Mum feeling today? What can I do to make...if Mum's not feeling too good, what can I say to make the situation different? [...] I used to think my mother could possibly even read my thoughts' (Interview 4: p9/10)

'I always remember one of the things that frightened me the most [...] especially with my family, they just ran around looking really sort of frightened of what I was going through. So frightened...the fear that was on their faces. And the more they were fearful like that, the more afraid I felt, and it was just like...no sort of ground to the world and that. And um...and I think things reached a real sort of pitch. I forgot how long it was after that course before I ended up in hospital in the end. It was probably a matter of weeks' (Interview 8 p5)

'When I look back on it I think there was a lot of stuff about protecting myself from them. So the more I could be strange...I mean I was feeling very strange, but I would just kind of act strange because it was a way of keeping them at a distance, and I couldn't trust anything' (p7)

'I felt a long time feeling kind of depressed and paranoid and anxious, really, really anxious.' (p9)

'I had a bad relationship with my Dad that I'd grown up with in some ways. And I used to...he used to sort of you know kind of really frighten me and he would punch me and hit me and, you know, smacking me and stuff, but I...it really terrified me. And I'd run away. And I'd run away and hide in the woods and that. And I'd wait until it had all gone before I came back. And it was something like that in a way.' (p17)

'All I can say is that the experience of...and having been abused later on, not just in childhood, but I've experienced assault on the grounds of being a woman and being black, of being an Asian woman [...] I've been assaulted on the street and in the underground, because of being a woman, because of not being white, and all these things kind of add up.' (Interview 12:p17)

'I thought M15, M16 was after me. So when these great, big burly policemen tried to get me from my house, I just thought, 'Well, it's true [...] So they had to come and knock my front door down [...] They threw me in the back of a meat-wagon.' (Interview 13: p1)

'I just thought it was M15/M16. They were spies watching me. And the neighbours were the spies. And everybody that moved in was a new spy. And the only reason they were moving in was to keep an eye on me. [...] Crazy, absolutely crazy. Awful illness. Frightening illness. Absolutely frightening illness. Because where do you go? (Interview 13: p20)

'Just after I'd qualified and I was working for _____. So I was doing interviews. And I actually went to one interview where a girl was depressed and hiding under the covers and stuff and it was a bit like what I'd gone through while I was a student. So um....I thought it was a set-up. Not thinking that it is quite common that people go through this. But it's only now I'm sort of thinking that way. But at the time I thought, 'Well, they know something. They know that I've had this and they've set this case up. And I didn't think it was a real home visit and they'd given me this referral. And the TV was a covered sheet and I thought it was some sort of recording device and I was really unaware of the interview situation but just looking at the environment and feeling really scared and [?] by it' (Interview 15: p10/11)

Theme 3: Looking at the experience from different angles and seeing the self in new ways

‘individuals [...] are working with the police now to prove that I am potentially dangerous to society [but] I have never been able to fight [...] And I can never be potentially dangerous’ (Interview 1: p6)

‘I was a complete social arsehole, really. Which has now changed dramatically because [I] started going to counselling’ (p7)

‘it is the instigation of a healing process’ (p10)

‘Hashimoto’s disease [...] the appreciation of psychotic events with thyroid disturbance [...] in the last five or six years I’ve been working in America to do the research which is light years ahead of us...’ (p20/21)

‘if you can realise eventually that it’s the other side of your own brain and then you can start talking to it, then...you’ve got to let it in.’ (Interview 2: p4)

‘If you believe that it’s a conspiracy against you [...] that’s a total nightmare’ (p6)

‘the Chinese symbol for ‘crisis’...It’s ‘opportunity’ and ‘danger’ put together. It’s the two [...] because everything’s in flux then’ (Interview 3: p30)

‘not necessarily a bad thing’ (p22)

‘you can’t be sensitive without being vulnerable’ (p22)

‘instead of saying, ‘You’re in a psychotic state’ you can say, you’re in a ‘state of prophecy’ or ‘you’re in an imaginative state’, ‘you’re in a poetic state’ (p26)

‘it was quite difficult when I first came out of hospital. It was like this sort of you know...everything came together...I’d be up all night...writing and writing...Just to handle all this new stuff that was coming in’
‘Just making sense of it all in a way that I hadn’t done before’ (p20)

‘so you can see yourself in this different way – as a victim of an unjust system’ (p19)

[my friend has] ‘decided that she’s a schizophrenic’ ; ‘had lots of ups and downs’ ‘she’s really nice, she’s a very creative person, she’s a poet’ but ‘she’s not fully the person I know’ (p28)

‘I thought God was in touch with me’ (Interview 4: p3)

‘and there it was just some trick of my mind and I was just ill’ (p3)

‘I thought God was giving me all this insight because I couldn’t see how I was understanding these things other than...God. It was coming from my unconscious, or whatever, but in the belief system I had, this was God again getting in touch with me.’ (p11)

‘I was talking about Christian and non-Christian families...where they would talk about functional and dysfunctional...but I was saying the same thing’ (p12)

'it was my belief system if you like to do with Christianity and God being in touch with me and stuff that I suppose you could put into the label 'psychotic' ' (p12)

'You can call it something – if you want, call it mental illness. But when I've been a nursing assistant I can't identify with a lot of the people I see in there at all. I mean, they're not on some 'getting well curve' ...was I really mentally ill like them? (p28/29)

'In fact, I didn't think I was ill at all because I thought, 'How can I be understanding all this stuff and so clued in and so sort of on the ball to all those things that were happening, if I was ill?' (p13)

'I just said, 'I'm not ill'. I'm only here for a rest. I kept saying that. And I would always get the answer, 'People don't come to mental hospitals for a rest.' (p13)

'a dramatic healing process that was happening in the brain' (p16)

'I think it was the psychosis that really sort of made me look at things just there...I had no choice but to look at them. And having looked at them I feel a lot more...calmer about myself and...probably that I actually like myself now as well which...which I think is quite rare, to be honest with you' (Interview 7:p7)

'I know a lot of people who find it quite difficult to look at psychosis in this way [...] But [...] I cherish it. I value it, basically. And I would not wish not to have had it.' (p7)

'The mania wasn't disturbing. The mania was fantastic, really. It was exhilarating. You were suddenly someone really powerful [...] So the psychosis in itself was actually quite exhilarating and I'm really glad to have gone through that experience' (p8)

'it [...] brought home how much of our brains we don't use' (p8)

'people can always look back and say, 'Oh but you were mad then' but you know I was making some sense as well. It wasn't all complete nonsense.' (p8)

'I started sort of believing in myself a bit because other people were sort of treating me as if I was the same as them' (p12)

'therapy [...] gave me the space to...reflect on my life and to sort of think about the themes [...] the exercise that really worked for me was the 'empty chair' exercise [...] it gave me a bit more of a sort of overall perspective [...] And just realising there were different parts of myself gave me encouragement' (p15)

'it made me sort of be objective, sort of go...look down and see...the whole thing...rather than just being caught up with the emotion and not knowing how to deal with it' (p16)

'And I suppose what I did it...I did cultural studies and I really focused on madness as a topic. So I started intellectualizing it which really helped. You know, all my stuff was on women and madness and you know just getting to grips with societal factors and stuff and environmental issues. It took...it took me away from it being just emotionally for me and made me realise that this was fairly common in a way and that really helped.' (p17)

'there was something for me of sort of like thinking...there was a feeling of 'you're playing with fire now' and I think it kind of dawned on me that I could get [...] there was a sort of a taking responsibility in some way [...] Like 'if you keep doing this you're going to get into real trouble...you're already in real trouble.' (Interview 8:p9)

'I think it [therapy] gave me tools and different ways of thinking and like I say, different ways of inhabiting...my life...or states of mind and stuff and reflecting on them.' (p13)

'to me the whole sort of thing...it's kind of actually exploring completely...you know becoming kind of quite different...growing...and going into completely different places' (p13)

'in some ways that psychotic kind of period [...] there was lots of stuff I loved about it' (p13)

'I understand it as a kind of protection in lots of ways [...] manic defence, or whatever. [...] I mean things are touching you, but you're not letting them touch you, and reflect on, and they hurt...as soon as it starts hurting you're rushing around to try and change it all around' (p13)

'you must accept that illness, But you must accept it in a way that it's only an obstacle' (Interview9: p2)

'People have got to take control of the illness. Not let the illness control you.' (p16)

'because you can't make sense, you become unable to function in society. And so my starting point was really that for me illness wasn't about the voices or about the psychosis, illness was about the inability to function, and that's the definition of illness I hold now.' (Interview 10:p1)

'In the ___ hospital they gave me the diagnosis of um...schizophrenia which I carried for the next ten, eleven years, really, when ___ changed it for me to 'post-traumatic stress disorder, now resolved' (p2)

'I became seen as extremely challenging to the system because I wouldn't take medication [...] And the sad thing was it wasn't until I gave in almost, that they treated me any differently. It was almost as if you had to...accept that you were ill according to their interpretation of illness before they would say there was any chance of you even slightly getting better' (p2)

'coming from a position in Thatcher's era from being um...I suppose the ideal of what Thatcher thought enterprise was [...] and to suddenly stop being that and become this large, dangerous, schizophrenic Scotsman was um...quite a shift' (p3)

'people mistake madness with intelligence [...] so if you're mad you have no intellect. That's limited. I have never lost my intellect. I have never lost my ability to think. And it was almost as if what the system said is, 'You have no ability left.' (p3)

'I think voices for me [...] has become almost an external way of having an internal dialogue. Probably because I'm too frightened to see what's in my head sometimes.' (p5)

'if we look at abuse...I mean, abuse is so prevalent in psychosis, especially sexual abuse. And yet people cannot, for some strange reason, put cause and effect together.' (p5)

'the first thing I discovered was that I was sane in the middle of it all' (Interview 12:p20)

'the psychosis is gone but it's the bringing your life together afterwards is a struggle. It takes a lot of self-belief.' (Interview13:p7)

'They don't believe you can lead a fulfilling life again. And at the moment I am still fighting, I believe I can have an 8 hour a day job, I believe I can keep well, because I've had a year of no psychosis, so that's something positive, isn't it?' (p8)

'I consider myself to be my old self before I was ill. Except I haven't got a job.' (p9)

'It seems that if you have experienced psychosis that your life should end and you end up this vegetable that just sits in drop-ins and you don't do anything' (p15)

'You need positive people in your profession. You don't need people who say, 'She'll never recover, she's for the scrapheap, she'll never work again, she's on medication for the rest of her life.' (p24)

'when I found myself in psychiatric hospital my feelings were totally dominated with fear of...what I felt as like ending up like my father...a life-long psychiatric patient' (Interview 14:p2)

'Because I was taking medication, I felt they had made me into...I got obsessed with feeling I was now a chronic psychiatric patient, as my father had been all his life. [...] I could hardly move, I was so depressed.' (p5)

'they started doing what I had been asking for, which was looking at my family. And listening to what I said about myself. And really validating what I had been demanding.' (p6)

'In the first ward I had said things like, 'All you can do is say I'm schizophrenic and give me drugs.' (p6)

'I felt very profoundly that there were other ways of looking at it than the 'medical model'. So um...the group-therapy ward...I had an opportunity to examine my past for the first time and...and it was as if it brought together the different strands of things that had caused me anguish in the first place.' (Interview 14 p7)

'Just trust your own feelings about it and don't allow them to tell you what...what you are' (p13)

'You are not telling me that I am...ill. Or that I am ill forever. I am just not. I am not going to be made to feel that, you know.' (p13)

'It was just time...if getting myself out of the flat...and maybe feeling as if I was being followed and thinking that things had been set up but...dealing with it. Really, sticking my neck out and thinking, 'I can cope, I can cope. It'll be fine. Because nothing's going to happen to me. Because everyone's watching me so I'm not going to be run over.' (Interview 15:p25)

Theme 4: Different realities/ different aspects of being human

'I would describe life as a very strong rope which had many different strands...and a breakdown is when all the strands are frayed and snapped' (Interview 1: p1/2)

'a thyroid deficiency' (Interview 1: p2)

'exhaustions' (p4)

'dehydration...diabetic comas...lack of glucose...overheating...salt' (p20)

'conscious is exhausted [...] living in a dream' (p9)

'it's very simple bit it's extremely complex' (p18)

'their inability to appreciate my thyroid' (p17)

'How is it that in psychiatry you cannot express pain?' (p26)

'they're so narrow-minded because they think you know there's just, you know, there's 'a normal state of mind' for a start, and then all the others are 'abnormal'. And that's just so stupid' (Interview 3: p25)

'you can't just say somebody's psychotic and somebody's...because everybody's different. And everybody's got different problems and they're dealing with it in different ways...' (Interview 3: pp25/26)

'He [the psychiatrist] thought I was a very frightened person' (Interview 4: p15)

'I was angry' (p11)

'this was it all coming out, to me, to find the person, the little person, the person that I really was, crushed, and I was going to find that person again and become well' (p11)

'We don't like giving people labels' (p12)

'I put it into an 'ill' category. This is just the way I think when I'm ill.' (p14)

'you were allowed to cry, be angry' (p14)

'it was as if when I was at home as a child I had *not felt* ...to get by. It was my way of coping. So I just didn't feel. But all of it, I didn't know it wasn't normal' (p25)

'I needed affirmation' (p28)

'the majority of people, they're still as psychologically damaged, if you like, they still have this disease, if you like, but it comes out not as psychological illness but it comes out as cancer or these things' (p30)

'don't we all need healing' (p30)

'I read a book when I was in America that the curve from functional to dysfunctional...that the hump is in the middle. It's not like there's just a few families dysfunctional, there's only a few families that are really functional. And of course now I'm reading books that are saying it's wider than that...it's the society itself [...] And the way, the whole thing isn't conducive to human well-being' (p30/31)

'I had epilepsy since I was 18 and I think something in that makes my unconscious mind a bit more available' (Interview 4: p7)

'I find it difficult to acknowledge or express feelings...particularly anger...and sad fe...those kind of feelings, that, yeh, that kind of thing. And I think maybe sometimes I have strong emotions and I can't deal with them and they come out in things like voices, or whatever.' (p7)

'I also find it difficult to be close to people .Or did.' (p7)

'when I've been on a higher dose [of antipsychotics] [...] it's not the...you know in the list of side-effects in the BNF, but I find I'm less confident and less assertive on higher doses of any anti-psychotic medication and it also affects my motivation when I'm on higher doses. You know I don't want to do things...I have absolutely no sense of urgency [...] and just feeling quite removed. Not feeling [...] really sad or really happy or anything. And that sort of thing is not really taken into account, I think.' (p17)

' It isn't possible to know in a sort of provable, scientific way. Clearly, that is completely the opposite of what anything like this could ever be. And that part of the internal battle for a long, long, time for the last ten years or so, every time I've come out of a state of psychosis I've just totally pushed myself away from

anything 'New Age' or you know 'holistic medicine' or...because it's part, it's part of what I am when I'm psychotic.'

(Interview 6: p11)

'But the...as far as understanding the relevance and the truth of spiritual connections and telepathic experiences or um...enlightenment or...expanded awareness or...any of those sorts of things...it's taken me...you know three years of being away from hospital, two years of being drug-free and you know a good four months I've actually, of being able to kind of be... a small part of who I am, you know. It's been a really long, long journey.'(p12)

'And part of that has been to do with diet and meditation and having a clean body, you know, without cigarettes, without tea and coffee, without drugs without...um...chemicals in processed foods. Natural foods that I make from vegetables and fish and [...] I truly believe that people who are so-called 'mentally ill' are people who are just being poisoned by society...poisoned by the pressure, poisoned by the food, they're poisoned by the poison...the nicotine and the cannabis and the alcohol...' (p13)

'I mean hospital, psychiatric hospitals [...] no-one there wants any expression of emotions. That is the last thing. And of course you've got a whole ward full of very angry, very frightened, very hurt, very upset, emotional people. And they are not allowed to express any of that. Hence all the drugs.' (p35)

'what we call psychosis is a spiritual journey and if it was set in the right context it could be really beneficial for all concerned, but it's not set in the right context. We're not allowed a context in which to experience our psychosis.' (p36)

'Although, you know, I see them now as delusions in the sense that they weren't reality as everyone else saw reality at the time, but I still sort of believe that they were reality for me.' (Interview 7:p6)

'An inner reality that was based on the experiences that I'd had previously' (p7)

'I feel more... that my personality has come back, whereas on lithium I just felt flat. I think it was a big step to come off medication and it's something that has changed my life. And I think that if I was still on lithium now, I'd be a very different person.' (p13)

'[My social worker] did very humane things that really, really made me feel she'd seen me as a person, as an individual' (p20)

'I suppose like a lot of people...of that kind of age...[...] I started going through really sort of difficult times...or...what would be called 'psychosis' ' (Interview 8:p1)

' And that doesn't surprise me because I come from a Celtic culture which is another thing the system didn't seem to take on board, that I come from a culture that is different from...the Anglo-Saxon, the ...[?] culture we have in medicine or certainly in psychiatry. I come from a culture where we're much more likely to believe in the psychic experience or second sight or even hearing voices. Bearing in mind 20% of my population in Scotland come from a Catholic background and we're actually encouraged to hear voices – call it conscience – we're encouraged to do that as children. So we must through that encouragement almost be open to evolving difficulties to do with voices. So I think in a sense I was trained to hear voices at an early stage in my life' (Interview 11: p4)

'the secret of recovery [is] [...] not to stop being psychotic, it's to integrate psychosis as just another part of your every day experience that has meaning but doesn't have the importance that it should control and dominate your life.' (p6)

'I'm angry about the lack of interdisciplinary...kind of relating as to what constitutes a human being and the imposition of the medical model without any thought of applying it to the cultural context the person comes from. And seeing each person as a unique person' (Interview 12:p1)

'But what I want is the dignity of somebody believing me and saying, 'I understand that you have these experiences. I don't experience the world that way but it must be very frightening for you...' (p3)

'I think it's an evolutionary process [...] we're not fully aware of everything that constitutes our capabilities as human beings' (p5)

'I think the process of evolution for me is evolving into a whole human being which is taking into account the physical, mental and emotional but also my spiritual aspects of who I am. You can't split them. I can't split my experiences as a child from my experiences as an adult human being growing and evolving into a wholer human being.' (p6)

'I started talking about karma and things like that and they'd think I was bonkers because they've got this western sort of...and they've got this medical model as well' (p10)

'part of that training has to be to understand the person in the context from which they're from and if you don't understand that context, then you're going to label them paranoid, you're going to label them stupid.' (p10)

'we're talking about sentient human beings here. And everybody needs to be heard [...] And I think that's what hurts the most, the inhumanity of being in the 21st century, or even the 20th century, and seeing these archaic practices.' (p11)

'Psychology and psychiatry have a place. But not on its own. You have to understand it in the wider context of what constitutes a human being and what affects a human being. And that means taking into account all sorts of things like physics, chemistry, biology, as well as religion and psychology [...] and my environment' (p15)

'it was as if all the trauma and anxiety of my family caught up with me when I was...in that year. And it felt to me like an explosion of emotion which had been gradually building up over many, many years, eventually became more than I could... contain. And it was very clearly connected to me with emotional confusion within myself. I didn't feel it was something inexplicable.' (Interview 14:p3)

'I had a very passionate feeling that I needed help with a great many human problems' (p4)

'One thing that was very important was that I had the skin condition psoriasis since I was a very little girl [...] [which was] a very hard thing to live with [also] [...] my father's illness [and] my family had just been very neglectful of everything emotional' (p8)

'I knew myself to be such an utterly kind of fragile person because of my family background' (p14)

'to me – my family was so full of anxiety that it was as if I had never even been known there in my real personality, you know? I'd never had a conversation about any difficulty with anybody. There was only my mother and she didn't have that kind of conversation. So it was as if in my real self I was unknown. And when I found myself in psychiatric hospital, I was trying to say, 'This is who I am. This is what made me go mad, but this is who I am.' [...] their attitude was... 'All that is irrelevant. You are now schizophrenic and we treat you with medication.' (p15)

'Having to adjust to sort of society, knowing that your elders are in a different society. Almost a different world to the one you're being brought up in and living in because people of my generation, younger ones, maybe older ones as well, they're more out in going into other organisations, white organisations, white institutions and what-have-you. And fitting in to that world. Whereas our elders, they tended to work in factories or have shops or be very sort of isolated in their own little worlds. They didn't feel they had to sort of do the communication thing. And being different. Because there is a different place [?] of being with people when you're with white people, to when you're with your family. Communication is just so different. So different. I don't know how to put it.' (Interview 15: p20)

'Fitting into two cultures is very difficult. And it's still...it's hard now. I still find it a struggle now.
'(Interview 15: p22)

'And I suppose things I wanted to say about different societies, that you have to juggle yourself in, in and out of, and how that can be quite stressful' (Interview 15: p30)

APPENDIX 13

Feedback from participants related to IPA analysis

Mary (Letter: 24.8.01):

'These 'symptoms' – 'paranoia' and 'ideas of reference' – are actually based on real life experiences of people (at school, for instance) being outwardly friendly but whose actions (such as what they were saying about me when I wasn't there, I later discovered) were anything but friendly. In psychiatry, of course, I had the same experiences writ large'

Mary (Letter: 18.5. 02)

'I think it's a really important study and hope the people who need to hear, hear what you're saying.'

Simon (Note: 14.6.02)

Commenting on my analysis of his interview, where I highlight that his account of hospital treatment is not characterised by 'beating up' or coercion (Cluster B) but by leaving him to make his own decisions, he says:

'This is ,as you say, particularly interesting and important for me reflecting on it since and now. I'd like to emphasise that I resisted the idea of taking psychiatric drugs and I was allowed to do so by the hospital. I wasn't forced to have that kind of (so-called) treatment – despite, in their terms (no doubt), being acutely psychotic. I believe that my 'psychosis'/ madness was given the chance to run a natural course and in time therefore 'burn itself out'. This is, however, an almost unheard of option in modern medical-model psychiatry – where to fail to suppress people's experiences with mind-numbing drugs flies in the face of accepted practice and training, and would indeed be considered severely negligent or some such.'

In response to my interpretation of the search for meaning in the psychosis (Cluster A) he says:

'I see my madness [as] [...] just as real for me as any other experience – but just like dreams or drug experiences, it's another sort of reality, an altered state reality. Yes I believe my experiences were profoundly meaningful, replete with meaning, and like dreams, I approach them as if there is meaning to be gleaned from them, rather than as if they're meaningless 'symptoms' of 'illness' or some such – not just froth and bubble.'

Meera (Note: 10.6.02)

In response to the analysis of her account of 'psychosis' being to do with 'living in fear' and recovery as about being able to trust people again she comments '*absolutely describes what I was feeling and saying.*' In response to my analysis that the beginning of her recovery has to do with viewing things in a new way, even within her delusional belief-system she says '*Brilliant*'. In response to the issues of cultural conflict, the breakdown of her marriage and psychosis she says '*I don't feel [...] that the main reasons for the conflict and lack of trust [between myself and my partner] were to do with cross-cultural divides. However I do believe that there were several cross cultural issues that could be considered [for example] [...] I think I was concerned about private investigators at this time as I had started seeing someone else and I was very fearful of how this would be viewed by my family in India and UK.*'

Kate (Letter: 21.8.02)

Kate wrote that she thought the most important point for her as a service user is that '*we can recover and overcome, even thrive in time, through strategies we have developed ourselves.*' She says, '*This is never mentioned by psychiatrists. Perhaps they don't want to give false hope, perhaps they really believe that a life time on damaging drugs is the only way to treat people who have experienced psychosis. To me this is a political issue.*'

George (Phone-call: Sept. 02)

George phoned and left a message at UCL. I returned his call. He commented that in the resume of the results I had sent him there was no mention of 'time-sharing' the strategy he had used to recover from schizophrenia. I explained that I had tried to draw out some of the common elements from time-sharing and other strategies which people found useful in the analysis, such as understanding the psychosis in a different way and self-acceptance. However I said I would make a point of trying also to mention particular strategies such as 'time-sharing' in any future publications or presentations.

APPENDIX 14

From notes taken during and after meeting with group of users and professionals where in a 15 minute slot, the results of this study were presented and discussed (15.05.02)

‘This sounds like a very good piece of work and a really important study’ (professional)

‘I’d like to hear more about what *hinders* recovery. My experience was having to get through a lot of things that hindered recovery, like how I was treated in hospital. Or ‘not treated’, more like. There wasn’t anything there that I would describe as good treatment. The nurses just sat around and looked down on you. Nobody really seemed to know what they were doing.’ (former user of mental health services)

‘How long did it take the people in your study to recover? It’s just that in my experience it’s taken me the best part of ten years to understand my psychosis and when you presented the results, that time-scale didn’t come across.’ (former user)

‘I’m not sure what you mean by ‘agency’’ (former user)

‘This is all very well. But who is going to hear about this study? How is it going to make any difference to how people are treated?’ (former user)

APPENDIX 15

From notes taken during meeting with 'Simon' and 'Patricia', preparing to present results of the study to a national conference (November 2002)

Simon

'In what I say, I'd like to take up the words 'psychosis' and 'recovery' really, and challenge them a bit. First of all, 'psychosis' is a medical term and my experience of recovery was to do with a firm rejection of the medical model. So I wouldn't use a medical term to describe what I went through. I reject all the paraphernalia of that model including concepts like 'diagnosis', 'illness', 'drugs', even the idea of 'mental health'. I don't know how it happened, but I found myself in a hospital where they did not force me to take medication. When I behaved in a disturbed way, instead of forcibly medicating me and sectioning me they *asked me to leave*. I got off lightly on the 'beating up' versus 'tea and sympathy' scale. I don't know what kind of model they were working with, but in the end I was thrown back on myself and I took responsibility for myself, the psychosis burned itself out and I let go of it. No-one told me I had a life-long mental disorder, and for that I am eternally grateful. I think I needed somewhere to go. I think I was too crazy for the world at that time and maybe the world was too much for me, too. But although I do feel I needed somewhere to go for respite, I think the fact it was a hospital is neither here nor there.'

I also want to question the word 'recovery'. I think 'recovery' can suggest recovering from an illness as well, or like a 'covering over', like medication tries to do. I go along with those people who talk about these experiences being as old as the human race and that they represent attempts at psychological re-organization, when someone meets serious obstacles to their growth and has to somehow deal with them. Someone once said 'treatment needs to be concerned with how we treat each other' and I hold to that. I think treatment is about treating people well, talking to people when they are ready to talk. I think for me, recovery, if you like, has also been to do with learning to live with difficult feelings, to 'inhabit those spaces'. I also have a motto 'Don't give up until you've tried it all'. I've used all kinds of therapies and techniques. And of course, you never will try it all, so you'll never give up.'

Patricia

'For me, I did feel ill when I went into hospital. I felt a risk to myself and possibly to others. I think the containment of hospital was helpful for me but there were things about hospital which weren't helpful like the sexism, racism, sleeping in a ward with 12 other people and being woken up in the middle of the night. I think I was lucky because I worked in mental health and I knew the system and even when I was unwell I retained that knowledge and I knew what to say and what not to say. In terms of the theme 'Telling stories' – I knew what not to say so I wouldn't be sectioned, for example. I continue to take medication. I find it helps me to engage with other people and other kinds of therapy. It helps me to do my work. It makes things less intense. But it has to be the right dose. If I'm on too much medication, I lose my motivation. I think part of recovery is 'discovery', learning new things. I've set up a training package with someone else I was in hospital with and we train mental health workers about the experience of psychosis. That's good because we're always learning something from it, too, and we make money out of it which is good! I think having a sense of humour is important, too, keeping it in perspective.'

APPENDIX 16

Comments from audience at Mind Annual Conference: 'Roots to Recovery', 12-14 November, 2002, Cardiff (from notes taken during and after presentation)

'I'd like to make 3 points. First of all, I'd like to say I think this is the most important presentation at this conference, and I don't know why it's not happening in the main hall. This conference is meant to be about recovery, and that's exactly what this is all about. Secondly, in terms of my own recovery, the most important thing I learned was that I had to find healing inside myself. And it is in each one of us, not in the medics, not in the professionals. Thirdly, I was one of the people who took part in this study. When Hermione interviewed me, I described myself as 'recovering'. I would say now that I am 'recovered'. I am further along that road. I also think that taking part in the research was a step on that road for me and it helped me to think about what I'd been through and where I was going.' ('Kate')

'One problem is psychiatry defines 'psychosis' as 'symptoms which have no meaning'. In your study, you talk about the symptoms having a meaning. This is a crucial difference and I think it's very important that these findings are made available for mental health professionals like psychiatrists.' (Audience member)

'Is this published anywhere?' (Audience member)

'How are you going to take this forward now? What are you going to do with the study?' (Audience member)

'Can we publish this in our user newsletter?' (Audience member)

'Can I present this to my colleagues when I go back to work, using the handouts?' (Audience member)

'Can you say something about how individuals get to different stages of recovery? I work in a project where people just have the attitude of keeping their head down, surviving. They have got no idea of recovery.' (Audience member)

APPENDIX 17

Worked examples of identifying narrative genre

- Step 1: Identify plot structure
- Step 2: Identify key aspects of narrative
- Step 3: Identify key quotations
- Step 4: Identify genre

Interview 14- Miriam

Plot structure

- 1) *she describes her experience of psychosis as 'an extremely...dangerous, really...experience really that might have [...] destroyed me' (p1)*
- 2) *she describes her father who 'had a serious...breakdown [...] when he was a very young man [and] [...] was never really free of the role of psychiatric patient' (p2)*
- 3) *She describes her episode of psychosis at the age of 27 and her admission to hospital where she was diagnosed with 'schizophrenia'*
- 4) *She describes a second admission shortly afterwards where she was admitted to a different hospital setting ('a group-therapy based ward' p5) and given a diagnosis of 'reactive depression'*
- 5) *She describes the therapeutic components of this approach*
- 6) *She describes her treatment here and change of diagnosis as 'an astonishing escape' and 'a kind of miraculous, possibly...escape' (p6)*
- 7) *She describes the discharge summaries from that time which indicate that the psychiatrist in the first ward expected her follow a chronic course e.g. 'Several factors make ____'s prognosis likely to be poor' (p8)*
- 8) *She describes how she 'feels very proud at times that I have come back from this thing people say they fear so much' (p12)*
- 9) *She sums up her battle during her first admission against the identity she was being given as someone with a chronic illness: 'don't allow them to tell you [...] what you are' (p13)*

- The plot structure is essentially one of equilibrium, followed by one major disruption, and then a return to equilibrium.

Key aspects of narrative

'progressive' (Gergen & Gergen, 1983)
'Restitution' (Frank, 1995)

Key quotations

'an extremely ...dangerous, really...experience' (p1)
'never really free of the role of psychiatric patient' (p2)
'an astonishing escape' (p6)
'a [...] miraculous [...] escape' (p6)
'to have come back from this thing people say they fear so much' (p12)

Identification of genre

Taking into account the plot-structure, key aspects of the narrative, and key quotations, this narrative was categorised as a 'narrative of escape'.

Interview 8 – Simon

Plot structure

- 1) sets scene of 'difficult times' in his youth
- 2) describes 'leaving school' and going out into the 'big wide world' (p1)
- 3) 'lost my footing where I was going' (p2)
- 4) started taking drugs – went from being 'totally kind of withdrawn, depressed' (p2) to 'surge of confidence' and 'high' – 'it was like enlightenment for me' (p2)
- 5) Got into debt and went into 'deep sort of depression', 'like being behind six feet of glass' (p3)
- 6) Signed up for an 'enlightenment forum' through a friend whose life 'seemed to have turned around' (p4)
- 7) 'it drove me completely kind of mad' (p4) 'like...I remember once believing that I had died, and I was a ghost, no-one could see me [...] I had special powers of communications with animals or things like this' (p5)
- 8) was admitted to hospital, resisted taking medication (p7/8)
- 9) had a moment in the hospital grounds where he decided to 'let go of [...] being that mad' (p8) something 'dawned on' him (p9) and there was a 'sort of taking responsibility in some way' (p9)
- 10) he returns to live with his girlfriend and 'never really got that kind of crazy again' (p9)
- 11) talks about feeling 'depressed and paranoid and anxious' (p9) for a long time and having 'a lot of therapy' (p9)
- 12) talks about the importance of other people and therapy
- 13) talks about recovery as 'actually exploring completely...you know becoming kind of quite different...growing...and going into completely different places' (p13)

- 14) Interviewer asks him to describe in more detail the moment when he decided to leave the hospital (p17)
- 15) He says 'It was like...it was like 'serendipity'...it was like a moment of, you know,...religious language would be kind of 'grace' or something' (p18)
- 16) Describes work, therapy, training in therapy, work in mental health as his trajectory (p20)

- The plot structure overall is one of gradual progression.

Key aspects of narrative

'progressive' (Gergen & Gergen, 1983)
 'conversion/ growth'; 'quest' (Crossley, 1999; Frank, 1995)

Key quotations

'it was like enlightenment for me' (p2)
 'enlightenment forum' (p4)
 something 'dawned on' him (p9)
 'exploring' 'growing' (p13)
 'serendipity' 'grace' (p18)

Identification of genre

Taking into account the plot-structure, key aspects of the narrative, and key quotations, this narrative was categorised as a 'narrative of enlightenment'.

Interview 9 – Hugh

Plot structure

- 1) situates himself as someone who has recovered (p1)
- 2) gives advice on how to recover e.g. talking to voices (p1/2)
- 3) sets out his relationship with his diagnosis of schizophrenia: 'you must accept that illness. But you must accept it in a way that it is only an obstacle [...] Just like people with diabetes, they can get on with everyday life although any time they could collapse' (p3)
- 4) talks about the importance of setting goals and taking control (p3)
- 5) talks about family background (p4)
- 6) Talks about what led up to his psychosis (p5)
- 7) Talks about his current involvement in the voluntary sector (p6/7)
- 8) Talks about attitudes towards mental illness (p8/9)

- 9) *Talks about usefulness of self-help groups (p10/11)*
- 10) *Getting a job (p12)*
- 11) *Sums up his philosophy: 'the way you live can affect your illness, whereas your illness can affect the way you live. That's the top and bottom of it.' (p14)*
- 12) *Describes different kinds of stress – the stress of doing something you enjoy is different from the stress of something you dislike (p15)*
- 13) *13) For him 'there is not total...recovery [...] but you can recover to look forward like everybody else to do...like a full-time job and have a family. But the recovery word really has got to be how the person sees recovery...what it is that will fulfill their lives' (p16)*
- 14) *Professionals should be responsible for helping individuals towards recovery and their valued goals, not just for medication (p17/18)*

- The plot structure is essentially one of retaining equilibrium.

Key aspects of narrative

‘stable’ (Gergen & Gergen, 1983)
 ‘normalising story’ (Crossley, 1999)

Key quotations

‘you must accept that illness’ (p3)
 ‘just like people with diabetes’ (p3)
 ‘there is not total...recovery’ (p 16)
 ‘but you can recover to look forward like everybody else to do...like a full time job and have a family’

Identification of narrative genre

Taking into account the plot-structure, key aspects of the narrative, and key quotations, this narrative was categorised as a ‘narrative of endurance’.

APPENDIX 18

Analysis of language and meta-narratives

Worked example of analysis of language and meta-narrative (from Interview 10)

Step 1: Relevant section of interview identified.

Step 2: Key phrases in these sections highlighted and collated.

Step 3: Phrases analysed in terms of how individual uses language and meta-narrative in story of recovery.

Step 4: Key aspects of how individual uses language and meta-narrative summarized.

Step 1

Extract from Interview 10 (Hugh) selected to analyse the use of the medical meta-narrative

‘ Well I think you’re recovering all the time. Um...I think I [...] when making diagnoses such as this illness, you must accept that illness. But you must accept it in a way that it’s only an obstacle [...] Just like people with diabetes, they can get on with everyday life although any time they could collapse or [...] get seriously ill. I think what I’ve said to people is...in ten years from now, where do you see yourself, what do you want to be doing? What do you want to achieve? And there are probably a lot of people saying...like I said...I wanted to be ...settled down with somebody...have children...and go to work. Like any individual my age would say. And when you’ve got that goal you’ve got to then start working out how you’re going to achieve it. You can set yourself minor tasks. And if it takes a bit longer than you were expecting, then it doesn’t matter because at the end of the day if you keep progressing then you’re going to reach your destination where you want to be. [...] recovering all the time...Self-management is a big issue, taking control for yourself. I often discuss with my GP and my psychiatrist what...how much medication I think I should be on. If I’m doing well, I might say could you cut it down a bit...you can always put it back up again. Or if I’m more anxious we look at increasing the medication. And... I suppose some of the recovery I have had from the early days is about getting out of bed in the morning – at eleven o’clock in the morning, when I wasn’t, you know. And that was the first step of recovery’

Step 2

Key phrases:

‘*you must accept that illness*’

‘*only an obstacle*’

‘*Just like people with diabetes*’

‘*What do you want to achieve?*’

'start working'
'keep progressing'
'self-management'
'taking control for yourself'
'discuss with my GP and my psychiatrist'

Step 3

Key aspects highlighted by these phrases

- the possibility of achieving goals and the illness as 'only an obstacle'*
- the power of the individual to affect the course of their illness: 'start working'*
- the importance of maintaining a sense of control over the illness and its treatment: 'self-management'; 'taking control for yourself'; 'discuss with my GP and my psychiatrist'*

Step 4

Thus having a sense of *power* and *agency* within the medical narrative seem to be key aspects of this analysis.

APPENDIX 19

Analysis of 'turning points' and 'stuck points'

Worked example of analysis of a 'turning point'

Step 1: Interviews were read and passages selected which described particular 'turning points' or 'stuck points'

Step 2: These passages were read a number of times and key quotes and themes were drawn out

Step 3: The analysis was summarized to provide an account of the crucial psychological aspects of the turning point or stuck point

Extract from Interview 3 (Mary): Example of a 'turning point'

'But at first...but what happened to me when I was in there was because I've been...I was in Amnesty for a couple of years before that and also through...I'm trying to think about the helpful things now as opposed to the saga business...When I was...when my started drinking again I went to AlAnon. And AlAnon was probably a big turning point which really made a difference because it was in AlAnon really that I started to find out who I was, who I am. Because I don't think I really knew that before. It made a big difference. Um...and also, the whole point about AlAnon (AA). [??] They're about, it's more to do with real life, 'you're the expert' and it was actually very revolutionary to me to discover that because it wasn't something that I had come across before. And also it was really good the way that they let me join, and that's something that...[??] And within about...within a couple of years of being in AlAnon I was actually...I was working on the phone lines...at the headquarters...and so that was really helpful. And I don't know why I had to go back and go through all this psychosis thing again. But I did. So that was really helpful. So once they let me join I realized that it was OK, that there were organizations that would let me join them, I joined Amnesty as well. And that's Well, hang on, human rights, what's happened to them in the mental health system ?' You know and so you can see yourself in this different way, as a victim of an unjust system, you know, you suddenly think, 'Oh, hang on,' you know. And I can remember saying that to a nurse in hospital, you know, in fact it was that time. It was that time when they were holding me and they weren't, they had no business to keep me there. And they weren't actually supposed to be...And I said to a nurse, 'I should be writing to Amnesty International about this'. [sighs]'

Key quotes

*'I started to find out who I was, who I am'
'you're the expert'
'very revolutionary'*

*'good the way that they let me join'
'working'*

*'it was OK, that there were organizations that would let me join them'
'so you can see yourself in this different way'*

Key aspects of the 'turning point'

Identity- *'started to find out who I am'*; *'see yourself in this different way'*; *'you're the expert'*; *'working'*.

Belonging- *'good the way that they let me join'*; *'there were organizations that would let me join them'*

APPENDIX 20

Narrative analysis: feedback from participants

‘Mary’ (Letter: 18.05.02): Extract

‘I would agree that my story could be characterised as a ‘narrative of escape’. I feel like I’ve had a very lucky escape. I could easily have lost my independence – job, job prospects, home, even child – and become a long-term service user. There were plenty of ‘turning points’ where this could have happened – like trapdoors opening beneath you – because of the way the system sees such expressions of dissent as are possible within it as ‘illness’.

I think the most important turning point for me was an ideological one – did I want to live in a narrow and pessimistic world where I had something inexplicably and incurably wrong with me? Or could I take a chance that what I went through was valid and real experience and that some of the insights I had might be true? (and that the world in reality and possibility is a very different place from the one I was taught to see).

It’s less than four years since my last hospitalisation – and I still have ups and downs- but I feel more secure in my recovery now since last year. I’m still digesting my experience of psychosis – getting a deeper understanding and using that creatively (in painting mostly at present). Feeling less angry and a lot more optimistic.’

Simon (Letter: 14.6.02)

‘about the idea of ‘enlightenment’ (which I first used to describe certain things I went through, and you took up in your analysis) and the danger, I suppose, of this description presenting a too romantic and simplistic version of (for me) a very complex reality.

Apart from the uncritical use of labels like ‘pathological’, ‘normal’ and ‘schizophrenics’, I particularly like the enclosed section from the book ‘Uncommon Wisdom – Conversations with Remarkable People’ by Fritjof Capra (Flamingo, 1989). He’s speaking to R.D. Laing about the ideas of American psychiatrist Stanislav Grof in relation to psychosis and ‘transpersonal’ states (see enclosed)’

[He encloses the following photocopied extract:]

‘I was especially interested in hearing Laing’s view on the similarities between the journeys of schizophrenics and mystics. I told him that Grof had pointed out to me that psychotic people often experience reality in transpersonal states of consciousness that are strikingly similar to those of mystics. Yet mystics, clearly, are not insane. According to Grof, our notions of what is normal and what is pathological should not be based on the content and nature of one’s experience, but rather on the degree to which one is able to integrate these unusual experiences into one’s life. Laing fully agreed with this view and confirmed that the experiences of schizophrenics, in particular, were often indistinguishable from those of mystics. ‘Mystics and schizophrenics find themselves in the same ocean,’ he said solemnly, ‘but the mystics swim whereas the schizophrenics drown.’ (p.135).