Quality of Life in Dementia

Lene Marie Harkjaer Thorgrimsen
University College London
PhD Psychology
"Rating my quality of life as a whole? I don't know, I haven't been dead yet."

Man with dementia in assessment interview.
ABSTRACT

Dementia is no longer perceived as an exclusively cognitive disorder, but encompassing other significant elements, such as functioning, the person's ability to cope with difficulties, and the person's subjective experience of her/his quality of life (QoL). As such, QoL is increasingly seen as one of the variables in need of identification and evaluation when assessing the outcomes of interventions for people with dementia. This thesis attempts to define and conceptualise QoL in dementia, and considers issues surrounding the assessment of this.

This thesis investigates QoL in dementia in the context of an evidence-based psychological group therapy programme. It examines variables associated with QoL in dementia, as well as the effects of the intervention conducted on QoL in dementia. A conceptual model of QoL in dementia is proposed. Additionally, the thesis evaluates a standardised scale for the assessment of QoL in dementia in terms of its reliability, validity, and sensitivity to change. The thesis includes three studies conducted: (1) Factors Associated with Quality of Life in Dementia (n = 201); (2) Factors Associated with Change in Quality of Life in Dementia (n = 201); and (3) The Validity and Reliability of the Quality of Life – Alzheimer’s Disease Scale (QOL-AD; n = 201 and n = 60). The results from these studies show that QoL in dementia is significantly
correlated with functioning and depression, but not with cognitive abilities. They also show that QoL in dementia is significantly predicted by dementia severity. Furthermore, the results show that an evidence-based psychological group therapy programme had a significant positive effect on QoL for people with dementia. Change in QoL in dementia was found in the studies reported in this thesis to be significantly correlated with improvements in cognitive functioning, level of depression, communication abilities and baseline level of QoL, and to be significantly predicted by having a lower QoL at baseline and being female. Lastly, the QOL-AD was found to be valid, reliable and sensitive to change.

As such, the evidence-based psychological group therapy programme was shown in a scientifically rigorous trial to make a significant difference to the QoL for people with dementia. Furthermore, the possibility of measuring QoL in dementia reliably, without proxy input, was demonstrated. Although some correlations between QoL and other variables in dementia was found, the results presented here suggest that QoL in dementia is a largely independent variable that needs to be measured in its own right.
ACKNOWLEDGEMENTS

I wish to thank my first supervisor, Dr Martin Orrell, for his invaluable guidance, support and kindness throughout my work on this thesis. I am also grateful to my second supervisor, Professor Bob Woods, for letting me benefit from his extensive knowledge and experience, and to Lindsay Royan and Steve Davies for their clinical supervision. I wish to thank Dr Aimee Spector for her substantial input into the development and execution of the studies presented in this thesis, and Dr Geraldine Hancock for constant support and help, and for offering some degree of sanity to the process of producing this thesis.

I am greatly appreciative to Professor Martin Knapp, whom without the economic evaluation presented as an appendix in this thesis would not have been possible, and to Angela Hallam and Dr Jeni Beecham for their input into the assembly and calculation of costs. I thank Professor Stephen Senn for making statistics somewhat more comprehensible, and Dr Caroline Selai, Dr Rebecca Logsdon, Dr Mel Walker, Dr Saskia Teunisse and Lucie Byrne for sharing with me their extensive expertise within the quality of life in dementia field.

I would like to thank all the residential homes and day centres that took part in the studies, particularly the care staff for taking time from their busy schedule to complete questionnaires and otherwise aid our research, as well as the people with dementia who participated in the groups. I thank Amber Selwood, Marta de Madariaga, Kate Abbott and Nicola Molloy for their assistance in conducting the
validation study. I wish also to thank North East London North Thames Executive Funding Group, PPP Healthcare Medical Trust North and East London Mental Health NHS Trust for funding this research.

Lastly, I want to thank my family, for instilling in me a firm belief that I could if I wanted to.
## CONTENTS

<table>
<thead>
<tr>
<th>Section</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>Abstract</td>
<td>3</td>
</tr>
<tr>
<td>Acknowledgements</td>
<td>5</td>
</tr>
<tr>
<td>Contents</td>
<td>7</td>
</tr>
<tr>
<td>Tables &amp; figures</td>
<td>18</td>
</tr>
<tr>
<td>Chapter 1: INTRODUCTION</td>
<td></td>
</tr>
<tr>
<td>1.0 OVERVIEW</td>
<td>20</td>
</tr>
<tr>
<td>1.0.1 Aims</td>
<td>21</td>
</tr>
<tr>
<td>1.1 DEMENTIA</td>
<td>21</td>
</tr>
<tr>
<td>1.1.0 Defining dementia</td>
<td>22</td>
</tr>
<tr>
<td>1.1.1 Types of dementia</td>
<td>25</td>
</tr>
<tr>
<td>1.1.2 Epidemiology of dementia</td>
<td>25</td>
</tr>
<tr>
<td>1.1.3 Social psychology of dementia</td>
<td>26</td>
</tr>
<tr>
<td>1.1.3.0 Kitwood’s social psychological theory of dementia</td>
<td>26</td>
</tr>
<tr>
<td>1.1.3.1 Other social psychological theories of dementia</td>
<td>28</td>
</tr>
<tr>
<td>1.1.3.2 Reminiscence disorientation theory of dementia</td>
<td>29</td>
</tr>
<tr>
<td>1.1.3.3 Attachment theory of dementia</td>
<td>30</td>
</tr>
<tr>
<td>1.1.3.4 Psychodynamic theories of dementia</td>
<td>30</td>
</tr>
<tr>
<td>1.1.4 Treatment of dementia</td>
<td>31</td>
</tr>
<tr>
<td>1.1.4.0 Validation therapy for dementia</td>
<td>32</td>
</tr>
</tbody>
</table>
QUALITY OF LIFE IN DEMENTIA

Contents

1.1.4.1 Reminiscence therapy for dementia 33
1.1.4.2 Reality orientation/cognitive stimulation for dementia 34
1.1.4.3 Other therapeutic factors in dementia 35
1.1.4.4 Group therapy for dementia 36
1.1.4.5 An evidence-based group therapy programme for dementia 38

1.1.5 In conclusion 39

1.2 CONCEPTUALISING QUALITY OF LIFE IN DEMENTIA 40
1.2.0 Definitions and conceptualisations of quality of life 41
1.2.1 Conceptualising quality of life in dementia 43
1.2.2 Qualitative explorations into quality of life in dementia 44
1.2.3 Conceptual models of quality of life in dementia 45
1.2.4 Dementia and disability 46
1.2.5 Quality of life as a dynamic construct 48
1.2.6 A conceptual model of quality of life in dementia 49
1.2.7 In conclusion 52

1.3 MEASURING QUALITY OF LIFE IN DEMENTIA 52
1.3.0 The value of quality of life assessment 53
1.3.1 Ethical issues in the assessment of quality of life 54
1.3.2 Quality of life as a quantifiable construct 54
1.3.3 Challenges in quality of life assessment 55
1.3.4 Quality of life assessment in dementia 58
1.3.5 'Patient' vs. proxy ratings of quality of life in dementia 58
1.3.6 The question of 'insight' 60
1.3.7 Using assessment scales in quality of life research 63
1.3.8 Psychometric properties of quality of life assessment
   Scales 64
   1.3.8.0 Validity of assessment scales of quality of life
   in dementia 64
   1.3.8.1 Reliability of assessment scales of quality of life
   in dementia 66
   1.3.8.0 Sensitivity to change of assessment scales of
   quality of life in dementia 67
1.3.9 Generic quality of life assessment 67
1.3.10 Assessment scales of quality of life in dementia 68
   1.3.10.0 Applying generic quality of life assessment
   scales to dementia 69
   1.3.10.1 Dementia-specific quality of life scales 72
1.3.11 Research into quality of life in dementia 75
1.3.12 In conclusion 77
1.4 Aims and hypotheses 78
1.5 Overview of thesis 80
Chapter 2: FACTORS ASSOCIATED WITH QUALITY OF LIFE IN DEMENTIA

2.0 AIMS 82

2.1 METHOD 82

2.1.0 Design 82

2.1.0.1 Recruitment of centres 82
2.1.0.2 Selection of participants 83
2.1.0.3 Assessment procedure 84

2.1.1 Diagnostic criteria 85

2.1.2 Measures 86

2.2 RESULTS 90

2.2.0 Characteristics of participants 90

2.2.1 Associations between quality of life & other variables in dementia 91

2.2.2 Correlations between QOL-AD items and other measures 92

2.2.3 Predictors of quality of life in dementia 94

2.3 DISCUSSION 95

2.3.0 Quality of life and functioning in dementia 95

2.3.1 Quality of life and mood in dementia 96

2.3.2 Quality of life and level of cognition and severity in dementia 96
Chapter 3: FACTORS ASSOCIATED WITH CHANGE IN QUALITY OF LIFE IN DEMENTIA

3.0 AIMS

3.1 METHOD

3.1.0 Design

3.1.0.1 Recruitment of centres

3.1.0.2 Selection of participants

3.1.0.3 Assessment procedure

3.1.0.4 Randomisation

3.1.1 Intervention

3.1.1.0 Procedure

3.1.1.1 Development of programme

3.1.1.2 Group programme

3.1.2 Diagnostic criteria

3.1.3 Outcome Measures

3.1.4 Analyses

3.1.4.0 Power analysis

3.1.4.1 Intention to treat analysis
QUALITY OF LIFE IN DEMENTIA

Contents

3.1.4.2 Statistical Analyses

3.2 RESULTS

3.2.0 Response rate and attrition

3.2.1 Characteristics of participants

3.2.2 Changes in quality of life in dementia

3.2.3 Gender & change in aspects of quality of life in dementia

3.2.4 Change in quality of life & other variables at baseline in dementia

3.2.5 Baseline & change in quality of life in dementia

3.2.6 Change in quality of life & change of other variables in dementia

3.2.7 Correlations between change in aspects of quality of life & change of other variables

3.2.8 Predictors of change in quality of life in dementia

3.3 DISCUSSION

3.3.0 Gender differences in improvement of quality of life in dementia

3.3.1 Associations between baseline & change in quality of life in dementia
3.3.2 Change in quality of life & other variables in dementia 122
3.3.3 Limitations 124
3.3.4 Conclusion 124

Chapter 4: VALIDITY AND RELIABILITY OF THE QUALITY OF LIFE – ALZHEIMER'S DISEASE SCALE 126

4.0 AIMS 126
4.1 METHOD 126
4.1.0 Design 126
4.1.0.0 Recruitment of centres, sample 1 126
4.1.0.1 Selection of participants, sample 1 127
4.1.0.2 Assessment procedure, sample 1 128
4.1.0.3 Dementia Care Mapping 129
4.1.0.4 Focus groups 129
4.1.0.5 Questionnaires 129
4.1.0.6 Recruitment of centres, sample 2 130
4.1.0.7 Selection of participants, sample 2 130
4.1.0.8 Assessment procedure, sample 2 130

4.1.1 Diagnostic criteria 130
4.1.2 Measures 130

4.2 RESULTS 133
4.2.0 Descriptive characteristics of participants, sample 1 133
QUALITY OF LIFE IN DEMENTIA

Contents

4.2.1 Face/Content validity (sample 1) 135
4.2.1.0 Focus groups with people with dementia (n = 20) 135
4.2.1.1 Focus groups with carers (n = 30) 136
4.2.1.2 Questionnaires for health care professionals working with people with dementia (n = 70) 138

4.2.2 Criterion concurrent validity (sample 1) 141

4.2.3 Inter-rater reliability (sample 1) 142

4.2.4 Test-retest reliability (sample 1) 143

4.2.5 Descriptive characteristics of participants, sample 2 144

4.2.6 Construct validity (sample 2) 145

4.2.7 Convergent and divergent concurrent validity (sample 2) 147

4.2.8 Known group concurrent validity (sample 2) 148

4.2.9 Internal consistency (sample 2) 149

4.3 DISCUSSION 150

4.3.0 Face and content validity 109

4.3.1 Construct validity 153

4.3.2 Criterion concurrent validity 153

4.3.3 Convergent and divergent validity 156

4.3.4 Known group concurrent validity 156

4.3.5 Inter-rater reliability 157
QUALITY OF LIFE IN DEMENTIA

Contents

4.3.6 Test-retest reliability 157
4.3.7 Internal consistency 158
4.3.8 Limitations 158
4.3.9 Conclusion 159

Chapter 5: DISCUSSION

5.0 OVERVIEW 161

5.1 CONCEPTUALISING QUALITY OF LIFE IN DEMENTIA 162

5.1.0 Associations between cognitive abilities and quality of life in dementia 163

5.1.1 Associations between physical functioning and quality of life in dementia 164

5.1.2 Associations between mood/emotional functioning and quality of life in dementia 166

5.1.3 Associations between social and physical environment and quality of life in dementia 167

5.1.4 Quality of life as conceptualised by people with dementia 168

5.1.5 Quality of life as conceptualised by proxies 169

5.1.6 Improvements in quality of life in dementia 171

5.1.6.0 Possible mechanisms for improvements in quality of life in dementia 172
<table>
<thead>
<tr>
<th>Contents</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>Clinical Dementia Rating (CDR)</td>
<td>283</td>
</tr>
<tr>
<td>Cornell Scale for Depression in Dementia (CSDD)</td>
<td>284</td>
</tr>
<tr>
<td>Rating for Anxiety in Dementia (RAID)</td>
<td>285</td>
</tr>
<tr>
<td>Clifton Assessment Procedures for the Elderly - Behaviour Rating Scale (CAPE-BRS)</td>
<td>286</td>
</tr>
<tr>
<td>Holden Communication Scale</td>
<td>288</td>
</tr>
<tr>
<td><strong>Appendix C: GROUP PROGRAMME</strong></td>
<td>289</td>
</tr>
<tr>
<td><strong>Appendix D: LETTERS/FORMS</strong></td>
<td>295</td>
</tr>
<tr>
<td>Example of letter of support</td>
<td>296</td>
</tr>
<tr>
<td>MREC approval</td>
<td>297</td>
</tr>
<tr>
<td>Example of LREC approval</td>
<td>299</td>
</tr>
<tr>
<td>Example of information sheet (1)</td>
<td>301</td>
</tr>
<tr>
<td>Example of consent form (1)</td>
<td>302</td>
</tr>
<tr>
<td>Example of information sheet (2)</td>
<td>303</td>
</tr>
<tr>
<td>Example of consent form (2)</td>
<td>305</td>
</tr>
<tr>
<td>Questionnaire for health care professionals</td>
<td>306</td>
</tr>
<tr>
<td>Exclusion criteria flow diagram</td>
<td>310</td>
</tr>
<tr>
<td><strong>Appendix E: ECONOMIC EVALUATION</strong></td>
<td>311</td>
</tr>
</tbody>
</table>
# TABLES & FIGURES

<table>
<thead>
<tr>
<th>Figure/Table</th>
<th>Description</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>Figure 1.</td>
<td>A conceptual model of quality of life in dementia</td>
<td>50</td>
</tr>
<tr>
<td>Table 1.</td>
<td>Descriptive characteristics of participants</td>
<td>90</td>
</tr>
<tr>
<td>Table 2.</td>
<td>Correlations between quality of life &amp; other variables</td>
<td>92</td>
</tr>
<tr>
<td>Table 3.</td>
<td>Correlations between elements of quality of life &amp; other scales</td>
<td>93</td>
</tr>
<tr>
<td>Table 4.</td>
<td>Predictors of quality of life in dementia</td>
<td>95</td>
</tr>
<tr>
<td>Figure 2.</td>
<td>Attrition</td>
<td>108</td>
</tr>
<tr>
<td>Table 5.</td>
<td>Descriptive characteristics of participants at baseline</td>
<td>109</td>
</tr>
<tr>
<td>Table 6.</td>
<td>Between group differences pre &amp; post intervention on the QOL-AD</td>
<td>110</td>
</tr>
<tr>
<td>Table 7.</td>
<td>Gender &amp; change in aspects of quality of life in dementia</td>
<td>112</td>
</tr>
<tr>
<td>Table 8.</td>
<td>Change in quality of life &amp; other variables at baseline in dementia</td>
<td>113</td>
</tr>
<tr>
<td>Table 9.</td>
<td>Baseline &amp; change in quality of life in dementia</td>
<td>115</td>
</tr>
<tr>
<td>Table 10.</td>
<td>Correlations between change in quality of life &amp; change on other measures in relation to baseline scores</td>
<td>116</td>
</tr>
<tr>
<td>Table 11.</td>
<td>Correlations between change in aspects of quality of life &amp; change on other variables</td>
<td>118</td>
</tr>
<tr>
<td>Table 12.</td>
<td>Predictors of change in quality of life in dementia</td>
<td>120</td>
</tr>
</tbody>
</table>
Table 13. Descriptive characteristics of participants, sample 1

Table 14. Scores given to the items of the QOL-AD by health care professionals (n = 90)

Table 15. Correlations between total QOL-AD score and other QoL indices in dementia (n = 60)

Table 16. Inter-rater reliability of the QOL-AD (n = 38)

Table 17. Test-retest reliability of the QOL-AD (n = 38)

Table 18. Descriptive characteristics of participants, sample 2

Table 19. Results from a principal component analysis of the QOL-AD items (n = 201)

Table 20. Associations between QOL-AD score and levels of depression in dementia (n = 201)

Table 21. Internal consistency of the QOL-AD (n = 201)

Figure 3. The elements of the conceptual model of quality of life in dementia investigated
CHAPTER 1: INTRODUCTION

1.0 OVERVIEW

Is there quality of life (QoL) in dementia? This question was the most common response the author had when answering questions from people on what this thesis involved. It represents a long standing and widespread attitude to dementia, which is often feared when people contemplate growing old, and has even been rated a state of living that is worse than death (Patrick et al., 1994). However, the latter years have involved a rapid growth in research into and knowledge about dementia, which is no longer perceived as an exclusively cognitive disorder, but encompassing other significant elements, such as functioning; the person’s ability to cope with difficulties; and the person’s subjective experience of her/his QoL. One consequence of this changing perception has been the increasing interest in identifying other forms of treatment than drugs, which have to date had only a limited effect on improving the lives of people with dementia (O’Brien et al., 2000). Another consequence has been the increased recognition of other significant outcome variables in need of identification and evaluation. These include activities of daily living (ADL) skills (e.g. Kempen et al., 1996), ability to interact and communicate (e.g. Holden & Woods, 1995), and QoL (e.g. Brod et al., 1999). This chapter aims to provide an introduction to differing psychological theories of dementia, a conceptualisation of QoL in dementia, and issues surrounding how to assess QoL in dementia.
1.0.0 Aims

♦ To define, describe and discuss dementia from a psychological perspective.

♦ To conceptualise quality of life in dementia.

♦ To discuss measurement of quality of life in dementia.

1.1 DEMENTIA

Traditionally, the term 'dementia' has been used to describe a syndrome characterised by a wide range of symptoms due to brain dysfunction (e.g. Fratiglioni, 1998), and includes a variety of sub-diagnoses, prognoses, and treatment options. Central features of this disorder are changes of cognitive and emotional abilities, and people with dementia and their families commonly report a significant negative effect on QoL and everyday functioning. All types of dementia are commonly thought to be progressive, to deteriorate through stages, and inevitably lead to death. Dementia has a long-standing history as a medical diagnosis, and the first well known clinical case written up on the subject was by Dr Alois Alzheimer of Frau Auguste D in 1907 (cited in Alzheimer, 1977). This was initially presented as a case of 'pre-senile dementia', which was based on Frau D's behaviour whilst in an asylum and the plaques and fibrils Dr Alzheimer found in her brain post mortem. 'Alzheimer's Disease' was in 1910 included as a subtype of 'senile dementia' in Kraepelin's psychiatric textbook. But, it was not until 1974 that Alzheimer's Disease (AD) and 'senile dementia' were suggested by Katzman to describe the same condition, and AD began to be adopted as the common term. Despite the advances made within the field of dementia, and the increasing
understanding of aetiology and sub-diagnoses, the term AD is still used in a broad manner, for example by organisations such as the Alzheimer’s Society, which actually deals with all types of dementia.

1.1.0 Defining dementia

Dementia can be defined as ‘the acquired and sustained deterioration of intellectual functions in an alert patient’ (Morris, 1994). The diagnostic criteria for dementia in DSM-IV (American Psychiatric Association, 1994) describe it as the development of multiple cognitive deficits manifested by both memory impairment and one or more of the following cognitive disturbances: aphasia, (i.e. language disturbance); apraxia, (i.e. impaired ability to carry out motor activities despite intact motor function); agnosia, (i.e. failure to recognise or identify objects despite intact sensory function); and/or disturbance in executive functioning, (i.e. planning, organising, sequencing, and abstracting). ICD-10 (World Health Organization, 1992) defines dementia as ‘a syndrome due to disease of the brain, usually of a chronic or progressive nature, in which there is disturbance of multiple higher cortical functions, including memory, thinking, orientation, comprehension, calculation, learning capacity, language and judgement....commonly accompanied, and occasionally preceded, by deterioration in emotional control, social behaviour, or motivation’. However, definitions and classifications such as these have in recent years increasingly been criticised for focussing too exclusively on brain functioning and cognitive loss (e.g. Cheston & Bender, 1999), whilst not really informing us as to what it is like to have with dementia.
In contrast, Kitwood (1997) gives a vivid depiction in an attempt to express what living with dementia may entail:

"You are in a swirling fog, and in half darkness. You are wandering around in a place that seems vaguely familiar; and yet you do not know where you are; you cannot make out if it is summer or winter, day or night. At times the fog clears a little, and you can see a few objects really clearly; but as soon as you start to get your bearings, you are overpowered by a kind of dullness and stupidity; your knowledge slips away, and again you are utterly confused.

Whilst you are in the fog, you have an impression of people rushing past you, chattering like baboons. Occasionally you pick up fragments of conversation, and have the impression that they are talking about you. Sometimes you catch sight of a familiar face, but as you move towards the face it vanishes. You feel desperately lost, alone,
bewildered,
frightened.
You find that you cannot control your bladder, or your bowels;
you feel dirty, ashamed;
it's so unlike how you used to be that you don't even know yourself.

Behind the fog and darkness is a vague memory of good times,
when you knew who and where you were,
and when you were able to perform daily tasks.
But now all that has been vandalised, ruined
and you are left in chaos,
carrying a terrible sense of a loss that can never be made good.

Once you were a person who counted;
now you are a nothing.”

Whilst this may signify a particularly pessimistic outlook, there is little doubt that important psychological changes are associated with developing dementia. These include aspects such as increased suspiciousness, aggression, restlessness, moodiness and overt sadness (Miesen, 1999). The person with dementia needs to be seen as more than somebody having an ‘illness of the brain’, but rather as somebody existing within a social world with a lifetime of experiences and knowledge (Cheston & Bender, 1999).
1.1.1 Types of dementia
The most common form of dementia is Alzheimer’s Disease (AD), which is characterised by gradual onset and continuing cognitive decline (O’Brien et al., 2000). AD is a global impairment thought to result from neurological changes, such as amyloid plaques and neurofibrillary tangles within the brain. Vascular Dementia (VaD) is the second most common type of dementia, and is a result of a series of small strokes occurring in the brain. Thus, this form of dementia typically has a more abrupt onset, with a pattern of patchy and stepwise decline in abilities. Focal neurological signs and symptoms such as gait abnormalities commonly accompany VaD. A relatively recently identified type of dementia is Lewy-Body Dementia (LBD). LBD is named after minute spherical structures found in the nerve cells of the brain (‘Lewy bodies’), and its presentation is very variable from day to day, often with extra pyramidal symptoms, delusions, and hallucinations. Other less common forms of dementia include Frontal Lobe Dementia, which is primarily associated with the degeneration of the frontal lobes; Dementia Pugilistica, which results from closed head trauma; Creutzfeldt-Jacob Disease, which is a form of transmissible dementia, dementia associated with Parkinson’s Disease; and Huntington’s Disease, which is an inherited disease linked to a faulty gene on chromosome 4 (O’Brien et al., 2000).

1.1.2 Epidemiology of dementia
With the growing number of old and very old people, dementia is becoming ever more common, with about 5% of over 65’s developing this disorder. It is estimated that the number of people with dementia in the UK alone will increase from the present 665,000
to 855,000 by the year 2020 (Department of Health, 1997). Dementia prevalence doubles with almost every five years after 60, and as such depends significantly on the age structure of the population. Approximately 1% of people between the age of 60 and 69 have dementia, whilst in 90+ year olds, the number increases to 50% (Fratiglioni, 1998).

1.1.3 Social psychology of dementia

There is currently a limited level of knowledge about the psychosocial factors in the aetiology of dementia, but suggestions have been presented, incorporating neurological changes and psychological factors. This thesis will focus on some explanatory models considering psychological factors as causing or accentuating dementia, with the view that these are more relevant to psychological interventions for dementia than biomedical models. This section will take as a starting point Tom Kitwood's model of dementia, as this has to date been the most influential model within the field of dementia care. Additionally, some other psychological models will be presented that support aspects of this model, which open up alternative possible pathways to developing dementia.

1.1.3.0 Kitwood's social psychological theory of dementia

Kitwood (1997) questioned the explanatory value of the medical model for 4 fundamental reasons: (1) Some cases of advanced dementia have shown no neurological damage at post-mortem (Homer et al, 1988); (2) There have been cases of substantial neuropathological decline with no accompanying dementia symptoms. For example a
degree of cerebral atrophy measured by CT scanning was found in a proportion of 'normal people' (Burns et al, 1991); (3) Paths of decline amongst people with dementia are often highly disparate, a strong and consistent correlation between a clinically established degree of dementia and extent of neuropathology at post mortem is lacking; and (4) Neurological processes proceed very slowly, yet dementia frequently proceeds much faster, for example following hospitalisation. Kitwood and Bredin (1992) further states that "the clinical presentation of dementia is far from being a direct consequence of degenerative process in nervous tissue. Rather, the dementing process should be viewed as a dialectical interplay between two tendencies. The first is neurological impairment, which does indeed set upper limits to how a person can perform. The second is the personal psychology an individual has accrued, together with the social psychology with which s/he is surrounded". They further hypothesise that many of the difficulties experienced by the person with dementia are not a result of the disorder, but the 'malignant social psychology' in which the person exists, where the people involved in care for the person might be well-intentioned, but lacking in insight and necessary skills. Kitwood and Bredin (1992) criticise the implicit 'hypercognitivism' (see Post, 1995) of Western accounts of dementia, where personhood is equated with cognitive abilities. Furthermore, they reject the traditional stage-theory of dementia, and considers instead the possibility of 'remitia' (see Sixsmith et al., 1993) representing a considerable reversal in dementia symptoms in some people. This notion of remitia they base mainly on anecdotal evidence, but also refer to a controlled study finding an experimental group of people with dementia receiving higher levels of activity input to at least deteriorate slower than controls receiving standard care (Rovner et al., 1990).
Additionally, Kitwood supports this concept with evidence from experiments with rats, where neurological developments were found in brains of rats following stimulation, having previously deteriorated in impoverished conditions (Diamond, 1985).

1.1.3.1 Other social psychological theories of dementia

Kitwood's theory of dementia was by no means the first that suggested possible pathways of developing dementia other than through neuropathological changes. Other social psychological theories of dementia that describes similar concepts to Kitwood's 'malignant social psychology' include Barnes, Sack and Shore's (1973) theory about the 'dementia spiral', in which they describe a self-reinforcing process triggered by role-loss, leading to loss of sense of identity and self-worth. According to this theory, impaired physical and mental health occurs later on in the process, and is reinforced by institutionalisation, which leads to withdrawal into the past, stigmatisation of the person as 'demented', and lastly vegetation & death. Sabat and Harré's (1992) theory of 'social disintegration of the self' is based on the social psychological division of the person into a private and a public self. They state that the private self remains relatively intact in dementia, while the person's public self is disintegrated, not through organic impairment, but though the social interactions the person with dementia is involved in. This disintegration follows from being corrected or rejected as a consequence of unclear or disorientated behaviour or speech. In this way the person does not get feedback on the public self s/he is trying to present. So, instead of building up a self as a lawyer or mother, the person builds up a public self as an irritating, difficult, and useless person. Bender and Wainwright (1998) have also presented a model of the aetiology of dementia...
where psychological and social factors play a significant role. They hypothesise that dementia can arise, or at least be accentuated by, internalised ageism, decreased mobility, and shrinking networks, via role loss and social withdrawal. Voss (1989) went as far as stating that if dementia is at all an illness, it is a social one, and although organic degenerative mechanisms have an effect on the aetiology of dementia, this does not mean that we know any more about the fundamental causes for it.

1.1.3.2 Reminiscence disorientation theory of dementia

'Reminiscence Disorientation Theory' (Jones & Burns, 1992) is another theory of dementia emphasising social and psychological factors, presented as explaining one type of disorientation. This theory states that everyone constantly moves between different realities, such as memories from the past, plans for the future, and events in the present. Dementia is thought to damage the ability to control these transitions. Thus, the person with dementia lives in a world where past, present and future are mixed together, and memories, dreams and hopes are masking the present. Hence people and events are misunderstood as belonging to a reality from a different moment in time. The causes for this are thought to be (1) the organic impairments which are making it difficult to analyse and reflect beyond the immediate experience of reality; (2) sensory deprivation making it difficult to make sense of stimuli; (3) the environment being stimuli-deprived and giving poor compensation for role-loss and limited opportunities for meaningful interactions with other people; and (4) reduced ability to control the situation, which is linked to passivity and reduced self-initiated actions, making it easier to drift with outer or inner events.
1.1.3.3 Attachment theory of dementia

Miesen (1992) has developed an explanatory model of dementia, or at least of some of the behaviour displayed by people with dementia, based on 'Attachment Theory', first presented by Bowlby (1969). He describes 'attachment behaviour' which is based on a fundamental need for close relations with other people and aimed at creating or maintaining closeness to another person. This behaviour is thought to be activated in situations where the person is feeling unsafe, threatened, or isolated, seemingly common feelings amongst people with dementia. Through his 'Standard Visiting Procedure', Miesen (1992) has shown that attachment behaviour is expressed in early stages of dementia through direct contact seeking, and in later stages through 'parent fixation', which is expressed through a wish to go home, worry about parents' well-being, and perception of being at home with parents. Thus, according to this theory, disorientation and insistence that parents are still alive is an expression of feeling unsafe in the situation and a wish for being protected. This is activated by a lack of available attachment figures in the present, so the person regresses back to the fundamental attachment to parents.

1.1.3.4 Psychodynamic theories of dementia

One example of a psychodynamic theory of dementia has been developed by Feil (1985). This is based on Erikson’s (1968) developmental theory in which the person goes through psychosocial crises throughout life, in need of resolution. To this Feil has added a psychosocial stage for people over 75, called resolution vs. vegetation. She states that people who are disorientated in old age, have always had a tendency to avoid
facing up to problems and conflicts in their lives. Thus, when organic damage and other physical or psychological impairment affect the defence that the avoidance represents, a person might find it necessary to ‘switch off’ from the challenges in the present, and seek refuge in the past and delusions. According to Feil (1985) this ‘disorientation’ state is meaningful, in that it is coloured by unresolved conflicts and non-accepted events, and if the person is not able to gain some resolution, s/he will go through a development of malorientation through time confusion and repetitive motion to vegetation and death.

1.1.4 Treatment of dementia

Dementia is not as yet curable, but it is seen as treatable to some extent (O’Brien et al, 2000). Recent years have seen an increase in the development and consumption of acetylcholine-esterase inhibitors, such as Donepezil HCI (‘Aricept’) and Rivastigmine (‘Exelon’), which are thought to slow down the deterioration of cognition in dementia. However, even when shown to have an effect in clinical trials, this effect has only so far been relatively modest for a proportion of people with AD in the early stages of the illness. Other drugs commonly prescribed to people with dementia are psychotropic medication for behavioural symptoms and sleep disturbances, and SSRI drugs and other anti-depressants for the low mood often accompanying dementia (Fastbom & Giron, 1998). All well as new drug-treatments being developed, over the last few decades there has been an increase in psychological interventions for dementia. The most widely used are Validation Therapy, Reminiscence Therapy and Reality Orientation/Cognitive Stimulation. These will be outlined below.
1.1.4.0 Validation therapy for dementia

Validation Therapy (VT) was developed by Feil (1982), and is described as being based on a fundamentally honest, valuing and accepting attitude to the person with dementia. In this approach, instead of orientating to facts, empathic listening is used. This means asking concrete follow-up questions whose tone is not judging the person’s perception as right or wrong, or evaluating it as good or bad. Thus, instead of responding to the factual content in what the person with dementia is saying, the emotional content is responded to, which can not be judged as right or wrong, but is real to the person. Feil (1982) suggests that the person with dementia deteriorates through four stages, which require different interactions: (1) ‘Malorientation’ is where the person is starting to lose grip of reality and as such feels easily threatened by intruders into her/his own space. S/he struggles with keeping it together, and will easily project own problems onto others, and deny any difficulties. The person will in this stage often be paranoid and think money or other things s/he can not find have been stolen. Close physical contact and questions about personal feelings can be too much in this stage. (2) ‘Time-confusion’, where the person operates in ‘emotional time’, which is the time when the person first had the feeling. Empathy, trying to understand the feelings, touch and eye contact are seen as important ways of engaging in this stage. (3) ‘Repetitive motion’ is where the person has little or no language left. Here mirroring movements and using non-verbal communication techniques are suggested as being ways of engaging. (4) ‘Vegetation’ is described as being the final stage, in which the person will have limited ability to communicate. Here, physical touch will be the only way of engaging.
Some anecdotal evidence for VT inducing immediate signs of well-being has been presented, as has some research (e.g. Feil, 1982; 1992; Solem, 1990), but not of rigorous designs. In their Cochrane systematic review, Neil and Briggs (2002) concluded that there currently is insufficient evidence available to make any conclusions about the efficacy of VT for people with dementia.

1.1.4.1 Reminiscence therapy for dementia

Reminiscence Therapy (RT) can be described as being vocal or silent recall of events in a person’s life, either alone, or with another person or group of people (Woods et al., 1992). In this approach, prompts are used in order to encourage the natural flow of reminiscence. While a diagnosis of dementia often emphasises illness and deficits, RT highlights peoples’ strengths. It provides a context in which a person can use her/his long-term memory, and since this generally remains more intact than other aspects of cognition in dementia, it reduces the experience of failure commonly felt by people with dementia. Ebersole (1978) identified some of the therapeutic factors of RT as inter-generational sharing and memory stimulation, whilst Kiernat (1979) concluded from his work on RT for people with dementia that conversation could be stimulated, interest sparked, and attention span increased. The effectiveness of RT for dementia has been evaluated in some small-scale studies (e.g. Cheston, 1996; Head et al., 1990), which have suggested that RT can increase verbal contributions, alertness, humour, responsiveness, and interaction. However, the designs of these studies fall short of the current gold standard for scientific rigour (randomised controlled trials), and as such include the possibility of several biases.
In order to establish a clearer evidence base, Spector et al. (1998) conducted a Cochrane systematic review of all available research of RT for dementia, the findings of which supported the contemporary view (e.g. Bender et al., 1999), i.e. that no firm conclusions could be reached about the effectiveness of RT for dementia due to the lack of scientifically rigorous research. However, a pilot randomised controlled trial has since been conducted (Thorgrimsen et al., 2002). The results from this study showed positive trends in support of the suggestion that RT stimulates memory and conversation.

1.1.4.2 Reality orientation/cognitive stimulation for dementia

Reality Orientation (RO) operates through the presentation and repetition of orientation information, thought to provide the person with a greater understanding of their surroundings, possibly resulting in an improved sense of control and self-esteem. RO can be of a continuous 24 hour nature, whereby people are involved throughout the day, or of a 'classroom' type, where people meet in groups on a regular basis to engage in orientation-related activities (Brook et al, 1975). Woods (1979) found that classroom RO led to some improvement in cognitive function but no effect on behaviour, whereas Baines et al (1987) found significant positive effects on behaviour, but not on cognition. RO lost considerable popularity in the 1980's, largely due to criticism of it being sometimes applied in a rigid and insensitive manner. However, it has formed the basis for more modern strategies involving memory training, commonly labelled Cognitive Stimulation (CS) programmes. For example, Zarit et al. (1982) provided participants with didactic training and problem solving and found small but short-lived changes in memory performance. Additionally, the use of external memory aids, such as diaries,
calendars, large clocks and clear signposting are becoming increasingly common for people with dementia. More recent research is identifying ways of creating an optimal learning environment, such as 'errorless learning' and 'spaced-retrieval' techniques.

In view of the lack of rigorous and up-to-date research also on the effectiveness of RO for dementia, a Cochrane systematic review was conducted (Spector et al, 1998, Spector et al., 2000). This found RO to be associated with significant improvements in both cognition and behaviour.

1.1.4.3 Other therapeutic factors in dementia

Following from the psychological theories of dementia presented in this thesis, are also differing strategies and approaches aimed at improving functioning in dementia. Kitwood (1992) suggests several changes that can be made to the person with dementia's social environment to prevent the 'malignant social psychology' from emerging. Other social psychological theories of dementia, such as Barnes, Sack and Shore's (1973) 'dementia spiral', and Voss' (1989) perception of dementia as a social illness imply that social measures to prevent loss of role, sense of identity, and self-worth could prevent, or at least reduce severity of decline in dementia. Also the other psychological theories of dementia open avenues for new approaches in dementia care. One such example follows from Jones and Burns' (1992) 'Reminiscence Disorientation Theory' that the severity of dementia can be reduced by improved sensory aids, enriched environments, and increased control over one's own situation. Attachment Theory (Miesen, 1992) might indicate that if attachment figures were more available in the present, the person's need to regress would be lessened. The theory presented by
Bender and Wainwright (1998) suggests that ageism is inherent in our society, and if combated, would reduce the impact of dementia.

1.1.4.4 Group therapy for dementia

Conducting therapy in groups is commonly thought to entail other therapeutic processes than therapy carried out on and individual basis. Yalom (1985) has outlined 10 therapeutic factors thought to be important underlying currents in any group: (1) **Instillation of hope** is seen as crucial in order to keep the group member in the group, and high expectations of help are suggested to be related with a positive therapy outcome. The group format offers a unique source of hope, in that members can share positive outcomes with each other. (2) **Universality** refers to the fact that many people come to a group with the sense that they alone have frightening and unacceptable problems, thoughts, impulses and fantasies, which they are not getting disconfirmed in their everyday lives. In the group, the disconfirmation of their feelings of uniqueness can be a powerful source of relief. (3) **Imparting information** or psycho-education entails using an implicit educational process informing about the meaning of symptoms or interpersonal and group dynamics. This is thought to be valuable as an initial binding force in a group, and may be the first step towards gaining control over a symptom or phenomena. Direct advice can also be used in groups, mostly in their early life, and even if the content of the advice is not very helpful, the process of giving it may be beneficial, implying and conveying mutual interest and caring. (4) **Altruism** describes the fact that the group setting is a place where the members can discover that they have something of value to give others, rather than being burdens or insignificant to them.
Group members can offer support, reassurance, suggestions, insight and share experiences with each other, and the act of altruism can also help to minimise unhelpful and morbid self-absorption or obsessive introspection. (5) The corrective recapitulation of the primary family group refers to the notion that many people have a background of unsatisfactory experiences from their first and most important group: the primary family. The group resembles a family in many ways, and can be used to relive early familial conflicts correctively, that is to explore and challenge them in order to work through unfinished business from long ago through the work in the group. (6) Development of socialising techniques, or social learning, is a therapeutic factor that operates in all group contexts, either explicitly through discussion or role-play, or more indirectly through feedback on maladaptive social behaviour from others in the group. (7) Imitative behaviour means people modelling themselves on aspects of other group members or the group leader(s). The group setting can allow people to experiment with new behaviour and learn new social skills. (8) Interpersonal learning entails that through feedback from others and self-observation, people may become aware of significant aspects of their interpersonal behaviour, such as maladaptive behaviour that elicits unwanted responses from others. People can then change by risking new ways of being with others. Subsequently, they may develop their skills of developing functional, gratifying interpersonal relationships within the group context. (9) Group cohesiveness refers to the attraction that members have for the group and other members. Members of a cohesive group are supportive of one another. In conditions of acceptance and understanding, people may be more inclined to express and explore themselves, and to relate more deeply to each other. A sense of group belonging may also have a positive
impact on self-esteem. (10) Catharsis describes the possibility for people to use the group setting to get things ‘off their chest’, and express positive or negative feelings towards members of the group or the group leader. It can help them learn to express their feelings, rather than holding them in. This process is thought to be more effective once supportive group bonds have formed.

Thus, according to the factors outlined above, there are certain therapeutic aspects to group therapy that are additional to those offered by individual therapy. How these apply to groups for people with dementia, is a topic for debate. For example, is the instillation of hope possible for groups consisting of people with a degenerative disorder? Similarly, is imparting information helpful to people who have a condition that when asked, a large number of respondents rate as a state of living that is worse than death (Patrick et al., 1994)? These are issues that will be addressed in the discussion of this thesis, in the context of the group therapy conducted with people with dementia.

1.1.4.5 An evidence-based psychological group therapy for dementia

On the basis of the above evidence for the effectiveness of different psychological therapies for dementia, a programme of evidence-based psychological group therapy was developed (Spector et al, 2001). The programme was designed to incorporate interventions and techniques found in research to be effective with people with dementia. As outlined above, the interventions with the most available efficacy data fall under the category of Reality Orientation/Cognitive Stimulation. Therefore, the programme relied heavily on these techniques. It also used Reminiscence Therapy in
parts, particularly as a way of ensuring group cohesion, and also as an enjoyable way of
orientating people to the present, as in ‘where are you now in relation to then?’. Validation Therapy was incorporated as an overall attitude and guideline as to how to run the groups, and would be used as ways of responding to people if they were struggling with any tasks. All memory tasks focused on implicit rather than explicit memory processes, and sessions encouraged the use of information processing rather than factual knowledge. This was to reduce failure experiences as far as possible. The group format allowed opportunities for therapeutic factors such as universality and altruism to operate. Additionally, the group format allowed for the creation of a reinforcing and supportive social environment, which valued making choices and forming attachments.

The programme was entitled Cognitive Stimulation Therapy (CST), and was found in a pilot randomised controlled trial to produce positive trends in cognition and depression (Spector et al., 2001). On the basis of these findings, a single-blind, multi-centre, randomised controlled trial of CST was conducted, which found significant improvements on measures of cognition (Spector, 2001; Spector et al., in press).

1.1.5 In conclusion.

Aiming to add to the current knowledge about dementia are several psychological theories. These take into account the effects of the environment surrounding the person with dementia, such as a lack of insight, ageism, sensory and stimuli deprivation and a low degree of control. These theories also incorporate the effects of common social
factors in old age in general, and dementia specifically. These factors include role-loss, stigmatisation, social disintegration of the self, internalised ageism, a greater need for available attachment figures as a result of a decreased feeling of safety, and impaired defence mechanisms. Several psychological therapies for dementia are widely in use, with varying degrees of evidence available as to their effectiveness. An evidence-based psychological group therapy programme known as CST has been developed, aiming to incorporate the most successful elements of these approaches to dementia, which has been found in the largest randomised controlled trial of any intervention for dementia to date to produce significant improvements in cognition.

1.2 CONCEPTUALISING QUALITY OF LIFE IN DEMENTIA

Objective dimensions of health are important when assessing the clinical course of an illness, and evaluating the effectiveness of interventions for it. However, there is increasing recognition that it may be as meaningful (or more) to establish how a patient/client feels, rather than how professionals think they feel on the basis of clinical measurements. The limitations of using survival rates and symptom levels as the only outcome variables have become more evident, particularly when treating people with chronic, incurable or degenerative disorders, such as dementia. An important indication is whether an intervention has the result of making life more or less ‘worth living’. As such, quality of life (QoL) is increasingly seen as a key consideration in; evaluating services; the ethical debate regarding health care resource allocation; testing the effectiveness of new treatments; and the development of clinical guidelines.
1.2.0 Definitions and conceptualisations of quality of life

There is no consensus over a definition of QoL. The literature covers a range of components: functional ability (including role functioning); the degree and quality of social and community interaction; psychological well-being; somatic sensation; and life satisfaction. In a review of the literature in 1988, Frank-Stromborg found a variety of terms equated with QoL: life satisfaction, self-esteem, well-being, health, happiness, adjustment, value of life, meaning of life, and functional status. The author further found QoL being described in terms of objective measures, such as income, housing, physical functioning, work, socio-economic status, and support networks, and in terms of subjective measures, such as attitudes, perceptions, aspirations, and frustrations. There is also little empirical research attempting to define those qualities that make life and survival worthwhile (Bowling, 1994).

There have been several attempts to define QoL. Mendola and Pelligrini (1979) defined QoL as “the individual's achievement of a satisfactory situation within the limits of perceived physical capacity”. Shin et al. (1978) suggested that QoL consists of “the possession of resources necessary to the satisfaction of individual needs, wants, and desires, participation in activities enabling personal development and self actualisation and satisfactory comparison between oneself and others”. Lawton (1997) defined QoL as the evaluation of the behavioural and environmental situation of the person, and has proposed a model of QoL consisting of four components: objective environment; behavioural competence; psychosocial well-being; and perceived QoL.
QoL is fundamentally recognised as a concept representing individual responses to the physical, mental, and social effects of daily living, which influence the extent to which personal satisfaction with life circumstances can be achieved. It encompasses more than adequate physical well being, it includes perceptions of well being, a basic sense of satisfaction and a general sense of self-worth (Bowling, 1994). Hence, one challenge when evaluating QoL for people with an illness or disorder, is getting beyond the limitations of the widely used negative definition of health as the absence of disease. The World Health Organisation's (WHO; 1952) definition of health is of total social, psychological and physical well being, but still evaluations of health status in the western world typically focus on disease, illness, and other negative concepts.

An important issue when conceptualising QoL is to recognise the impact of cultural and social factors. If QoL is a subjective perception, it will necessarily be influenced by the individual's frame of reference, as is recognised in the WHO QoL Group (1995), who included in their definition of QoL the individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals. This inclusion will be particularly potent when evaluating QoL for people who belong to a devalued group in society, as could be argued is the case for people with dementia and older people in general. If groups such as these internalise the negative attitudes and beliefs that surround them, they may have particularly modest reference points when evaluating their QoL.
1.2.1 Conceptualising quality of life in dementia

For many chronic degenerative disorders, the ability of health care professionals to affect QoL for the person affected is more realistic than to alter the course of the disorder. This is also true for dementia. QoL in dementia needs to be conceptualised as a complex, comprehensive construct if researchers and clinicians are to fully understand the impact of this disorder. QoL in dementia is a key consideration in: (a) evaluating service programmes; (b) testing the efficacy of new drug treatments; (c) the ethical debate regarding health care resource utilisation; (d) end of life decision making; and (e) developing clinical guidelines (Brod et al., 1999). QoL for people with dementia has not always been a recognised concept. Only 10 years ago, the issue was whether people with dementia could even experience QoL (Brod et al., 1999). People with dementia have even been described as “approaching more closely the condition of animals than normal adult humans in their psychological abilities” (Buchanan & Brock, 1989).

QoL for people with dementia has been defined in variety of ways, or often, not at all (Lawton, 1997). Lawton (1991) has defined QoL as “the multidimensional evaluation, by both the interpersonal and social-normative criteria, of the person-environment of the individual”, which is a generic definition that can be made more relevant to a group by establishing the domains most significant to them. There has not however, been much research into the inter-relationships between domains of QoL, nor have the determinants or the intervening variables that might mediate these relationships been described. Lawton (1997) has suggested five concepts that are relevant to people with
dementia: self-esteem, satisfaction with health care, spare time, meaningful time use, and social engagement.

1.2.2 Qualitative explorations into quality of life in dementia

The subjective meaning of QoL has been qualitatively explored by observation of and conversation with people with dementia. Kitwood and Bredin (1992) listed 12 indicators of well being, which were independent of cognitive functioning, through the development of Dementia Care Mapping, a structured observational method of the quality of care in institutional settings: (1) the assertion of desire or will; (2) the ability to experience and express a range of positive and negative emotions; (3) initiation of social contact; (4) affectionate warmth; (5) social security; (6) self-respect; (7) acceptance of other people with dementia; (8) humour; (9) creativity and self-expression; (10) showing evident pleasure; (11) helpfulness; and (12) relaxation. They further hypothesised that there are 4 global sentient states that are expressed by these indicators: (1) sense of personal worth; (2) sense of agency; (3) social confidence; and (4) hope. Along similar lines John Killick (1997; Killick and Cordonnier, 2000) has in his work with people with dementia enabled them to express their emotions in poetry. One person with dementia expressed in the poem ‘You Are Words’:

"Life is a bit of a strain,  
in view of what is to come.

Sometimes I feel embarrassed  
talking to anybody, even you.  
You don’t really like to burden  
other people with your problems.

I have been a strict person."
What people do now
is completely different. Any beauty
or grace has been desecrated.
The circle of life is shot away.

I want to thank you for listening.
You see, you are words.
Words can make or break you.
Sometimes people don't listen,
they give your words back,
and they're all broken, patched up.

But will you permit me to say
that you have the stillness of silence,
that listens, and lasts."

Through these and other pieces of work there is a consistent thread running, which is the affirmation that people with dementia do find a varying degree of meaning in their lives, and have a strong sense of their own QoL.

1.2.3 Conceptual models of quality of life in dementia

Conceptual models are only beginning to be developed for QoL in dementia. Brod et al. (1999) present the underlying context of dementia-specific QoL, which refers to the individual characteristics and life circumstances that help shape the individual’s subjective experience of QoL. These include: dementia signs and symptoms; co-morbid illness; environment; and non-disease related individual characteristics. In this model, objective functioning and behaviour are considered as intermediate elements resulting from the context, also determining QoL. However, although these can impact on QoL, it is according to this model the individual’s subjective experience of her/his behaviour and functioning that determines how s/he will perceive her/his QoL. Based on their
qualitative work, literature reviews, and clinical experience they define dementia-specific QoL as consisting of five domains: positive affect; negative affect; feelings of belonging; self-esteem; and sense of aesthetics. These are similar to the four sentient states suggested by Kitwood and Bredin (1992) as described above. Hence, central to the model by Brod et al. (1999) is the notion that although the objective dimensions of health are important when assessing the clinical course of illness, it is the person’s subjective interpretation of the objective that truly defines QoL.

Byrne (personal communication, 2002) has hypothesised that QoL in dementia is largely a result of the person’s ability to cope with/adapt to influences in her/his life. As such, a conceptual model of QoL in dementia is currently being developed, where important issues in a person’s life and subjective evaluations via social comparisons form a primary appraisal, which leads to QoL through a secondary appraisal affected by self efficacy and mood.

1.2.4 Dementia and disability

As mentioned above, QoL includes perceptions of well-being, a basic sense of satisfaction and a general sense of self-worth (Bowling, 1994). With the inherent ageism in our society, and the bio-medical model’s conceptualisation of dementia as comprising impairment and disability, these QoL elements might be seen by some as unrealistic. Two points are worth mentioning here. First, the differences between the bio-medical model of disability and the social model of impairment (Makin, 1995). While the bio-medical model sees disability as caused by a disorder, the social model
perceives the disorder as causing impairment, which becomes a disability when society fails to support the individuals special needs. Hence, when the person with dementia cannot function in her/his social and physical environment, this could be perceived as a failure to address her/his individual needs. Meeting these individual needs can be achieved through adapting the environment in which the person functions, for example through carefully worked out routines, labelling, and the use of other appropriate aids.

Secondly, these elements that are crucial to QoL challenge us to open our minds to a new and inclusive view of dementia. As expressed by Russell (1996): "An individualised approach challenges us to go beyond the narrow idea of dementia as a contraction of life to a new and more complex vision of a unique and creative world of those persons living with dementia. This new vision is one in which people with dementia may actually have a more personal, unique, and individual experience because of their dementia". The central word here is because, not despite. This is a position that has been presented for other disorders, for example by Oliver Sacks (1985) in his case descriptions of people with Gilles de la Tourettes Syndrome. Sacks describes people who value the tics and the rapid reactions they have as a consequence of their disorder, and although on medication during the week to conform to the restricted societal view of normality, are medication-free at the weekends to then utilise these tics in their creative outlets. Similarly, some researchers have found cancer patients to report benefits from their illness, such as an increased ability to appreciate each day and greater feelings of personal strength, self assurance, and compassion, thus being more satisfied with their global QoL than healthy comparison groups (e.g. Taylor et al., 1984).
Similarly, Killick (1997; Killick and Cordonnier, 2000) has, through his work, enabled people with dementia to become poets, and thereby express their inner worlds in a creative format. Other people with dementia have discovered their ability to draw and paint, and some artists have reached new dimensions in their work, subsequent to them developing dementia (Allen, personal communication, 2000). Brod et al. (1999) have also recognised this to some extent, and have included 'sense of aesthetics' in their dementia-specific QoL scale. It is important not to misrepresent how it is to live with dementia, but it might be important to recognise the possibility of dementia enriching some aspects of people’s lives, particularly when considering QoL. For example, the author has in her clinical work met people whose relationships to their spouses have improved after they developed dementia, and since most of us have inhibitions imposed on us from a very early age, it might be possible that some degree of disinhibition can be liberating. After all, who is to say that our carefully controlled and polite social being is our true or real self?

1.2.5 Quality of life as a dynamic construct

A primary aim of treatment is to enhance QoL by reducing the impact of illness, particularly in chronic disorders. However, patients with severe disease do not automatically report having a poor QoL (Evans, 1991). Thus, the correlation between QoL and symptoms is neither simple nor direct (Carr et al., 2001). One way of explaining this incongruity has been suggested by Calman (1984), who proposed that we consider QoL as the discrepancy between our expectations and our experience. Psychological, sociological, and health services research all provide evidence that QoL
is a dynamic construct, thus the reference value of people's expectations may change over time (Carr et al., 2001). The latter has been labelled a 'response shift'. Hence, suggestions have been put forward that raising expectations of health is an essential part of the 'critical consciousness' of improving community health. According to a model developed by Sprangers and Schwartz (1999), the response shift is only one of the determinants of changes in self-assessment of QoL. The other elements that may influence this, which might work in interaction, are: a catalyst, such as a change in health status; mechanisms, such as behavioural, cognitive, and affective processes that accommodate changes in health status; and antecedents, that is stable characteristics or the individual's disposition. For example, in a community sample of 348 healthy volunteers, eight of the nine medical outcome study subscales were found to significantly correlate with neuroticism (Muldoon et al., 2001).

1.2.6 A conceptual model of quality of life in dementia

Based on the literature covered above, the following conceptual model of QoL in dementia will be proposed (Figure 1): The person experiences a 'catalyst' (Sprangers and Schwartz, 1999), which is the onset of dementia. The person's QoL while living with this disorder is fundamentally based on the way the person appraises her/his situation (Byrne, personal communication, 2002). This includes the person's perception of her/his worth or usefulness, the person's sense of agency or control over her/his situation; self-confidence; social confidence; abilities and hope, as well as others (Kitwood & Bredin, 1992). This appraisal is influenced by previously established coping mechanisms (and vice versa), and antecedents, which are relatively stable
Figure 1. A conceptual model of quality of life in dementia

- Cognitive abilities/functioning
- Physical health/functioning
- Mood/emotional functioning

Social and physical environment, e.g., ability to adapt to needs, availability of attachment figures, response to person's expression etc.

Appraisal:
- Sense of worth/usefulness
- Agency/control
- Self-confidence
- Social confidence
- Abilities
- Hope etc.

Quality of life in dementia

Catalyst: Onset of dementia

Previously established coping mechanisms

Stable antecedents, such as attachment, personality characteristics etc.

Specific weights affected by culture, wider environment etc.

Universal reference points as to what good QoL entails
characteristics of the person (e.g. attachment, personality etc; Sprangers and Schwartz, 1999). This appraisal process is also influenced by universal reference points as to what good QoL entails, to which specific weights are attached depending on the person’s culture and environment (Carr & Higginson, 2001). Additionally, this appraisal is influenced by the person’s physical health, cognitive abilities and mood/emotional factors (Lawton, 1997). These factors, however, affect the person with dementia’s appraisal of her/his situation through her/his social and physical environment, such as the environment’s ability to adapt to the person’s needs, the availability of attachment figures, and response to the person’s expressions, which again could have an effect on the person with dementia’s cognition, health and mood (Brod et al., 1999; Kitwood & Bredin, 1992; Miesen, 1992).

An example to illustrate this proposed model could be Ms A, who has flexible and well adapted coping strategies, and has been relatively well supported though childhood (i.e. has a secure attachment). Her current environment promotes her individuality and meets her basic needs (physical and mental). Although Ms A’s cognitive abilities are deteriorating and her physical health has a detrimental effect on her ability to move around independently, she feels overall that she has a good life and is currently being adequately cared for. She appraises herself as having a good QoL compared to others she knows. By contrast, Mr B has relatively intact cognitive and physical abilities, but the relatively modest levels of assistance he needs from his environment are not being provided. This has a negative effect on his mood, which again has a detrimental effect on how he is perceived by the people around him. In the past, Mr B has coped with
stress by drinking with his friends, which he can no longer do, and he is finding it difficult to form close relationships with the people around him. As a consequence, he feels that he has a poor QoL, a perception that is amplified by knowing that most of his old friends are still able to live independently and meet for a drink in the pub.

1.2.7 In conclusion

QoL is fundamentally recognised as a concept representing individual responses to the physical, mental, and social factors affecting well being, which influence the extent to which personal satisfaction with life circumstances can be achieved. QoL in dementia needs to be conceptualised as a complex, comprehensive construct if researchers and clinicians are to fully understand the impact of this disorder, but it has only recently become a recognised concept. Qualitative explorations have been conducted into the subjective meaning of QoL in dementia, and conceptual models are beginning to be developed. Based on the current literature, a conceptual model of QoL in dementia has been proposed, in which the person’s QoL is based on the way the person appraises her/his situation. This appraisal is influenced by previously established coping mechanisms and antecedents, universal reference points and specific cultural weights, and the person’s physical health, cognitive abilities and mood through her/his social and physical environment.

1.3 MEASURING QUALITY OF LIFE IN DEMENTIA

There has been a rapid increase in the use of QoL evaluations as a technique of clinical research since 1973, when only 5 articles listed ‘quality of life’ as a reference key word
in literature databases. During the subsequent five-year periods, there were 195, 273, 490, and 1252 such articles (Testa & Simonson, 1996). There are currently over 1000 generic and health-related QoL instruments that have been developed using a multitude of approaches to measurement (Hedrick et al., 1996), and over 1000 new articles are each year indexed under 'quality of life' (Muldoon et al., 2001).

1.3.0 The value of quality of life assessment

QoL measures have at least eight potential uses in aiding clinical practice: (1) prioritising problems; (2) facilitating communication; (3) screening for potential problems; (4) identifying preferences; (5) monitoring changes or response to treatment; (6) training staff; (7) aiding clinical audits; and (8) facilitating clinical governance (Higginson & Carr, 2001). In addition to the properties needed when using an assessment scale in research (such as those mentioned above), there are other properties required to ensure that a measure can be used routinely in clinical practice. These properties include: (a) the appropriateness of the measure (which is not always the case, as most assessment scales were developed for use in clinical research where time and budgetary constraints are different from those in clinical practice, and the purpose is to assess changes over longer periods of time in individual patients rather than differences between groups of patients in relatively short-term studies); (b) its responsiveness to clinical change; and (c) its interpretability in terms of what it is that constitutes a meaningful change, and to whom (Higginson & Carr, 2001).
1.3.1 Ethical issues in the assessment of quality of life

There are some difficult ethical issues to consider when aiming to evaluate QoL. Some people will resist even opening up to the possibility that one can put a value upon QoL, because all life is sacred (e.g. Aksoy, 2000). Some of this resistance might have been accentuated by historical events, such as the Holocaust, where Jewish and other minorities' lives were rendered 'life not worthy of life' by their Nazi executioners.

On a different scale, people are every day faced with making life-or-death decisions, regarding lives artificially prolonged by life-sustaining technology, and sometimes the courts will be the setting where these decisions will be made (e.g. Keown, 1997). One example well covered by media was the case of the conjoined twins, Mary and Jodie, who had a common aorta, and who were separated against their parents' wishes after a ruling by the Court of Appeal. As expected, the weaker twin died. One could conclude that this was a judgment made on QoL grounds, which contrasts with the doctrine of the sanctity of life (Huxtable, 2000). There have also been recent cases in the courts, such as the ones involving Diane Pretty and Mrs H, arguing for a person’s right to die.

1.3.2 Quality of life as a quantifiable construct

Frank-Stromborg (1988) identified decisions regarding the assessment of QoL as: (a) qualitative versus quantitative measures; (b) objective (the person's QoL measured by a health professional) versus subjective measures (the person assessing her/his own QoL); (c) objective indicators (housing, income, work) versus subjective measures (psychosocial); and (d) generic versus domain-specific measures. Additionally, it has been pointed out that clinicians and researchers should consider whether a conceptually
complex notion such as QoL can and should be quantified (e.g. Canam & Acorn, 1999). The EuroQol Group (1990) argues that there are two schools of thought regarding this issue. Although both schools agree that QoL is a multidimensional phenomenon, they disagree as to the implications of this. One school of thought states that the measurement of QoL must necessarily be multidimensional, and the appropriate aim is for a QoL profile, in which assessment only is possible within a dimension. The second school of thought, however, notes that people have to weight the diverse attributes of health to determine which is seen as the more important, and thus it should be possible to generate a single index value for each health state by a suitable investigatory method. Both subjective and objective indicators might be needed to measure QoL, if subjective indicators address life experiences whereas objective indicators address the factors that influence those experiences. However, there are restrictions to the use of multiple measures when assessing QoL, such as feasibility, cost, and time required (Canam & Acron, 1999).

1.3.3 Challenges in quality of life assessment

Callahan (1992) has defined QoL as "the subjective experience or consciousness possible for a person in an ongoing situation". He further states that 'Reality as we know is bipolar: subjective consciousness inescapably exists as individuals respond from their particular standpoints, and objective reality exists beyond individual perspectives, for things are as they are ... Because of the dynamic, ever changing nature of subjectivity, it is extremely difficult to make reliable and valid assessments of another individual's consciousness or potential competencies. When dealing with
human beings who can pretend, deceive, cooperate or not, the problems and obstacles of objective assessment are legion'. Indeed, Aksoy (2000) concluded that it is not possible to measure the QoL of an individual either accurately or reliably!

Thus, the greatest challenge of assessing QoL lies in its uniqueness to individuals, which assessment scales might not be taking into account when imposing standardised models of QoL and preselected domains. They may therefore be measures of health status rather than QoL. In this vein, three problems of assessing QoL have been put forward: (1) people have different expectations, that is their evaluations of their QoL are made within the horizons of possibilities that they see for themselves; (2) people might be at different points on their illness pathway when their QoL is measured; and (3) psychological, sociological, and health services research all provide evidence that QoL is a dynamic construct, thus the reference value of their expectations may change over time (Carr et al., 2001).

Through attempting to quantify and compare QoL between different groups using standardised generic assessment scales, an incongruence has been found, labeled the 'disability paradox'. That is, people's QoL scores do not necessarily seem to correspond with their functional and health problems. For example, one study found more than half of a group of patients to report having good or excellent QoL despite reporting severe problems in performing daily tasks, being socially isolated and having limited income and benefits (Albrecht & Devlieger, 1999). Similarly, people with neoplasms rated their QoL in the top quarter of the WHOQOL questionnaire across all life domains, which
was better than all other groups including those attending a family planning clinic (Skevington, 1999), and people in hospices reported lower scores than apparently healthy adults on psychophysiological and functional well being, but not on social and spiritual well being (McMillan & Weitzner, 1999). Furthermore, Bowling (1994) found discrepancies between the free responses people made about the areas of their life that were most affected by their illness and those elicited using ‘prompt cards’, which casts further doubt that the scores from standardised measures captures the person’s QoL. However, using individualised assessment scales also has inherent difficulties. For example, some people may not understand a weighting system (Macduff & Russell, 1998). Furthermore, people assessed might not readily volunteer all factors important to them, particularly those related to mood (Vachon et al., 1995), or this information may change over time (Higginson et al., 1994).

The complexity of QoL as a concept means that difficulties might be identified that are outside the usual remit of medical care (Feinstein, 1992). Higginson and Carr (2001) have suggested that this raises a number of ethical concerns: (1) The act of assessing QoL in a clinical setting might result in an expectation that the clinician will be able to influence it, if not what would the purpose of measuring it? (2) Some pressure groups, such as The Movement for Independent Living in the US, have objected to the clinical measurement of QoL as it represents the ‘overmedicalisation’ of life and clinical interference in aspects of peoples’ lives that should not be the concern of the clinician; and (3) Chronic disorders affect and are affected by broader aspects of peoples’ lives,
such as their relationships and social support, and information on these aspects can influence treatment decisions and assessment of health care needs.

1.3.4 Quality of life assessment in dementia

QoL assessments comprise a highly complex procedure of introspection and evaluation, involving several components of cognition including implicit and explicit memory (Barofsky, 1996), and so after a certain level of cognitive decline, self-assessment of QoL is commonly thought of as becoming too difficult (e.g. Selai et al. 2000). At what stage this cut-off applies is not made clear. A cut-off point of 9/10 on the Mini Mental State Examination (MMSE; Folstein et al., 1975) has been suggested (Mozley et al, 1999), but the rationale for this is not made explicit. Other challenges include the dilemma of how to address the different stages of dementia, and compare small improvements late in the disease progression with small differences early on that might not be particularly beneficial or noteworthy (Selai, 1998). Among the ethical issues in need of consideration when assessing QoL in dementia are those concerning personhood, the self, and the value of life (Harris, 1988; Post, 1995). When assessing QoL almost inevitably language has to be used, which may pose problems for people with dementia, since language impairment can be one early symptom of this condition, as can loss of ‘insight’ or ‘awareness’ (Markova & Berrios, 1992).

1.3.5 ‘Patient’ vs. proxy ratings of quality of life in dementia

Whether people with dementia can evaluate their own QoL has been a much debated issue, which has evolved around the use of subjective versus objective entities (e.g.
Lawton, 1994, 1997), and whether to use patient or proxy ratings, or both. Although it is generally agreed that because of the highly subjective nature of this concept, any appraisal of QoL should rely where possible on the perception of the individual person. Albert et al. (1996) stated that people with AD "cannot comprehend questions or report on subjective states", and have further concluded that "while the subjective world of the demented patient is not directly assessable, readily observable behaviours offer a basis for assessing quality of life" (Albert et al., 1996). However, as pointed out by Whitehouse (1998), the subjective world is not directly accessible in any individual, whether they have dementia or not. Additionally, as Lockwood (1990) emphasised: "people have what philosophers call 'privileged access' to their own lives; they know better than anyone else can, just what it is like to be them".

Direct respondent assessment has therefore, until recently, seldom been undertaken due to the presumed logistical and methodological issues, such as concerns about comprehension and reliability (Steward et al., 1996). However, inferring subjective QoL from external circumstances or 'objective' domains does not fully take into account the values, needs, and adaptations of individuals to various life circumstances (Flanagan, 1982; Sanifort et al, 1996). Furthermore, the use of proxies to measure QoL for people with dementia has inherent difficulties. These include characteristics of the proxy such as the nature of the relationship and time spent with the person with dementia, the degree of objectiveness of the questions, and the level of impairment may influence the degree of correspondence between proxy and client responses (Magaziner et al., 1988; Zimmerman & Magaziner, 1994). Both relatives and healthcare professionals have also
been found to frequently underestimate peoples QoL (Sprangers & Aronson, 1992). How people perceive behaviour and overt expressions of emotion varies. For example, Innes (1998) found that what behaviour staff in a residential home perceived as ‘challenging’, varied according to their relationship to the person, with behaviour displayed by residents previously defined as challenging being described as difficult, whilst similar behaviour by other residents with whom the staff had a better relationship, might be described as ‘attempts to communicate’. Thus, even if the proxy is someone who knows the person with dementia in depth and is concerned for the person’s well being, they will be imposing their own subjectivity upon their judgments, which is likely to be affected by their own sense of well being and mood. For instance, caregivers’ QoL has been found to be related to their perception of the QoL of terminally ill cancer patients (McMillian & Mahon, 1994). Research has also shown that there are discrepancies in how people with dementia and their carers put value on different health states to disease severity (Neumann et al., 1998).

1.3.6 The question of ‘insight’

The main argument that has been used by researchers and clinicians for using ‘objective’ measures or proxy reports to assess QoL in dementia is that due to the cognitive deficits that are the main features of this disorder, the person with dementia cannot report reliably on internal states. They are thought to lack ‘insight’. However, whether a person has insight or not, is typically based on what is defined as ‘reality’ by another person with greater power or status than the person (Cheston & Bender, 1999). For example, if a person with dementia does not think that s/he has a problem with her/his...
memory, s/he will be described as lacking in insight, but who is to say that the person’s impaired memory is a problem for her/him? And, if a person thinks that her/his memory is not impaired relative to others surrounding them, or to previous achievements, is it thereby our right as health professionals to conclude that the person’s reference point is inferior, or that her/his expectations of declining memory in old age are faulty? Mozley et al. (1999) presented the possibility of a person with dementia answering questions about the residential home in which s/he is residing whilst it was clear that the person thought s/he was living in her/his mother’s care. According to these authors, this would then be evidence that the person with dementia’s answers were unreliable. However, as long as researchers and clinicians are interested in the person’s perception of her/his QoL, is this really a problem? Furthermore, this author has through her clinical work experienced people with dementia being clear that they have dementia, but touching their heart every time they talk about ‘their problem’. Is this insight? Lawton (1997) states than when individuals have an ‘idiosyncratic, deviant, or psychotic’ assessment of her/his QoL there is a need for a frame of reference against which the individual’s subjective assessment can be compared. However, this ‘frame of reference’ will inevitably have to be somebody’s judgement of the person’s QoL, based on ‘objective criteria’ or clinical experience.

Lawton (1997) further states that emotions and moods long have been known to compose major aspects of the quality of daily life, and that these change from day to day and in rough synchrony with changing circumstances and daily events. If this is so, maybe the variability of response is more of an issue than whether the person with
dementia’s perception of her/his QoL corresponds with ours, and as such the assessment of QoL may need to be conducted over a certain time-span rather than being a ‘snapshot’ of one moment in time. This is an issue central also to the methods used to assess people with dementia on other variables than QoL, and also taps into the debate about to what extent QoL can be considered a dynamic construct.

Another important issue in this regard is the function of denial. According to Chester and Bender (1999) denial can be functional and adaptive. These authors state that denial as a coping mechanism can protect the person against something that is too traumatic and overwhelming to deal with. Research has also shown denial as being linked to survival in women with breast cancer (Greer et al., 1979). The difficulty arises when the denial is no longer adaptive, but this might not be the case at the time of the QoL assessment.

Thus, the view that people with dementia cannot reliably report on their QoL seems to be taken much at face value, but is lacking in empirical support. As expressed by Russell (1996), “the issue of judging something as nonsensical may have less to do with the (dis)abilities of the person with dementia than the (dis)abilities of the researcher”. Just because we have not been able to find a way of reliably assessing people with dementia’s QoL as yet, does not mean that it is not possible. For example, Parmelee et al. (1989) found the Geriatric Depression Scale (GDS; Yesavage et al., 1983) to be as useful with nursing home residents with moderate cognitive impairment as with
residents with relatively intact cognitive abilities. Maybe similar studies need to be conducted before dismissing self-report QoL assessments with people with dementia.

1.3.7 Using assessment scales in quality of life research

When assessing QoL, relevant components and domains are typically identified, as simply asking people to rate their QoL on a Likert scale is too vague and ambiguous. Hence, these domains and components might then be translated into a quantitative value that indicates overall QoL. This is a complex task, drawing from the field of clinimetrics, psychometrics, and clinical decision theory (Testa & Simonson, 1996). Because most components of QoL cannot be observed directly, they are commonly evaluated according to the classic principles of item-measurement theory (Lord, 1980).

The three study designs most commonly used in QoL evaluations are: (1) cross-sectional or non-randomised longitudinal studies, describing predictors of QoL; (2) randomised studies of clinical interventions; and (3) the study of cost effectiveness and cost-benefit. The rationale for a QoL evaluation in clinical research should be described in an analytic model, including a hypothesis of the relationship between predictor variables, response variables, and the time frame within which the effects on QoL will be obtained (Testa & Simonson, 1996). Additionally, the inclusion of a QoL evaluation in a study must be meaningful. The routine inclusion of QoL assessments in clinical trials without a clear structure or well-defined rationale has been criticised (Lancet, 1995).
1.3.8 Psychometric properties of quality of life assessment scales

A critical appraisal of the use of QoL assessment scales was conducted by Gill and Feinstein (1994). A total of 75 articles were included, using 159 different scales, of which many were judged by the authors to be unlikely to capture the essence of QoL. The conclusion reached by the authors was that the psychometric principles underlying these assessment scales might not be satisfactory for the clinical goal of indicating what clinicians and individuals assessed perceive as QoL. Hence, most of these scales were judged to have poor face, or construct validity.

1.3.8.0 Validity of assessment scales of quality of life in dementia

Validity refers to the extent of which an assessment scale measures what it set out to measure (Prince, 1998). There are several aspects of validity worth establishing, which in the literature seems to have different definitions and categories. The following classifications are all taken from Prince (1998).

*Construct validity* refers to what extent the construct that the assessment scale aims to measure is indeed a real and concrete entity, and the salience of the scale to that construct. Although this can not be demonstrated empirically, evidence can be sought to support it. This can be done through semi-structured interviews or focus groups with 'key informants', where the construct is discussed, as is the appropriateness of the assessment scale ('face validity'). Additionally, an exploratory factor analysis may help to establish whether the construct is homogenous or multi-dimensional. With constructs as complex as QoL, it could be argued that construct validity is most meaningful (Senn,
personal communication, 2001) of all the aspects of validity. Although difficult to quantify, focus groups with people with dementia and their carers has commonly been used the aid the development of new assessment scales of QoL in dementia (Brod et al., 1999; Byrne, personal communication, 2002). When investigating the use of generic scales to assess QoL in dementia, their poor construct validity for this use has been emphasised (Selai, 2000; Silberfeld et al., 2002).

Concurrent validity is tested by the extent to which an assessment scale relates to other measures given at the same moment in time. This can be done in several ways. The assessment scale can be compared to an existing criterion measure, which should be the current 'gold standard' for assessing the construct. As there is currently no such gold standard for assessment scales of QoL in dementia, this entails a real difficulty when attempting to establish the criterion validity of these scales. Alternatively, convergent and divergent validity can be tested in relation to each other. This means comparing the assessment scale to a measure of a similar construct and also to a different one, hypothesising that it would correlate more strongly with the former than the latter. Lastly, known group validity can be used, in which the scores obtained from the scale are divided into groups defined by a pre-defined criterion expected to relate to the construct assessed. The value of the latter two types of validity will depend on the rationale underlying the chosen constructs/criterion.
Finally, *predictive validity* refers to the extent to which an assessment scale can predict future variables. This type of validity is not commonly reported in the literature, possibly due to data for most studies being collected over short time intervals.

### 1.3.8.1 Reliability of assessment scales of quality of life in dementia

Reliability refers to the consistency of an assessment scale when given repeatedly under similar circumstances (Prince, 1998). The following differentiations are based on Prince (1998).

*Inter-rater reliability* tests the stability of the assessment scale when given and rated by different researchers in the same interview. This might be seen as a particularly important aspect of reliability to establish in this context, since many assessment scales of QoL in dementia need to interviewer-assisted, as the person with dementia may find self-completion difficult. There will then be a degree of interpretation present on the part of the assessor.

*Test-retest reliability* tests the stability of an assessment scale over time. The scale is given to the person assessed by the same assessor at two moments in time under the same conditions, and the correlation between the two established. The time interval used is a matter of judgement on part of the researcher. Within the field of dementia, this needs to be within a timeframe based on good clinical judgement estimating the rate of deterioration. However, with the fluctuations often found in dementia, it could be
argued that poor test-retest reliability is not necessarily that meaningful (Selai, personal communication, 2002).

Finally, the *internal consistency* of an assessment scale refers the extent to which its component parts, or individual items, address a common underlying construct. However, it has been argued that this psychometric aim might be in disagreement with the goals of attaining construct validity and comprehensiveness (Brazier & Deverill, 1999).

### 1.3.8.2 Sensitivity to change of assessment scales of quality of life in dementia

As well as being valid and reliable, the assessment scale must be responsive to changes caused by clinical interventions or other changes, be sensitive to true changes in QoL and not include an inadequate range of responses leading to floor or ceiling effects (Testa & Simonson, 1996). A challenge in this regard is the question of what constitutes a clinically meaningful change in dementia, and what effects deterioration will have on a person's QoL.

### 1.3.9 Generic quality of life assessment

One generic method that has been developed to aid the assessment of QoL is the use of Quality Adjusted Life Years (QALYs). The QALY approach represents life as a series of 'quality-weighted' health states, where the quality weights reflect the desirability of living in each state. These quality weights are then multiplied by the time spent in that state, and these products are summed to obtain the total number of QALYs (Neuman et
Advantages of this method include the possibility of capturing both quantity- and quality- of life effects, as it includes preference weightings. Another advantage is the transparency of the calculations. Additionally, this approach permits comparisons of QoL across diseases and interventions. There are however, important methodological issues to consider when using QALYs. One is the question of whose preference should form the basis of the quality weights. Another concerns what measurement technique to use.

Another generic QoL scale commonly used is the EuroQoL EQ-5D, which was developed by the EuroQoL Group (1990), an international and multi-disciplinary research group whose members are involved in assessments of QoL for different client groups. This scale produces a single index measure based on self-reported scores on five dimensions: mobility, self-care, usual activities, pain/discomfort, and anxiety/depression. The EQ-5D additionally includes a self-rated visual analogue scale. It has been validated in several countries, and it is uncomplicated and can be completed in a short time-span. However, questions have been raised as to whether this scale is sensitive to the aspects of importance to the QoL of all client groups (e.g. Silberfeld et al., 2002).

1.3.10 Assessment scales of quality of life in dementia

According to Selai and Trimble (2001) QoL should be regarded as a multidimensional construct comprising physical, psychological, and social well being. Furthermore, QoL is a subjective, individual experience (Callahan, 1992), and as stated by Whitehouse and
Rabins (1992) "ultimately, it is up to each individual to evaluate and assess her or his own QoL based on the importance that s/he gives to each component". Thus, it has been suggested that summing up all the dimensions together to calculate a person's overall score does not take into account that each person places a different value on the importance of each dimension in contributing to her or his QoL (Canam & Acorn, 1999). Despite this, most research into QoL in dementia to date has used a single construct to assess QoL.

1.3.10.0 Applying generic quality of life assessment scales to dementia

One option when attempting to assess QoL in dementia is using the generic QALY approach, as described in paragraph 1.2.1.4 - Generic quality of life scales of this chapter. This raises several specific challenges. One involves the sensitivity of generic health-state classification systems to the changing characteristics of dementia (Neumann et al., 1998). Some dementia-specific attributes that might not be well captured by generic QALYs include: ability to participate in enjoyable activities, ability to perform household tasks, the degree of frustration or confusion, the extent to which a person can leave her/his immediate neighbourhood and travel on public transportation, and ability to function in social settings (DeJong et al., 1989). Changes attributable to settings of care may also be important to capture, for example moving to a residential home might cause feelings of depersonalisation, lack of autonomy, and social distance from friends and family (Stewart et al., 1996). These are not challenges unique to the QALY approach. A more central issue is that when comparing QALYs across client groups, difficulties arise for people suffering from degenerative disorders, such as dementia. A
relatively small improvement in their situation will be much more costly than a cheaper, relatively effective intervention for people who suffer from less severe, short-lived diseases for example, or the prevention of accidents among the general population. Thus, QALYs must be used with caution, because they might discriminate against people suffering from disorders such as dementia resulting in them being given a low priority for health care. However, one strong feature of the QALY approach is the preference weighting aspect, which is all but unique to this approach and gives it stronger measurement powers than many QoL scales.

Also described in paragraph 1.2.1.4 of this chapter is the EuroQoL EQ-5D, which is one QoL scale used to calculate QALYs. This has been used to assess QoL in dementia (e.g. Coucill et al., 2001), as have the Health Utilities Index (Kerner et al., 1998) and the Quality of Well Being Scale (Neuman et al., 1999). However, the appropriateness of using these measures with this client group has been questioned, particularly as they have not as yet been validated for this use (Selai, 2001). One pilot study conducted, questioned the face/content validity of the EQ-5D (Selai et al., 2000). Similarly, in a study investigating the face/content validity of all the above measures, the conclusion was made that all three measures had important shortcomings in this regard, as they were missing attributes identified by people with dementia and their carers as essential for people with dementia's QoL. These included coping with memory loss, feeling useful/valuable to others, and fear of embarrassment and being alone (Silberfeld et al., 2002). Therefore, if these scales are used to make comparisons of the effectiveness of
interventions for dementia and others disorders, dementia may not compare favourably, as the scales do not include aspects important to this disorder.

A more individualised approach has been adopted by Selai et al. (2000) through the adaptation of the Quality of Life Assessment Schedule (QOLAS) for dementia. The basis for this instrument is the belief that QoL instruments developed within the psychometric tradition commonly have excluded items important to the beliefs and values of the person assessed (Gill, 1995). The QOLAS is a subject-driven approach, in that it is personally tailored to the person assessed. This instrument has its basis in psychological theories and methods such as Personal Construct Theory and the Repertory Grid Technique (Fransella & Bannister, 1977). Here, the respondents are first asked to give an account of the elements important to their QoL, from which 10 key constructs are extracted. The person is then invited to rate how much of a problem each of these constructs is now on a six-point scale. Hence, the QOLAS produces both qualitative and quantitative data. This instrument has been found to have good content, construct and criterion validity and internal reliability (Selai et al., 2000). However, it is a relatively time-consuming scale to use, and as such may prove difficult to combine with the measurement of other outcome variables in clinical trials.

Another individualised generic QoL scale that has been used with people with dementia is The Schedule for the Evaluation of Individual QoL-Direct Weighting Method (SEIQoL-DW; O’Boyle et al., 1996), which is the revised version of The Schedule for the Evaluation of Individual QoL (SEIQoL; McGee et al., 1991). This consists of 3
QUALITY OF LIFE IN DEMENTIA

Introduction...

stages. During the first stage the person being assessed extracts 5 areas of life most important to them, which s/he then rate in stage 2 on a visual analogue scale from 0 (worst possible) to 100 (best possible). In stage 3, the person being assessed rates the relative importance of each of the 5 areas using coloured discs that create a pie chart of which each colour represents an area. The SEIQoL has been found to have high criterion validity in a sample of healthy people (Browne et al., 1997), to be sensitive to change and have reasonably good construct validity, but relatively poor test-test reliability (Murrell et al., 1999).

1.3.10.1 Dementia-specific quality of life scales

Research has shown that the effects of therapeutic interventions to improve QoL in any condition are best measured with sensitivity by disease-specific instruments that focus on the domains most relevant to the disease under investigation (e.g. Epstein et al., 1989; Testa & Simonson, 1996). These also have an increased likelihood of capturing change over time (Guyatt et al., 1987; Howard & Rockwood, 1995). It is generally agreed that due to the highly subjective nature of this concept, any appraisal of QoL should rely, where possible, on the perception of the individual person. Despite this, proxy reports have often been used when assessing QoL in dementia, for the reasons discussed above, as are the problems with using proxy reports to infer QoL. One of the scales used is the Alzheimer’s Disease Related Quality of Life (ADRQL; Rabins et al., 1999). This scale has 47 items that relate to 5 dementia-specific domains: (1) Relating to and being around other people; (2) The person’s special identity and important relationships; (3) Different types of distress behaviour; (4) Usual activities; and (5) Behaviour in a person’s living
environment. Other dementia-specific scales rated by proxies include the Progressive Deterioration Scale (DeJong et al., 1989) and the Pleasant Event Schedule – AD (Teri & Logsdon, 1991). However, the last few years have also seen the development of several dementia-specific self-report scales, and more are under development. Three of these scales will now be outlined.

The Bristol Quality Of Life – Dementia (BQOLS-Dementia; Byrne, personal communication, 2002) is a recently developed, individualised, self-report, dementia-specific QoL measure. It is based on literature reviews and 9 focus groups conducted, each consisting of 2-4 people with dementia scoring between 1 and 3 on the Clinical Dementia Rating scale (CDR; Hughes et al., 1982). From these focus groups 7 themes were identified as important for QoL for in dementia: (1) Social life (relationship with spouse, children etc.); (2) Psychological well being (happiness, feeling of usefulness etc.); (3) Religion/Spirituality (connections with religious community etc.); (4) Independence (not being dependent upon others, living in own home etc.); (5) Cognition (confusion, effect on spouse of memory difficulties etc.); (6) Ways to spend one’s time (hobbies, housework etc.); and (7) Financial security (not being in debt, having money to pay bills etc.). Based on these findings, Byrne (personal communication, 2002) developed a computer programme that aims to measure QoL in dementia. This presents one pair of the items extracted from the focus groups at the time on the computer screen, and the person with dementia is asked to rate one as more important than the other, and has a built-in reliability measure. When all the items have been compared with all others, they are each given a position of importance in relation to each other, which is
used to weight the items after the person with dementia has scored them on a 100 mm Likert scale from ‘bad’ to ‘good’. However, due to the recent development of this scale, it has not been properly validated as yet. As with the QOLAS (Selai et al., 2000) described above, this is also a relatively time-consuming scale to use. As such it may prove difficult to combine this with the measurement of other outcome variables in clinical trials.

The Dementia Quality of Life Scale (DQoL; Brod et al., 1999) is a 29-item scale based on 5 domains identified as important to people with dementia. These domains were extracted from three focus groups consisting of caregivers for people with dementia, health staff working with this client group, and people with mild to moderate dementia. These five domains are: positive affect; negative affect; feelings of belonging; self-esteem; and sense of aesthetics. The scores are given by the person with dementia on a 5-point Likert scale. Brod et al. (1999) have found their scale to have good internal consistency, test-retest reliability, and construct validity. This is a standardised scale, and as such is easier to comprehend than the individualised assessment scales outlined above. However, it does focus heavily on internal states (‘how loveable do you feel?’) and concepts seemingly quite alien to British participants (‘how often do you enjoy looking at colours?’). As such, it can also be quite time-consuming and complex to complete.

The Quality Of Life – Alzheimer’s Disease (QOL-AD) has been developed by Logsdon et al. (1999). This obtains a rating of the person with dementia’s QoL from both the
person and the caregiver, and is based on a literature review of QoL in older people and on the assessment of QoL in other chronically ill populations. It has 13 items covering the domains of physical health, energy, mood, living situation, memory, family, marriage, friends, chores, fun, money, and self and life as a whole. This scale has the advantage of being brief, which is often essential when assessing people with dementia with a typically decreasing attention span. The QOL-AD also has the advantage of being of a self-report format, and incorporating both the person with dementia and caregivers’ ratings. Early studies by Logsdon et al. (1999) suggest it to have good internal consistency, construct validity and test-retest reliability. The QOL-AD has also been administered to a convenience sample in the UK, who was then interviewed about the comprehensibility of the instrument by Selai et al (2001), who found no problems in understanding the scale, or any need for adaptation for the UK.

1.3.11 Research into quality of life in dementia

Most studies of QoL are hampered by poor designs and inadequate assessment methods (Bowling, 1994). As mentioned above, a problem for validity purposes is that there is no ‘gold standard’ to compare instruments against, because initial decisions on content and structure made at the design stage of instruments were guided by the specific purpose of each instrument, and compatibility with other instruments was not usually given any consideration (EuroQol Group, 1990).

To date, few studies have empirically investigated QoL in dementia. Additionally, when QoL instruments have been included in trials, for instance of the effects of anti-dementia
drugs, the QoL scales utilised have either not been well-validated for use with people with dementia (Howard & Rockwood, 1995), or have not assessed QoL comprehensively, but have evaluated only some aspects of affect or activities of daily living (Salek et al., 1998). Albert et al. (2001) examined three developed indicators of low QoL in advanced AD: confinement to home, null activity, and null positive affect, as reported by patient proxies. The researchers found these indicators to be predicted by increased dementia severity. Kutner et al. (1999) investigated family members’ and care staff’s perception of QoL changes for residents with dementia in a special care unit (SCU) and an intermediate care facility (ICF). These authors found these ratings to reflect greater improvement in global ratings of QoL for the residents since moving into the SCU than for the ICF. Ballard et al. (2001) used Dementia Care Mapping (DCM; Kitwood & Bredin, 1994) in a study of QoL for people with dementia living in residential and nursing home care. Their findings showed lower performance on activities of daily living, increased social withdrawal, reduced engagement in activities, and taking psychotropic medication to be associated with reduced QoL, but not with psychiatric symptoms.

Logsdon et al. (1999) found high QoL in AD to be predicted by low levels of depressive symptoms, more independent functioning in activities of daily living, and more years of education. Their results also suggested good agreement between the person with dementia and caregiver report versions of their measure (QOL-AD). This contrasts with the findings by Selai et al. (2001), which indicated discrepancies between patient and proxy ratings on the QOLAS. However, the QOL-AD differs greatly from the QOLAS.
the latter being an individualised and person-centred assessment technique, while the QOL-AD is of a standardised format, placing equal emphasis on each QoL component. The difference between these two scales illustrates the tension in the measurement of QoL between the acknowledgement that this is a subjective and idiosyncratic concept and the need for data collection to be reliable and valid. The suggestion has been put forward that qualitative methods of assessing QoL are more valid, whilst quantitative methods are more reliable (Mays & Pope, 1996). The evaluation of QoL for people with dementia is still in its early development, and it is likely that a number of approaches will be developed, each appropriate for a different purpose, as has been the case with other client groups (Selai et al., 2001).

1.3.12 In conclusion

There are many challenges to be addressed when attempting to measure QoL for any group of people, and perhaps even more when doing so for people whose disorder might entail some degree of confusion and comprehension difficulties, such as those with dementia. QoL is a complex and dynamic construct, and as such its relationship with illness progression is not as straightforward as was previously believed. Whether a conceptually complex notion such as QoL can and should be quantified has been questioned. Additionally, there are difficult ethical issues to consider when aiming to evaluate QoL, such as putting a value upon this, and particularly so on behalf of another person. The challenge of assessing QoL lies in its uniqueness to individuals. However, whether people with dementia can evaluate their own QoL has been a much debated issue.
Measurement of QoL should: address the objective and subjective components important to the population assessed and target and measure what it claims to measure (be valid) and generate values that are consistent under constant conditions (be reliable). Additionally, the measurement must be sensitive to true changes in QoL. In general, generic assessment scales seem to be lacking construct/face validity when applied to dementia, whilst the validation of dementia-specific scales is still in its infancy. Furthermore, most studies of QoL are hampered by poor designs and inadequate assessment methods, and few studies have to date empirically investigated QoL in dementia. When QoL instruments have been included in trials, for instance of the effects of anti-dementia drugs, the QoL scales utilised have either not been well-validated for use with people with dementia, or have not assessed QoL comprehensively.

1.4 AIMS AND HYPOTHESES

This thesis will explore the factors associated with QoL in dementia, in an attempt to investigate aspects of a proposed conceptual model of QoL in dementia. This will also involve examining factors associated with change in QoL in dementia, in the context of an evidence-based psychological group therapy programme. Lastly, the validity, reliability and sensitivity to change of the shortest and most easily intelligible assessment scale of QoL in dementia currently available; the QOL-AD (Logsdon et al., 1999) will be investigated.

Aim 1: To explore what factors are associated with QoL in dementia, such as functioning, cognition and mood.
Aim 2: To investigate whether environmental factors such as size and location of residential homes and day centres are associated with QoL in dementia.

Aim 3: To establish whether demographic factors such as age, education and gender are associated with QoL in dementia.

Aim 4: To investigate what factors are associated with change in QoL in dementia, in the context of an evidence-based psychological group therapy programme.

Aim 5: To investigate the reliability and validity of the QOL-AD scale (Logsdon et al., 1999), and its sensitivity to change.

Hypotheses:

Hypothesis 1: There will be a significant relationship between higher QoL, and better physical functioning; cognitive functioning; and better mood.

Hypothesis 2: Environmental factors such as size and location of residential homes and day centres will be associated with QoL in dementia.

Hypothesis 3: Demographic factors such as age, education, and gender will be associated with QoL in dementia.

Hypothesis 4: An evidence-based psychological group therapy programme will have a significant positive effect on QoL in dementia.
Hypothesis 5: There will be a significant relationship between improvement of QoL and a positive change on other factors, such as functioning, cognition and mood.

Hypothesis 6: The QOL-AD will be found to have good validity and reliability, and sensitivity to change.

1.5 OVERVIEW OF THESIS

Chapter 2 will examine factors associated with QoL and other variables in dementia, including levels of physical functioning, cognitive functioning, anxiety and depression. This chapter will also investigate the effects on QoL in dementia of demographic factors, such as age, education, gender and different aspects of living in residential homes or attending day centres. Chapter 3 will present the effects found on QoL in a single-blind randomised controlled trial of an evidence-based psychological group therapy programme for people with dementia. It will also examine associations between change in QoL and the other variables in dementia described above. Chapter 4 of this thesis will present a study of the validity and reliability of the Quality of Life-Alzheimer's Disease Scale (QOL-AD; Logsdon et al., 1999). It will describe investigations into the psychometric properties of this scale, including its: face/content validity; construct validity; criterion concurrent validity; convergent and divergent concurrent validity; know group concurrent validity; inter-rater reliability; test-retest reliability; and internal consistency. The final chapter of this thesis (Discussion) will attempt to evaluate the studies described above, and outline their strengths and limitations. This chapter will also aim to put these findings into context, and to form
some conclusions as to how the findings presented in this thesis have added to our knowledge of QoL in dementia.
CHAPTER 2: Factors Associated with Quality of Life in Dementia

2.0 AIMS

Aim 1: To explore what factors are associated with QoL in dementia, such as functioning, cognition and mood.

Aim 2: To investigate whether environmental factors such as size and location of residential homes and day centres are associated with QoL in dementia.

Aim 3: To establish whether demographic factors such as age, education and gender are associated with QoL in dementia.

2.1 METHOD

2.1.0 Design

2.1.0.1 Recruitment of centres

Various health authorities and organisations were contacted by mail, inquiring about possible interest in running the project in residential homes and day centres within their trust/organisation. Letters of support were received from Barking, Havering & Brentwood Community NHS Trust, Quantum Care Ltd. (a voluntary care organisation in Hertfordshire), Enfield & Haringey Health Authority, Camden and Islington Community Health Services NHS Trusts, Mid-Essex Community & Mental Health NHS Trust, and Tower Hamlets Healthcare NHS Trust (Appendix D). Approval was then sought and obtained from the Multi-Research Ethics Committee for the North Thames area, and Local Research Ethics Committees in the relevant
areas (Appendix D). Addresses for the private and local authority residential homes and day centres in each trust were obtained from social services, or the central body of the organisation. These were then sent: (a) an introduction letter providing a background to the project, what it involved, and its main objectives (Appendix D); (b) a copy of the information sheet and consent form (Appendix D); and (c) for the second half of the study, a copy of the inclusion flow chart (Appendix D), which was developed on the basis of the inclusion criteria (see below), in order to make them more accessible for managers and care staff. This information was followed up with a phone call to the manager of the day centre (DC) or residential home (RH) within a week, inquiring about interest in participating in the project and suitability of the centre, and providing any additional information required. If appropriate, a meeting was then arranged with the manager.

2.1.0.2 Selection of participants

The inclusion criteria were as follows: (1) Meeting the DSM-IV (APA, 1994) criteria for dementia; (2) Scoring between 10 and 24 on the Mini Mental State Examination (MMSE; Folstein et al., 1975); (3) Some ability to communicate and understand communication, which was determined by a score of 1 or 0 in questions 12 and 13 of the CAPE Behaviour Rating Scale (Pattie and Gilleard, 1979); (4) Being able to see and hear well enough to participate in a meaningful assessment; (5) Not displaying behaviour that would make interview impossible, such as constant wandering, shouting, or aggression; and (6) Not having a diagnosis of learning disability or current clinical depression, which would also make reliable assessment difficult. These inclusion criteria entailed a continuous exclusion of inappropriate participants.
throughout the assessment stage. In the initial meeting with the manager of the DC or RH, the inclusion flow chart was used to select the service users or residents appropriate for screening. These were then approached by their key worker with information about the project (Appendix D), and their relatives were contacted to ensure their approval of their relative being included in the project. Although not an ethical requirement, this was done to minimise the risk of participating in the project putting any strain on the relationship between the person with the dementia and her/his relative, or between the DC/RH and the person with dementia’s family. In DCs, the informed consent of the relative was also sought, in relation to their own participation in the study. Subsequently, possible participants were screened, using the MMSE. Before screening, informed consent was obtained in conjunction with the person’s key worker. A day was then agreed upon to conduct the full assessments.

2.1.0.3 Assessment procedure

The possible participants were reminded again on the day of the full assessment of the purpose and procedures of the project, and asked if they still consented to taking part. If they consented, an interview was conducted with the researcher and the possible participants individually in a quiet room, lasting approximately 45 minutes. The measures given in this interview were the Quality of Life-Alzheimer’s Disease Scale (QOL-AD; Logsdon et al., 1999), the Mini Mental State Examination (MMSE; Folstein et al., 1975) and the Alzheimer’s Disease Assessment Scale – Cognition (ADAS-Cog; Rosen et al., 1984). Subsequently, the person’s key worker completed the Clifton Assessment Procedures for the Elderly - Behaviour Rating Scale (CAPE-
BRS; Pattie & Gilleard, 1979) and the Holden Communication Scale (Holden & Woods, 1995). Additionally, the person’s key worker completed the Cornell Scale for Depression in Dementia (CSDD; Alexopoulos et al., 1988) and the Rating Anxiety in Dementia (RAID; Shankar et al., 1999) in conjunction with the researcher. For DCs, an interview was additionally arranged with the participant’s informal carer or closest relative, where the QOL-AD was completed from their perspective.

2.1.1 Diagnostic criteria

**DSM-IV (APA, 1994):** The diagnostic criteria outlined in DSM-IV describe dementia as the development of multiple cognitive deficits manifested by both memory impairment (impaired ability to learn new information or to recall previously learned information) and one (or more) of the following cognitive disturbances: (1) aphasia (language disturbance, i.e. inability to name people or objects); (2) apraxia (impaired ability to carry out motor activities despite intact motor function); (3) agnosia (failure to recognise or identify objects despite intact sensory function); and (4) disturbance in executive functioning (i.e. planning, organising, sequencing, abstracting). These cognitive deficits need to each cause significant impairment in social or occupational functioning and represent a significant decline from a previous level of functioning. The deficits must not occur exclusively during the course of a delirium. The disturbance must not be better accounted for by another Axis I disorder (e.g. Major Depressive Disorder). Other symptoms include: motor disturbances of gait (leading to falls), disinhibited behaviour, slurred speech (in
dementia associated with subcortical pathology such as Parkinson's disease and Huntington's disease), delusions and visual hallucinations.

2.1.2 Measures

A) Quality of Life – Alzheimer’s Disease (QOL-AD): The QOL measure used in this study was the Quality of Life- Alzheimer’s Disease (QOL-AD; Logsdon et al., 1999). This can obtain a rating of the person with dementia's QoL from both the person and the caregiver, and these scores can be combined into a single score, weighting the person with dementia's own QoL score twice as heavily as the carer’s. The QOL-AD is based on a literature review of QoL in older people and on the assessment of QoL in other chronically ill populations. It has 13 items covering the domains of physical health, energy, mood, living situation, memory, family, marriage, friends, chores, fun, money, self and life as a whole. These are scored on a scale ranging from 1 (poor) to 4 (excellent), with a possible range from 13 to 52. This scale has the advantage of being brief. The QOL-AD also has the advantage of being of a self-report format, and making it possible to incorporate both person with dementia and the caregivers' ratings. Early studies by Logsdon et al. (1999) suggest it to have good internal consistency, construct and test-retest reliability. The fact that the QOL-AD is a four-point scale, has certain psychometric implications. There is not much room for variation on the individual items, and thus it is possible that change on these items may not be easily detected. However, for the scale overall there is scope for detecting change. Additionally, a four-point scale has the advantage of having no mid-point (average), and as such the participant cannot
remain 'undecided'. It is also relatively easy to complete, which is essential for use with people with dementia.

B) **Clinical Dementia Rating:** Dementia severity was measured using the Clinical Dementia Rating (CDR; Hughes et al., 1982). This is a global scale completed on the basis of interviews with both the person with dementia and a member of her/his care staff team, and describes performance in six areas of cognitive functioning; memory, orientation, judgement and problem solving, communication skills, domestic skills, and personal care. Dementia is staged in five levels: 0 = No impairment; 0.5 = Questionable impairment; 1 = Mild dementia; 2 = Moderate dementia; and 3 = Severe dementia. Good reliability and validity have been demonstrated for this scale. For the purpose of analyses in this study, the CDR was recoded into a dichotomous variable; low (0.5-1.0) and high (2.0-3.0) dementia severity.

C) **Mini Mental State Examination:** Cognitive function was measured using the Mini Mental State Examination (MMSE; Folstein et al., 1975), which is a brief and well-established test of cognitive function. It consists of 11 items, involving orientation to time, orientation to place, registration of three words, attention, calculation, recall, language, and visual construction. The scale ranges from 0 to 30, with 0-10 commonly described as severe dementia, 11-20 moderate dementia, and 21-26 mild dementia. Good reliability and validity have been demonstrated for this scale.
D) *Alzheimer's Disease Assessment Scale – Cognition:* A second measure of cognitive level was the Alzheimer's Disease Assessment Scale – Cognition (ADAS-Cog; Rosen et al., 1984), which is more sensitive to change than the MMSE and includes more items which assesses short term memory. It assesses word recall and recognition, naming objects, following commands, orientation, praxis, drawing, and observations of language ability. The standardised scoring method gives a range from 0 to 70, where 70 indicates the greatest impairment. Inter-rater and test-retest reliability and validity have been found to be high.

E) *Cornell Scale for Depression in Dementia:* For measuring depression, the Cornell Scale for Depression in Dementia (CSDD; Alexopoulos et al., 1988) was used, which includes 19 items under 5 categories: mood related signs, behavioural disturbance, physical signs, biological functions, and ideational disturbance. These are scored on a three-point scale, ranging from 0 (Absent); 1 (Mild/intermittent); to 2 (Severe). A score of 7 or more is thought to indicate clinical depression. This scale uses information from the researcher’s interview with the person with dementia and a member of her/his care staff team. Good reliability and validity have been demonstrated.

F) *Rating Anxiety in Dementia:* The Rating Anxiety in Dementia (RAID; Shankar et al., 1999) was used for measuring anxiety, in which 18 items are included under 6 categories: worry, apprehension and vigilance, motor tension and autonomic hypersensitivity, phobias, and panic attacks. It scores symptoms from 0 to 3, where 0 = Absent; 1 = Mild/intermittent; 2 = Moderate; and 3 = Severe. A score of 11 or
above indicates clinical anxiety, and possible scores range from 0 to 54. This scale uses information from clinician’s interview with carer and patient, and good reliability and validity have been shown.

G) **Clifton Assessment Procedures for the Elderly - Behaviour Rating Scale:**
The Clifton Assessment Procedures for the Elderly - Behaviour Rating Scale (CAPE-BRS; Pattie & Gilleard, 1979) was selected as a measure of dependency and functioning. It consists of 18 items, which cover general behaviour, personal care, and behaviour towards others. Questions include an evaluation of the person's ability to bathe and dress her/himself, walk, take care of personal appearance, socialise, keep active, communicate, understand communication, help out in the home/RH, and sleep. This scale ranges from 0 to 36, and possible item scores range from 0 to 2, with 2 representing the most difficulty. It has been shown to have good reliability and validity.

H) **Holden Communication Scale:** The Holden Communication Scale (HCS; Holden & Woods, 1995) was used as a measure of communication and interaction. It is a 12-item scale, covering a range of social behaviour and communication variables, including conversation, attempts to communicate, awareness, pleasure, humour, and responsiveness. The scores range from 0-4, and the score most adequately describing the person's behaviour in the two weeks prior to assessment is noted. The scale correlates well with measures of dependency and cognition. It ranges from 0 to 48, and was included because it includes items that might be particularly responsive to change following small group work.
2.2 RESULTS

2.2.0 Characteristics of participants

In total, 292 people were screened. Of these, 201 were included. Reasons for exclusion were: Scoring less than 10 on the MMSE or having communication difficulties (44); having hearing impairment that was too great to participate in groups (10); having visual impairment that was too great to participate in groups (7); not having dementia (15); having a learning disability (3); becoming distressed or aggressive during assessment (10) and dying between screening and full assessment (2). The ages of the participants ranged from 66 to 101, with a mean age of 85.3 (Table 1). The sample consisted of 158 (78.6%) females, with 172 participants

Table 1. Descriptive characteristics of participants

<table>
<thead>
<tr>
<th></th>
<th>n = 201 mean (sd) [range]/no. (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age</td>
<td>85.3 (7.0) [66-101]</td>
</tr>
<tr>
<td>Female</td>
<td>158 (78.6%)</td>
</tr>
<tr>
<td>In residential care</td>
<td>172 (86.4%)</td>
</tr>
<tr>
<td>Cognition (MMSE)</td>
<td>14.4 (3.8) [7-24]</td>
</tr>
<tr>
<td>Cognition (ADAS-Cog)</td>
<td>27.0 (7.5) [8.0-48.5]</td>
</tr>
<tr>
<td>Dementia Severity (CDR)</td>
<td>1.4 (0.5) [0.5-2.0]</td>
</tr>
<tr>
<td>QoL (QOL-AD)</td>
<td>33.3 (5.8) [17-47]</td>
</tr>
<tr>
<td>Depression (CSDD)</td>
<td>5.5 (4.9) [0-25]</td>
</tr>
<tr>
<td>Anxiety (RAID)</td>
<td>9.1 (8.2) [0-55]</td>
</tr>
<tr>
<td>Dependency (CAPE-BRS)</td>
<td>11.4 (4.8) [0-23]</td>
</tr>
<tr>
<td>Communication (HCS)</td>
<td>10.6 (5.7) [0-31]</td>
</tr>
</tbody>
</table>
QUALITY OF LIFE IN DEMENTIA
Factors Associated with Quality of Life in Dementia...

(86.4%) living in residential care. The sample scored on average as having moderate to severe dementia on the MMSE (14.4) and the CDR (1.4), and scored in the middle range on the QOL-AD (33.3). Furthermore, the participants' mean scores were below the cut-off for clinical depression (5.5) and anxiety (9.1), and in the middle range on the measures of dependency (11.4) and communication (10.6)

2.2.1 Associations between quality of life & other variables in dementia

In order to investigate the relationships between QoL and the other variables studied, One-way Anovas were carried out for the categorical data (gender, RH vs. DC, and the recoded CDR), while Pearson's Correlations were conducted for the continuous data. The results are shown in Table 2, which shows a significant correlation between level of depression and QoL (-0.195, p < 0.01), with lower levels of depression correlating with higher QoL. Additionally, higher levels of functioning correlated with higher QoL (-0.139, p < 0.05). There was a trend for lower levels of anxiety to be correlated with higher QoL (- 0.120, p = 0.052). Age, gender, communication abilities, cognitive functioning, dementia level, and whether the participant lived in a residential home or attended a day centre were not associated with QoL.
Table 2. Correlations between quality of life & other variables

<table>
<thead>
<tr>
<th>VARIABLE</th>
<th>Quality of Life (QOL-AD)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Statistical analysis</td>
</tr>
<tr>
<td>Age</td>
<td>Pearson's correlation</td>
</tr>
<tr>
<td>Gender</td>
<td>Anova</td>
</tr>
<tr>
<td>Residential – Day Centre</td>
<td>Anova</td>
</tr>
<tr>
<td>Cognition (MMSE)</td>
<td>Pearson's correlation</td>
</tr>
<tr>
<td>Cognition (ADAS-Cog)</td>
<td>Pearson's correlation</td>
</tr>
<tr>
<td>Dementia level (CDR)</td>
<td>Anova</td>
</tr>
<tr>
<td>Depression (CSDD)</td>
<td>Pearson's correlation</td>
</tr>
<tr>
<td>Anxiety (RAID)</td>
<td>Pearson's correlation</td>
</tr>
<tr>
<td>Communication (HCS)</td>
<td>Pearson's correlation</td>
</tr>
<tr>
<td>Functioning (CAPE-BRS)</td>
<td>Pearson's correlation</td>
</tr>
</tbody>
</table>

2.2.2 Correlations between QOL-AD items and other measures

To investigate how the components of QoL measured by the QOL-AD were linked with other factors, Pearson’s Correlations were performed using the QOL-AD items and the scales that were associated with total QOL-AD score, the CSDD, CAPE-BRS and RAID (Table 3). However, due to the large number of comparisons made, and the increased risk of Type I error this entailed, only correlations reaching the 0.001 level of significance are discussed (Bonferroni correction). There were only two correlations found to be significant at this level, both ‘life situation’ and ‘money’ on
Table 3. Correlations between QOL-AD items & other scales

<table>
<thead>
<tr>
<th>SCALE</th>
<th>physical health</th>
<th>energy</th>
<th>mood</th>
<th>life situation</th>
<th>memory</th>
<th>marriage</th>
<th>family</th>
<th>friends</th>
<th>self</th>
<th>chores</th>
<th>fun</th>
<th>money</th>
<th>life</th>
</tr>
</thead>
<tbody>
<tr>
<td>CSDD</td>
<td>-.041</td>
<td>.157</td>
<td>-.142</td>
<td>-.241</td>
<td>-.052</td>
<td>-.087</td>
<td>-.076</td>
<td>-.169</td>
<td>.013</td>
<td>-.025</td>
<td>-.122</td>
<td>-.243</td>
<td>-.086</td>
</tr>
<tr>
<td>RAID</td>
<td>-.011</td>
<td>.050</td>
<td>.066</td>
<td>-.210</td>
<td>-.014</td>
<td>-.061</td>
<td>.017</td>
<td>-.120</td>
<td>.035</td>
<td>-.049</td>
<td>-.080</td>
<td>-.209</td>
<td>.001</td>
</tr>
<tr>
<td>CAPE-BRS</td>
<td>-.142</td>
<td>.184</td>
<td>.020</td>
<td>-.198</td>
<td>.110</td>
<td>-.169</td>
<td>-.034</td>
<td>-.111</td>
<td>-.014</td>
<td>-.048</td>
<td>-.032</td>
<td>-.178</td>
<td>.042</td>
</tr>
</tbody>
</table>

Factors Associated with Quality of Life in Dementia: .93
the QOL-AD were found to be correlated with depression (CSDD; -.241 and -.243 respectively).

2.2.3 Predictors of quality of life in dementia

To investigate which variables predicted total QoL score, a Stepwise Multiple Regression was performed. As such, all the variables investigated were entered simultaneously, and the effect of each was examined at every step for entry or removal. As there was great variation between centres used in the study, this variable was recoded into a series of dichotomous variables (as discrete variables could not be included in the regression). These were: residential vs. day care; setting (inner city location vs. urban/rural); size/number of residents; and publicly vs. privately funded service providers. The results are shown in Table 4, which shows the unstandardised coefficients (B), the standardised coefficient (beta), and significance of each variable entered into the model, the variance explained by this model (R square), and the significance of this. As can be seen in this table, the variables that reached statistical significance as predictors of total QOL-AD score were CDR group (0.5-1 vs. 2-3), i.e. having more severe dementia was predictive of having higher perceived QoL (p < 0.05); setting, i.e. living in or attending a centre in an urban/rural location was predictive of having higher QoL (p < 0.01) relative to living in an inner city location; and total number of residents/service users, i.e. living in or attending a centre with more residents or service users was predictive of higher QoL (p < 0.05). This model as a whole only explained 11.2% of the variance found in QoL for people with dementia, although this was a significant value (p < 0.01). Age, gender, cognition (as measured by the MMSE and the ADAS-Cog), depression (CSDD), anxiety (RAID),
communication (HCS), functioning (CAPE-BRS) or other differences between centres (residential vs. day care and publicly vs. privately funded service providers) did not enter the model.

Table 4. Predictors of quality of life in dementia

<table>
<thead>
<tr>
<th>VARIABLE</th>
<th>B</th>
<th>beta</th>
<th>Significance</th>
</tr>
</thead>
<tbody>
<tr>
<td>CDR group</td>
<td>2.144</td>
<td>0.196</td>
<td>p &lt; 0.05</td>
</tr>
<tr>
<td>Setting</td>
<td>3.666</td>
<td>0.284</td>
<td>p &lt; 0.01</td>
</tr>
<tr>
<td>Number of residents/attenders</td>
<td>0.033</td>
<td>0.214</td>
<td>p &lt; 0.05</td>
</tr>
</tbody>
</table>

Total variance explained

R square = .112 p < 0.01

2.3 DISCUSSION

2.3.0 Quality of life and functioning in dementia

The results from this study showed a significant correlation between higher levels of functioning and higher QoL for people with dementia. These findings are similar to those of Logsdon et al. (1999) who found high QoL in AD to be predicted by more independent functioning in activities of daily living. In the present study, trends were found for functioning to be more closely correlated with aspects of QoL, such as higher ratings of physical health, energy, life situation, marriage/significant other, and financial situation. While some of these aspects would be expected to correlate with level of functioning (e.g. physical health and energy), other correlations might be seen as being more unclear. However, as these aspects reflect the perception of the person with dementia, it might be that higher levels of functioning are associated
with higher levels of perceived control, and as such these aspects might be framed more positively by the person with dementia.

2.3.1 Quality of life and mood in dementia

This study found a significant correlation between level of depression and QoL, with lower levels of depression correlating with higher QoL. This is similar to the findings of Logsdon et al. (1999), who found high QoL in AD to be predicted by low levels of depressive symptoms. The present study also found lower levels of depression to be significantly correlated with positively perceived life situation and positively perceived financial situation. Depression would be expected to be associated with these aspects of QoL, but the same could be said for other items of the QOL-AD. Maybe there are certain relationships in life, such as with partner or significant other, family, and oneself that are relatively stable and are not greatly affected by depression? Lower levels of anxiety were correlated with higher QOL-AD score, although not significantly. However, the relationship between QoL and mood in dementia might be different in a sample experiencing higher levels of depression and anxiety.

2.3.2 Quality of life and level of cognition and severity in dementia

QoL in dementia was not found to be correlated with cognitive abilities or dementia level. However, using multiple regression to control for other variables, dementia level was found to significantly predict QoL in dementia, with a score of moderate/severe dementia being predictive of having higher QoL than a score of mild dementia. This contrasts with the findings by Albert et al. (2001), who found three
indicators of QoL to be predicted by dementia severity, with people with more severe dementia having lower QoL. However, Albert et al. (2001) used proxies to determine people with dementia's QoL which, has amongst other things, been found to be associated with caregiver burden and caregiver depression (Karlawish et al., 2001). Thorgrimsen et al. (2002) found in a randomised controlled trial of reminiscence therapy that as cognitive abilities deteriorated, QoL as perceived by the person with dementia increased, while QoL for the person with dementia as perceived by her/his closest relative deteriorated. These contrasting findings might be explained by both dementia severity and QoL being assessed in non-comparable ways. The present study used the Clinical Dementia Rating (CDR; Hughes et al., 1982) to assess dementia level, which is different from assessing level of dementia with the use of cognitive tests, and might explain why level of cognition was not found to be predictive of QoL. The finding that people with more severe dementia perceived their QoL as being higher than people with mild dementia could be due to a difference in how people with dementia appraise their situation. This would be supported by findings by Zank and Leipold (2001), who found that people with mild dementia reported more depressive symptoms and less life satisfaction than people with more severe dementia, if there were few physical health constraints.

2.3.3 Quality of life and other variables in dementia

A mean range of nearly 30 points on the QOL-AD between the 23 centres included was found out of a total possible range of 39 (13 items rated 1 to 4 each) in this study. This means that the scale is sensitive to different levels of QoL and the full range of scores are required. Investigations of the different elements that varied
between centres found the setting and size of the centre to be partially predictive of its residents’ (or attendees’) QoL. People with dementia living in a residential home or attending a day centre in an urban/rural area would, on the basis of these findings, be expected to have higher QoL than those in an inner city location. Possible reasons for this finding could be that residents/attendees in these centres belonged to a group different in terms of education or financial situation, or that these centres had less staffing problems than their inner city counterparts. Also living in or attending a centre with more residents/service users was found to be predictive of having a higher QoL. This could be due to the fact that these centres were different in terms of resources, or that they are aimed at catering for people with dementia with lower levels of disability, or were able to provide a range of activities to serve a wider range of people and disabilities. Other variables studied, such as age, gender, communication level, whether in residential or day care, and whether funded by private or public sources, were not found to have an effect on QoL in dementia.

2.3.4 Limitations

One limitation of this study is that people with severe dementia, learning disabilities, severe depression, or profound hearing difficulties or blindness were excluded, as it would have not have been possible to conduct valid assessments. Hence, there is a possibility that these groups would have differed in some way in relation to QoL. Other limitations include the fact that while QoL and cognition were rated in assessment interviews with the person with dementia, the perceptions of care staff and the researchers were a necessary component for the other variables studied, as it often the case. Thus, these involve a degree of subjectivity from proxy reporters,
which although based as far as possible on objective indicators might not correlate
with the person with dementia's own experience, which is assessed by the QOL-AD.
Furthermore, although aiming to include the QOL-AD as completed by the person
with dementia's carer, this proved a problem. Not many carers were available, as the
majority of people with dementia lived alone, and as such the data obtained was so
sparse that its inclusion did not seem meaningful. However, the agreement between
people with dementia and their carers' ratings of the QOL-AD has repeatedly been
found to be good (Logsdon et al, 1999; Logsdon et al, in press). Lastly, there were
only a few correlations detected between QoL and other variables in this study, and
these were relatively low, although statistically significant. However, it has been
argued that only correlations of 0.4 and above may be clinically significant (Dunn &
Everett, 1995). Thus, the results presented in this chapter must be considered with
cautions, as none of the correlations reported reached this suggested level of clinical
significance. Similarly, the variables found to significantly predict QoL in dementia
only explained 11.2% of the variance in scores, which further suggests that the
factors associated with QoL in dementia are largely unknown. Therefore, more work
is needed in this area, and other variables are in need of study, in order to find out
more about what affects QoL in dementia.

2.3.5 Conclusion

This study found statistically significant correlations between better perceived QoL
and higher levels of functioning and lower levels of depression in dementia, although
whether these are clinically significant associations is unclear. The variables were
found to correlate more strongly with certain aspects of QoL, such as more positively
perceived life situation, relationship with partner/significant other, and financial situation. QoL in dementia was not found to be correlated with cognitive function. In a multivariate analysis higher QoL was associated with more severe dementia, being in a larger residential home or day centre and not living in an inner city area, but these variables only explained 11.2% of the variance. This suggests that QoL is a largely independent variable, which needs to be measured in its own right, rather than using other variables as proxy measures in order to make assumptions about the person with dementia’s QoL. QoL in dementia is subjective by its very nature. This study suggests that it is independent of level of cognitive function, but might be influenced by mood and environmental factors. Therefore, these results suggest that interventions aimed at improving QoL in dementia might be better served by not focussing exclusively on cognition.
CHAPTER 3: Factors Associated with Change in Quality of Life in Dementia

3.0 AIMS

Aim 4: To investigate what factors are associated with change in QoL in dementia, in the context of an evidence-based psychological group therapy programme.

3.1 METHOD

3.1.0 Design

3.1.0.1 Recruitment of centres

Described in Chapter 2 - 2.1.0.1, Recruitment of centres, page 84-85 of this thesis.

3.1.0.2 Selection of participants

Described in Chapter 2 - 2.1.0.2, Selection of participants, page 85-86 of this thesis.

3.1.0.3 Assessment procedure

Described in Chapter 2 - 2.1.0.3 Assessment procedure, page 86 of this thesis.

All assessments were repeated 8 weeks after the initial assessment.

3.1.0.4 Randomisation

This was done by the researcher blind to the outcomes of the assessment, by drawing sealed envelopes containing participants’ names from a container. The 5 first names to be drawn were allocated to the experimental group, and the remaining names
(minimum 3) to the control group. This meant that each centre needed a minimum of 8 suitable participants to be included in the study. Group allocation was not disclosed to the researcher doing the follow-up assessments.

3.1.1 Intervention

3.1.1.0 Procedure

The groups commenced on the week subsequent to the baseline assessment being completed. They ran for 7 weeks, twice weekly for 45 minutes, in the same room at the same times. The group each consisted of the five participants randomly allocated to the experimental group, the researcher blind to assessment outcomes, and one member of the care staff team in the DC or RH where the group was conducted. The aim was for this to be the same person for every session. This is reported more fully in Spector (2001).

3.1.1.1 Development of programme

In view of the lack of rigorous and up-to-date research on the effectiveness of reality orientation and reminiscence therapy, two Cochrane systematic reviews were conducted (Spector et al, 1998a, Spector et al., 1998b) on these two therapies for dementia. Combining the data from six randomised controlled trials which met standards for methodological quality, RO was found to be associated with significant improvements in both cognition and behaviour. The results of the Cochrane review of reminiscence therapy for dementia concluded that there was not currently sufficient evidence for its effectiveness, but a reminiscence element was also included in the programme, as there is evidence of a less scientifically rigorous kind
to support its use with people with dementia (e.g. Head et al., 1990; Cheston, 1996),
The elements found to be effective in the trials identified, were then used to develop
a programme of evidence-based psychological group therapy (Spector et al., 2001).
This was piloted in three residential care homes and one day centre and there were
appreciable improvements in cognition and depression for people participating in the
programme compared to a no-treatment control group (Spector et al., 2001).

3.1.1.2 Group programme

The full programme can be found in Appendix C.

Features of the programme included:

(1) A reality orientation board, displaying both personal and orientation information,
including the group name (chosen by participants). The board would provide a focus,
reminding people of the name and nature of the group, and creating continuity.

(2) A warm-up activity, typically a soft ball game. This was a gentle, non-cognitive
exercise, aiming to provide continuity and orientation by beginning all sessions in the
same way.

(3) Sessions focusing on themes (such as childhood and food), allowing the natural
process of reminiscence but with an additional focus on the current day. Multi-
sensory stimulation was introduced when possible.

(4) Sessions encouraging the use of information processing rather than factual
knowledge. For example in ‘faces’, people were asked “who looks the youngest?”,
“what do these people have in common?”, with factual information as an optional extra.

(5) A choice of activities in each session, enabling the facilitator to adapt the session according to the group's capabilities, interests and gender mix.

Sessions:

1) Introduction
2) Sound
3) Early memories
4) Food
5) Current affairs
6) Faces / scenes
7) Associated words/discussion
8) Categorising objects
9) Orientation
10) Using money
11) Number-related activity
12) Word-related activity
13) Using objects
14) End of programme activity
3.1.2 Diagnostic criteria

*DSM-IV.* As described in Chapter 2 - 2.1.1 Diagnostic criteria, p 86-87 of this thesis.

3.1.3 Outcome Measures

A) Quality of Life – Alzheimer’s Disease (QOL-AD; Logsdon et al., 1999).
B) Clinical Dementia Rating (CDR; Hughes et al., 1982).
C) Mini Mental State Examination (MMSE; Folstein et al., 1975).
D) Alzheimer’s Disease Assessment Scale – Cognition (ADAS-Cog; Rosen et al., 1984).
E) Cornell Scale for Depression in Dementia (CSDD; Alexopoulos et al., 1988).
F) Rating Anxiety in Dementia (RAID; Shankar et al., 1999).

All measures are described in Chapter 2 – 2.1.1, Measures, page 89-92 of this thesis.

3.1.4 Analyses

3.1.4.0 Power analysis

Power analysis calculations were made as part of the development of the protocol, in order to determine how likely the study was to produce a statistically significant result for a difference between groups of a given magnitude. Professor Stephen Senn, Department of Statistical Sciences at UCL, provided assistance in calculating power by using the MMSE results from a pilot study conducted, including the same
procedures and measures as the main study with 17 participants in 2 centres (Spector et al., 2001). The mean difference in MMSE score at follow-up was equivalent to 3.1 (sd = 5.5) for both the experimental and the control group. This gave an estimated effect size of 0.56 (3.1 over 5.5). Referring to the appropriate table in Sample Size Tables for Clinical Studies (Machin et al., 1997) with power set at 80%, 0.05 level of significance and an effect size of 0.56, the sample needed in both experimental group and control group was 53. This implied that in order to achieve an 80% chance of detecting the specified difference of 3.1 points on the MMSE with a significance level of .05, a total sample of 106 participants was needed.

3.1.4.1 Intention to treat analysis

An ‘intention to treat’ analysis was conducted, as it was thought important to include if possible in the analysis people who had discontinued their participation in the study. This was done to ensure that the participants in the sample were representative of the target population. This involved including all the people who were randomised, whether they took part in the whole programme or not. Thus, all participants were invited to attend follow-up assessments. In comparison to ‘per protocol analysis’, which only includes people who accepted treatment, it avoids attrition biases and increases external validity. However, due to various factors (outlined in paragraph 4.1.0 of this chapter), it was not possible to conduct follow-up assessment on all participants.
3.1.4.2 Statistical Analyses

Assessments were scored and data entered into SPSS (version 10) by one researcher and checked by another. ANCOVA (analysis of covariance) was used as the method of analysis. This controls for variability in pre-test scores (the 'covariate'). It is a sensitive test, which increases the power of an F-test for the main effects or interaction by removing the predictable variance associated with covariates from the error term (Tabachnick & Fidell, 2001). This implies that undesirable variance in the dependent variable (e.g. individual differences) are estimated by scores on covariates. By providing adjustments, the relationship between the dependent variable and covariates are removed from the error term.

Statistical advice was sought on the methods of multivariate analysis. It was suggested that initially, the main effects alone should be entered into the ANCOVA. Hence when investigating QOL-AD, the model would include QOL-AD1, QOL-AD2, centre and condition. An additional analysis should include the interaction of centre and condition. This was because treatment participants might not be considered to be one large group receiving an identical intervention, but as a set of groups receiving an intervention of which the effects were a result of a) the content of the programme (which was fixed); and b) the group dynamics (which were variable). Hence the random effects model was used, as this model allows centres to be considered a random factor. Analysis was performed for treatment and control participants within each centre, and then combined between centres to get an overall result. The advisor suggested that this should be conducted separately to a main
effects only model, as there is no certainty as to how SPSS weights centres (e.g. according to size or equally), reducing the accuracy of the calculations.

Instructions to SPSS, when analysing the QOL-AD using ANCOVA were as follows:

Analyse -> general linear model -> univariate

Dependent variable: QOL-AD 2 (QOL-AD at follow-up)

Fixed factor: Condition (1 = treatment, 2 = control)

Random factor: Centre (1-16)

Covariates: QOL-AD 1 (QOL-AD at baseline)

Age

Gender

Additionally, the model option was entered, and type II error was highlighted. This considers the effect of the intervention once baseline scores and the effect of the centres (the covariates) are taken into account. The main effects of 'condition', 'centre', 'QOL-AD1', 'age' and 'gender' were highlighted. An interaction between 'centre' and 'condition' was created in the second analysis.

3.2 RESULTS

3.2.0 Response rate and attrition

Response rate

Twenty-three centres (18 residential homes and 5 day centres) were included in the project. Out of 292 people screened 201 met the inclusion criteria. There were 115 treatment participants at baseline and 97 at follow-up and 86 control participants at
baseline and 70 at follow-up. (Figure 2). The mean attendance was 11.6 sessions (sd 3.2) (range 2 to 14) and 89% of people attended 7 or more sessions.

**Figure 2. Attrition**

![Attrition chart]

Reasons for exclusion:

44: MMSE <10 or communication difficulties.
10: Too hearing impaired
7: Too visually impaired
15: Did not have dementia
3: Had learning disabilities
10: Became distressed or aggressive during assessment
2: Died between screening and full assessment
3.2.1 Characteristics of participants

The study included 201 participants, of whom 115 were in the experimental group and 86 acted as controls. Characteristics of the participants are shown in Table 5. As can be seen in this table, the experimental groups had a higher female – male ratio. Additionally, participants in the experimental group were somewhat older than the controls, and were reported as having slightly lower levels of anxiety and depression and slightly higher levels of communication abilities. Level of cognition, dementia level, functioning and QoL were similar between the two groups. None of the differences reached statistical significance.

Table 5. Descriptive characteristics of participants at baseline.

<table>
<thead>
<tr>
<th>CHARACTERISTICS</th>
<th>TREATMENT</th>
<th>CONTROL</th>
<th>ALL</th>
</tr>
</thead>
<tbody>
<tr>
<td>Number</td>
<td>115</td>
<td>86</td>
<td>201</td>
</tr>
<tr>
<td>Mean age (sd), [range]</td>
<td>85.7 (6.2) [66-101]</td>
<td>84.7 (7.9) [66-99]</td>
<td>85.3 (7.0) [66-101]</td>
</tr>
<tr>
<td>Gender ratio (female, male)</td>
<td>4.0 : 1 (96, 24)</td>
<td>3.3 : 1 (62, 19)</td>
<td>3.7 : 1 (158, 43)</td>
</tr>
<tr>
<td>Mean cognition; MMSE (sd), [range]</td>
<td>14.2 (3.9) [7-22]</td>
<td>14.8 (3.8) [8-24]</td>
<td>14.4 (3.8) [7-24]</td>
</tr>
<tr>
<td>Mean cognition; ADAS-Cog (sd), [range]</td>
<td>27.4 (7.2) [11.0-48.5]</td>
<td>26.8 (7.9) [8.0-44.0]</td>
<td>27.0 (7.5) [8.0-48.5]</td>
</tr>
<tr>
<td>Mean dementia level; CDR (sd), [range]</td>
<td>1.4 (0.5) [0.5-2.0]</td>
<td>1.4 (0.5) [0.5-2.0]</td>
<td>1.4 (0.5) [0.5-2.0]</td>
</tr>
<tr>
<td>Mean depression; CSDD (sd), [range]</td>
<td>5.2 (5.0) [0-25]</td>
<td>6.9 (4.7) [0-19]</td>
<td>5.5 (4.9) [0-25]</td>
</tr>
<tr>
<td>Mean anxiety; RAID (sd), [range]</td>
<td>8.4 (8.0) [0-55]</td>
<td>10.1 (8.5) [0-39]</td>
<td>9.1 (8.2) [0-55]</td>
</tr>
<tr>
<td>Mean dependency; CAPE-BRS (sd), [range]</td>
<td>11.3 (4.7) [3-11]</td>
<td>11.5 (5.1) [0-23]</td>
<td>11.4 (4.8) [0-23]</td>
</tr>
<tr>
<td>Mean communication; HCS (sd), [range]</td>
<td>11.1 (5.9) [0-31]</td>
<td>9.9 (5.5) [0-25]</td>
<td>10.6 (5.7) [0-31]</td>
</tr>
<tr>
<td>Mean QoL; QOL-AD (sd), [range]</td>
<td>33.2 (5.9) [17-46]</td>
<td>33.4 (5.7) [17-47]</td>
<td>33.3 (5.8) [17-47]</td>
</tr>
</tbody>
</table>
3.2.2 Changes in quality of life in dementia

In order to investigate the effect of the intervention on the QoL for people with dementia, an ANCOVA was conducted, as described in the method. To further explore what aspects of QoL the intervention had an effect on, a Mann-Whitney test was carried out on the items of the QOL-AD. This non-parametric analysis was chosen because it compares medians, converting the continuous variable into ranks, and as such, the distribution of the scores is not important. The results are shown in Table 6, which also reports the means. As can be seen here, the results showed that the intervention had a significant positive effect on total QOL-AD score (F = 6.87, p < 0.01). The aspects of QoL that improved significantly for the participants in the experimental group relative to controls were: 'energy level' (Z = -1.97, p < 0.05),

Table 6. Between group differences pre & post intervention on the QOL-AD.

<table>
<thead>
<tr>
<th>ITEM</th>
<th>Exp. Gr. DIFF. T1&amp;T2 mean (sd)</th>
<th>Contr. Gr. DIFF. T1&amp;T2 mean (sd)</th>
<th>SIGNIFICANCE</th>
</tr>
</thead>
<tbody>
<tr>
<td>(1) Physical health</td>
<td>-0.00 (0.78)</td>
<td>-0.03 (0.94)</td>
<td>Z = -0.32, p = 0.75</td>
</tr>
<tr>
<td>(2) Energy</td>
<td>0.19 (0.68)</td>
<td>0.01 (0.96)</td>
<td>Z = -1.97, p &lt; 0.05</td>
</tr>
<tr>
<td>(3) Mood</td>
<td>0.00 (0.70)</td>
<td>0.00 (0.91)</td>
<td>Z = -0.37, p = 0.71</td>
</tr>
<tr>
<td>(4) Life situation</td>
<td>-0.01 (0.68)</td>
<td>-0.12 (0.87)</td>
<td>Z = -1.32, p = 0.19</td>
</tr>
<tr>
<td>(5) Memory</td>
<td>0.14 (0.68)</td>
<td>-0.22 (0.82)</td>
<td>Z = -2.78, p &lt; 0.05</td>
</tr>
<tr>
<td>(6) Significant other</td>
<td>0.19 (0.90)</td>
<td>-0.16 (0.72)</td>
<td>Z = -2.33, p &lt; 0.05</td>
</tr>
<tr>
<td>(7) Family</td>
<td>0.06 (0.75)</td>
<td>-0.07 (0.69)</td>
<td>Z = -1.16, p = 0.24</td>
</tr>
<tr>
<td>(8) Friends</td>
<td>0.05 (0.81)</td>
<td>-0.19 (0.83)</td>
<td>Z = -1.76, p = 0.08</td>
</tr>
<tr>
<td>(9) Self</td>
<td>0.21 (0.76)</td>
<td>0.03 (0.87)</td>
<td>Z = -1.62, p = 0.11</td>
</tr>
<tr>
<td>(10) Chores</td>
<td>0.18 (0.78)</td>
<td>-0.06 (0.73)</td>
<td>Z = -2.09, p &lt; 0.05</td>
</tr>
<tr>
<td>(11) Fun</td>
<td>0.12 (0.80)</td>
<td>-0.03 (0.69)</td>
<td>Z = -1.30, p = 0.19</td>
</tr>
<tr>
<td>(12) Money</td>
<td>-0.04 (0.71)</td>
<td>-0.04 (0.67)</td>
<td>Z = -0.17, p = 0.86</td>
</tr>
<tr>
<td>(13) Life</td>
<td>0.08 (0.73)</td>
<td>-0.12 (0.80)</td>
<td>Z = -1.56, p = 0.12</td>
</tr>
<tr>
<td>TOTAL QOL-AD</td>
<td>1.3 (5.1)</td>
<td>-0.8 (5.6)</td>
<td>F = 6.87, p &lt; 0.01</td>
</tr>
</tbody>
</table>
'memory' (Z = -2.78, p < 0.05), 'marriage/significant other' (Z = -2.33, p < .05), and 'ability to do chores' (Z = -2.09, p < 0.05). The ANCOVA also revealed gender to be a significant factor in the improvement of overall QoL (F = 6.9, p < 0.01).

3.2.3 Gender & change in aspects of quality of life in dementia

In order to further investigate whether QoL improved more for females relative to males or vice versa, a Mann-Whitney test was conducted on total QoL score and the 13 items of the QOL-AD. The results are shown in Table 7. As can be seen here, while both males and females in the experimental group experienced an improvement of their QoL subsequent to the intervention (0.94 and 1.36 respectively), females experienced a greater improvement, although not significant (p = 0.54). The difference between genders that resulted in the significant difference overall was due to a significant deterioration in QoL for males relative to females in the control group (-4.33 vs. 0.47, p < 0.01). Overall, the aspects of QoL that deteriorated significantly more for males than females were 'ability to do chores' (Z = -2.57, p < 0.05), and 'ability to do things for fun' (Z = -2.22, p < 0.05). For participants in the control group, the aspects of QoL deteriorating more for males relative to females were 'physical health' (Z = -2.28, p < 0.05), 'energy' (Z = -2.28, p < 0.05), 'mood' (Z = -2.02, p < 0.05), and 'life' (Z = -2.03, p < 0.05). None of the differences between males and females in the experimental group reached statistical significance.
Table 7. Mean changes & associations between gender & change in aspects of quality of life in dementia

<table>
<thead>
<tr>
<th>VARIABLE</th>
<th>Experimental Group mean (sd)</th>
<th>Control Group mean (sd)</th>
<th>All mean (sd)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Males</td>
<td>Females</td>
<td>Sign.</td>
</tr>
<tr>
<td>Physical health</td>
<td>.06 (.43)</td>
<td>-.1 (.84)</td>
<td>Z = -0.25 p = 0.81</td>
</tr>
<tr>
<td>Energy</td>
<td>.29 (.59)</td>
<td>.17 (.70)</td>
<td>Z = -0.77 p = 0.44</td>
</tr>
<tr>
<td>Mood</td>
<td>.12 (.86)</td>
<td>-.03 (.67)</td>
<td>Z = -0.51 p = 0.61</td>
</tr>
<tr>
<td>Life situation</td>
<td>-.12 (.49)</td>
<td>.01 (.72)</td>
<td>Z = -0.90 p = 0.37</td>
</tr>
<tr>
<td>Memory</td>
<td>.35 (.70)</td>
<td>.09 (.67)</td>
<td>Z = -1.42 p = 0.15</td>
</tr>
<tr>
<td>Family</td>
<td>-.06 (.75)</td>
<td>.09 (.75)</td>
<td>Z = -1.11 p = 0.27</td>
</tr>
<tr>
<td>Marriage</td>
<td>.06 (.75)</td>
<td>.22 (.93)</td>
<td>Z = -0.62 p = 0.03</td>
</tr>
<tr>
<td>Friends</td>
<td>.12 (1.05)</td>
<td>.04 (.76)</td>
<td>Z = -0.33 p = 0.74</td>
</tr>
<tr>
<td>Self</td>
<td>.12 (.70)</td>
<td>.23 (.78)</td>
<td>Z = -0.47 p = 0.14</td>
</tr>
<tr>
<td>Chores</td>
<td>-.12 (.70)</td>
<td>.25 (.78)</td>
<td>Z = -1.52 p = 0.13</td>
</tr>
<tr>
<td>Fun</td>
<td>-.06 (1.03)</td>
<td>.16 (.75)</td>
<td>Z = -1.40 p = 0.16</td>
</tr>
<tr>
<td>Money</td>
<td>-.24 (.83)</td>
<td>.00 (.67)</td>
<td>Z = -0.86 p = 0.39</td>
</tr>
<tr>
<td>Life</td>
<td>.19 (.66)</td>
<td>.05 (.74)</td>
<td>Z = -0.53 p = 0.59</td>
</tr>
<tr>
<td>TOTAL QOL</td>
<td>.94 (5.48)</td>
<td>1.36 (5.09)</td>
<td>Z = -0.62 p = 0.54</td>
</tr>
</tbody>
</table>
3.2.4 Change in quality of life & other variables at baseline in dementia

In order to investigate the relationships between change in QoL and the other variables studied, One-way Anovas were carried out for the difference between baseline and follow-up QoL scores and baseline categorical data, i.e. center and CDR, which was recoded into low (0.5-1.0) and high (2.0-3.0) dementia severity. Pearson’s Correlations were conducted for the baseline continuous data. The results are shown in Table 8. The results showed no significant associations between any of the baseline data and change in QoL. This suggests that no baseline variables can be

Table 8. Change in quality of life & other variables at baseline in dementia

<table>
<thead>
<tr>
<th>VARIABLE (baseline)</th>
<th>Change in Quality of Life (QOL-AD)</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Experimental Group</td>
<td>Control Group</td>
<td>All</td>
</tr>
<tr>
<td>Age</td>
<td>0.17</td>
<td>-0.05</td>
<td>0.06</td>
</tr>
<tr>
<td>p = 0.11</td>
<td>p = 0.67</td>
<td>p = 0.43</td>
<td></td>
</tr>
<tr>
<td>Centre</td>
<td>F = 1.13</td>
<td>F = 1.08</td>
<td>F = 1.02</td>
</tr>
<tr>
<td>p = 0.34</td>
<td>p = 0.40</td>
<td>p = 0.45</td>
<td></td>
</tr>
<tr>
<td>Cognition (MMSE)</td>
<td>0.03</td>
<td>-0.03</td>
<td>-0.02</td>
</tr>
<tr>
<td>p = 0.78</td>
<td>p = 0.79</td>
<td>p = 0.81</td>
<td></td>
</tr>
<tr>
<td>Cognition (ADAS-Cog)</td>
<td>0.03</td>
<td>-0.08</td>
<td>-0.01</td>
</tr>
<tr>
<td>p = 0.75</td>
<td>p = 0.52</td>
<td>p = 0.91</td>
<td></td>
</tr>
<tr>
<td>Dementia level (CDR)</td>
<td>F = 0.70</td>
<td>F = 0.91</td>
<td>F =1.67</td>
</tr>
<tr>
<td>p = 0.83</td>
<td>p = 0.58</td>
<td>p = 0.16</td>
<td></td>
</tr>
<tr>
<td>Depression (Cornell)</td>
<td>0.07</td>
<td>0.15</td>
<td>0.10</td>
</tr>
<tr>
<td>p = 0.53</td>
<td>p = 0.25</td>
<td>p = 0.23</td>
<td></td>
</tr>
<tr>
<td>Anxiety (RAID)</td>
<td>-0.09</td>
<td>0.15</td>
<td>0.01</td>
</tr>
<tr>
<td>p = 0.42</td>
<td>p = 0.25</td>
<td>p = 0.92</td>
<td></td>
</tr>
<tr>
<td>Communication (Holden)</td>
<td>-0.10</td>
<td>0.10</td>
<td>0.01</td>
</tr>
<tr>
<td>p = 0.35</td>
<td>p = 0.44</td>
<td>p = 0.94</td>
<td></td>
</tr>
<tr>
<td>Dependency (CAPE-BRS)</td>
<td>-0.16</td>
<td>-0.03</td>
<td>-0.10</td>
</tr>
<tr>
<td>p = 0.13</td>
<td>p = 0.81</td>
<td>p = 0.23</td>
<td></td>
</tr>
</tbody>
</table>
used as predictors of QoL improvements in dementia.

3.2.5 Baseline & change in quality of life in dementia

In order to investigate the association between QoL at baseline and improvement in QoL, One-way Anovas were conducted for the experimental group, control group and across the two groups, after dividing the participants into four groups depending on their baseline QoL score (17-24; 25-32; 33-40; 41-47). The results are shown in Table 9. As can be seen in this table, participants with a lower baseline QoL score (groups 1 and 2) reported an improvement of their QoL at follow-up (4.15 and 2.56 respectively), while participants with a higher QoL score at baseline (groups 3 and 4) reported a deterioration of their QoL at follow-up (-0.7 and -3.0) overall. This was true for both participants in the experimental group and the control group for those scoring the in the ranges of 17-25, 25-32 and 41-47 on the QOL-AD. However, for participants scoring between 33 and 40 on the QOL-AD, there was a difference of 2.97 points change on the QOL-AD between participants in the experimental group (0.61) and control group (-2.36). The differences between the four groups divided according to QOL-AD scores reached statistical significance (p < 0.01).

3.2.6 Change in quality of life & change of other variables in dementia

In order to establish whether or not change in QoL in dementia was correlated with change of other variables, Pearson’s Correlations were conducted for the continuous data. The results are shown in Table 10. As shown here, change in QoL in dementia was found to be significantly correlated with improvement of cognition, as measured
Table 9. Associations between baseline & change in quality of life in dementia

<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Exp.</td>
<td>Contr.</td>
<td>All</td>
<td>Exp.</td>
<td>Contr.</td>
</tr>
<tr>
<td>Baseline QoL</td>
<td>Mean (sd) [range]</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>21.44 (2.1) [17-23]</td>
<td>21.83 (2.5) [17-24]</td>
<td>21.60 (2.2) [17-23]</td>
<td>29.05 (2.3) [25-32]</td>
<td>29.33 (2.3) [25-32]</td>
</tr>
<tr>
<td>Change QoL</td>
<td>Mean (sd) [range]</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>3.63 (7.6) [-7-17]</td>
<td>5.00 (5.8) [-7-15]</td>
<td>4.15 (6.8) [-7-17]</td>
<td>3.07 (5.2) [-5-17]</td>
<td>1.79 (6.1) [-7-17]</td>
</tr>
</tbody>
</table>
by the MMSE and the ADAS-Cog, for the experimental group (0.26 and -0.33 respectively, p < 0.01) as well as for the sample as a whole (0.25 and -0.23, p < 0.01). Additionally, improvement in QoL correlated significantly with a reduction of symptoms of depression (CSDD; -0.15, p < 0.05) and improvement of communication abilities (HCS; -0.17, p < 0.05) for the sample as a whole. The change in communication and depression, however, was mainly due to the control group scoring better at follow-up (-0.21, p = 0.06; -0.27, p < 0.05).

Table 10. Change in quality of life & change on other measures in relation to baseline scores

<table>
<thead>
<tr>
<th>Change from baseline scores</th>
<th>Change in Quality of Life (QOL-AD)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Experimental Group</td>
</tr>
<tr>
<td>Cognition (MMSE)</td>
<td>0.26</td>
</tr>
<tr>
<td></td>
<td>p &lt; 0.01</td>
</tr>
<tr>
<td>Cognition (ADAS-Cog)</td>
<td>-0.33</td>
</tr>
<tr>
<td></td>
<td>p &lt; 0.01</td>
</tr>
<tr>
<td>Depression (CSDD)</td>
<td>-0.10</td>
</tr>
<tr>
<td></td>
<td>p = 0.19</td>
</tr>
<tr>
<td>Anxiety (RAID)</td>
<td>0.02</td>
</tr>
<tr>
<td></td>
<td>p = 0.44</td>
</tr>
<tr>
<td>Communication (HCS)</td>
<td>-0.03</td>
</tr>
<tr>
<td></td>
<td>p = 0.41</td>
</tr>
<tr>
<td>Functioning (CAPE-BRS)</td>
<td>0.06</td>
</tr>
<tr>
<td></td>
<td>p = 0.30</td>
</tr>
</tbody>
</table>
3.2.7 Correlations between change in aspects of quality of life & change of other variables

In order to investigate what aspects of QoL improved when other aspects of dementia improved, Pearson's Correlations were conducted on the variables found to be correlated significantly with total QoL score and the 13 items of the QOL-AD. The results are shown in Table 11. However, due to the large number of comparisons made, and the increased risk of Type I error this entailed, only correlations reaching the 0.001 level of significance are discussed (Bonferroni correction). Only one correlation reached this level of statistical significance. This was between improvement on the MMSE (cognition) and 'ability to do chores' (.30, p < 0.001).

3.2.8 Predictors of change in quality of life in dementia

To investigate which variables predicted change in the total QoL score, a Logistic Regression was conducted. However, in order to attempt to establish which of these predicted a clinically significant change in QoL, total QOL-AD scores were recoded. Based on the improvement found in QoL for the participants in the experimental group reported above, this was set at an improvement of 2 points or above, which approximates 1/3 of the standard deviation detected. Therefore, the participants' scores were recoded into a no clinical improvement group (less than 2 points) and a clinical improvement group (2 points and above). A logistic regression was then used to ascertain which variables predicted membership of the clinical improvement group. The variables included in the Logistic Regression as independent variables were those shown previously to relate to change in QoL-AD: gender, QoL at baseline


Table 11. Correlations between change in aspects of quality of life & change on other variables

<table>
<thead>
<tr>
<th>Change in baseline scores</th>
<th>phys. health</th>
<th>energy</th>
<th>mood</th>
<th>life sit.</th>
<th>memory</th>
<th>family</th>
<th>marriage</th>
<th>friends</th>
<th>self</th>
<th>chores</th>
<th>fun</th>
<th>money</th>
<th>life</th>
</tr>
</thead>
<tbody>
<tr>
<td>MMSE</td>
<td>0.11</td>
<td>0.03</td>
<td>0.10</td>
<td>-0.04</td>
<td>0.18</td>
<td>0.16</td>
<td>0.15</td>
<td>0.06</td>
<td>0.09</td>
<td>0.30</td>
<td>0.08</td>
<td>0.05</td>
<td>0.07</td>
</tr>
<tr>
<td></td>
<td>p=0.08</td>
<td>p=0.36</td>
<td>p=0.10</td>
<td>p=0.29</td>
<td>p&lt;0.01</td>
<td>p&lt;0.05</td>
<td>p&lt;0.05</td>
<td>p=0.23</td>
<td>p=0.13</td>
<td>p&lt;0.001</td>
<td>p=0.16</td>
<td>p=0.25</td>
<td>p=0.18</td>
</tr>
<tr>
<td>ADAS-Cog</td>
<td>-0.07</td>
<td>-0.19</td>
<td>-0.00</td>
<td>-0.02</td>
<td>-0.25</td>
<td>-0.02</td>
<td>-0.12</td>
<td>-0.10</td>
<td>-0.06</td>
<td>-0.14</td>
<td>-0.16</td>
<td>-0.05</td>
<td>-0.08</td>
</tr>
<tr>
<td></td>
<td>p=0.18</td>
<td>p&lt;0.01</td>
<td>p=0.50</td>
<td>p=0.39</td>
<td>p&lt;0.01</td>
<td>p&lt;0.01</td>
<td>p&lt;0.05</td>
<td>p=0.10</td>
<td>p=0.23</td>
<td>p&lt;0.05</td>
<td>p=0.16</td>
<td>p=0.25</td>
<td>p=0.15</td>
</tr>
<tr>
<td>CSDD</td>
<td>-0.08</td>
<td>-0.08</td>
<td>-0.16</td>
<td>-0.14</td>
<td>-0.01</td>
<td>-0.07</td>
<td>-0.04</td>
<td>-0.06</td>
<td>0.01</td>
<td>-0.10</td>
<td>-0.16</td>
<td>-0.05</td>
<td>-0.03</td>
</tr>
<tr>
<td></td>
<td>p=0.17</td>
<td>p=0.18</td>
<td>p&lt;0.05</td>
<td>p=0.05</td>
<td>p=0.44</td>
<td>p=0.21</td>
<td>p=0.34</td>
<td>p=0.25</td>
<td>p=0.43</td>
<td>p=0.13</td>
<td>p&lt;0.05</td>
<td>p=0.28</td>
<td>p=0.34</td>
</tr>
<tr>
<td>HCS</td>
<td>-0.10</td>
<td>-0.02</td>
<td>-0.08</td>
<td>-0.09</td>
<td>-0.07</td>
<td>-0.04</td>
<td>-0.02</td>
<td>-0.11</td>
<td>0.02</td>
<td>-0.22</td>
<td>-0.12</td>
<td>-0.03</td>
<td>-0.06</td>
</tr>
<tr>
<td></td>
<td>p=0.013</td>
<td>p=0.42</td>
<td>p=0.18</td>
<td>p=0.15</td>
<td>p=0.21</td>
<td>p=0.32</td>
<td>p=0.43</td>
<td>p=0.11</td>
<td>p=0.43</td>
<td>p&lt;0.01</td>
<td>p=0.09</td>
<td>p=0.35</td>
<td>p=0.33</td>
</tr>
</tbody>
</table>
QUALITY OF LIFE IN DEMENTIA
Factors Associated with Change in Quality of Life in Dementia...

(QOL-AD), difference in cognition between baseline and follow-up (MMSE and ADAS-Cog), difference in levels of depression between baseline and follow-up (CSDD) and difference in communication level between baseline and follow-up (HCS). The dependent variable was the recoded QOL-AD. The results are shown in Table 12, which shows the unstandardised coefficients (B), the Wald statistic giving the significance of each variable entered into the model, the variance explained by this model (R square) and the significance of this. The table additionally show the result from the Hosmer and Lesmeshow Test, which indicates goodness-of-fit between the observed and predicted number of cases for the two QoL categories. As can be seen in this table, the variables that reached statistical significance as predictors of total QOL-AD score were QOL-AD at baseline (-0.12, p < 0.01), i.e. people with a lower QoL at baseline improved more, and gender (-1.58, p < 0.01) i.e. being female significantly predicted a higher improvement of QoL. Cognition as measured by the MMSE and ADAS-Cog were not found to significantly predict change in QoL. Depression (CSDD) and communication (HCS) were not included in the model, as estimation was terminated prior to including these variables because the −2 Log likelihood then decreased by less than 0.01%. The model as a whole explained 23% of the variance found in change of QoL for people with dementia, which was a significant value (p < 0.001). The Hosmer and Lesmeshow Tests showed a chi-square value of 6.313 and a p-value of 0.612, and as such indicating a good fit.
Table 12. Predictors of change in quality of life in dementia

<table>
<thead>
<tr>
<th>VARIABLE</th>
<th>B</th>
<th>Wald</th>
<th>Significance</th>
</tr>
</thead>
<tbody>
<tr>
<td>QOL-AD at baseline</td>
<td>-0.12</td>
<td>9.96</td>
<td>p &lt; 0.01</td>
</tr>
<tr>
<td>Gender</td>
<td>-1.58</td>
<td>7.07</td>
<td>p &lt; 0.01</td>
</tr>
<tr>
<td>MMSE</td>
<td>0.08</td>
<td>1.76</td>
<td>p = 0.19</td>
</tr>
<tr>
<td>ADAS-Cog</td>
<td>-0.02</td>
<td>0.45</td>
<td>p = 0.50</td>
</tr>
</tbody>
</table>

Total variance explained  
R square = 0.230  
p < 0.001

Hosmer & Lesmeshow Test  
Chi square = 6.313  
p = 0.612

3.3 DISCUSSION

This study found significant improvements in QoL as measured by the QOL-AD, and specific aspects of this, for people with dementia living in residential settings and attending day care subsequent to attending a twice-weekly evidence-based psychological therapy group over 7 weeks relative to controls. This programme has also been found to be cost-effective in an economic evaluation (Appendix E). The QoL improvements found were significant for QOL-AD items relating to energy level, memory, relationship with spouse, partner or significant other, and ability to do chores. Thus, the psychological therapy programme improved people with
dementia's perception of their closest relationships and their capabilities. This could be as a consequence of finding themselves functioning successfully in groups where the focus was on avoiding failure experiences, with an overall validating attitude to people's remaining abilities. These encouraging results highlight the value of group therapy, where positive reinforcements can be provided by other group members as well as the group leader/therapist. Such findings are very encouraging for the use of such therapies in dementia care. These findings additionally show that the QOL-AD is an instrument that is sensitive to change, suggesting that it is useful as an outcome measure for evaluating the effects of interventions for people with dementia.

3.3.0 Gender differences in improvement of quality of life in dementia

Gender was found to be a significant factor in the improvement in QoL for people with dementia. While both males and females in the experimental group experienced an improvement of their QoL after attending the groups, females experienced a greater improvement. However, the main difference between genders was a significant deterioration in QoL for males relative to females in the control group. The aspects of QoL that deteriorated significantly more for males than females were ability to do chores and do things for fun. This might reflect a general issue in residential and day care, where men are usually a minority, and their preferred activities more difficult to accommodate. In the groups we were careful to modify the tasks appropriately to the attendees, particularly so where there were a majority of males. Nevertheless, the small number of males overall meant that in general there was an average of only one male per group. Centres wishing to run such groups for
males may wish to separate the groups along gender lines and modify the activities accordingly.

3.3.1 Associations between baseline & change in quality of life in dementia

A significant correlation was found in this trial between baseline QoL and change in QoL in dementia for both participants in the experimental group and the control group. People in both groups, but particularly the controls, with a lower QoL score at baseline reported a higher increase of QoL than people reporting better QoL before attending the group. In contrast, the group with the highest QoL tended to have a reduction in QoL scores. This may be a reflection of regression to the mean whereby the highest/lowest scores have a tendency to get closer to the mean over time. However, in the two groups with QoL scores in the middle range there was a strong improvement in QoL in the experimental group relative to the controls. This was true particularly for group 3, where there was a mean difference of around 3 points.

3.3.2 Change in quality of life & other variables in dementia

Improvement in QoL was not found to be significantly correlated with baseline scores on other measures, but improvement in cognition for people with dementia attending the groups was significantly correlated with improved QoL, while the deterioration in cognition for controls was not associated with a decline in QoL. There was a pattern linking improved cognition with improved QoL in three general areas: Memory, social functioning (relationships with family and partner/significant other), and activity level (energy, ability to do chores and ability to do things for fun).
These findings were consistent with the groups, which were intended to be cognitively stimulating in the context of social and enjoyable activities. Additionally, improvement in QoL in dementia was found to be significantly correlated with a reduction of symptoms of depression and improvement of communication for the sample as a whole. In the multivariate analysis the best predictors of QoL were gender and QoL at baseline. Thus, the factors most likely to predict improved QoL were being female and having a low QoL score at baseline (and having possibly greater scope for improvement?).

Factors that may have influenced these encouraging findings include the therapeutic factors that are thought to present in any group, such as instillation of hope and the opportunity to display altruism (Yalom, 1995). These factors are not separable from the intervention itself. Being invited to a therapeutic group is also likely to at least to some degree curb the ‘Malignant Social Psychology’ described by Kitwood (1997), by positively strengthening the group members’ personhood through the validating approach of the group leaders. However, these variables are not seen by the researchers as confounding, but rather an inherent element of any therapeutic group intervention. It could be argued that a control condition should have been included, where people in groups did not receive the treatment programme. This was discussed, and decided against as it would have introduced a host of other variables, which would have been problematic to control for, such as the dynamics of these groups. Additionally, in the two Cochrane reviews carried out, which formed the basis for the programme, it was concluded that including this kind of control group did not influence the outcomes (Spector et al., 1998a; Spector et al., 1998b).
3.3.3 Limitations

While QoL and cognition were rated in assessment interviews with the person with dementia, the perceptions of care staff and the researchers were a necessary component for the other variables studied, as is often the case. Thus, these involve a degree of subjectivity from proxy reporters, which although based as far as possible on objective indicators might not correlate with the person with dementia's own experience, which is assessed by the QOL-AD. Additionally, due to a limited number of available caregivers, their input was not included in this study. Furthermore, as outlined in Chapter 2, Limitations, p. 100 of this thesis, correlations of 0.4 or less, although statistically significant, might not necessarily be clinically significant (Dunn & Everett, 1995). None of the statistically significant correlations reported between change in quality of life and change on other measures in relation to baseline scores, as well as change in aspects of quality of life and change of other variables reached this level. Therefore, these results must be considered in this light.

3.3.4 Conclusion

An evidence-based psychological group therapy programme was found to significantly improve the QoL for people with dementia in a single-blind randomised controlled trial. The main improvements were found on items relating to energy level, memory, relationship with spouse, partner or significant other, and ability to do chores. Statistically significant correlations were found between a higher QoL score and improvement of cognition, suggesting the perceived improvement of memory reported by participants was reflecting an actual change for the better. Gender was
found to be a significant factor in the improvement of QoL for people with dementia, with females improving more than males subsequent to participating the groups, and males deteriorating more than females in the control group, specifically on items relating to ability to do chores and things for fun. A statistically significant correlation was also found between baseline QoL and change in QoL, with people with a low QoL score at being more likely to benefit from the intervention. Additionally, improvement in QoL in dementia was found to be statistically significantly correlated with a reduction of symptoms of depression, improvement of cognition and communication abilities, which might be reflecting greater degree of awareness or ability to reflect upon one's own situation.
CHAPTER 4: Validity and Reliability of the Quality of Life – Alzheimer’s Disease Scale

4.0 AIMS

Aim 5: To investigate the reliability and validity of the QOL-AD scale (Logsdon et al., 1999), and its sensitivity to change.

4.1 METHOD

4.1.0 Design

4.1.0.0 Recruitment of centres, sample 1

Residential, nursing homes, day centres and hospitals within the area of North East London Mental Health NHS Trust were contacted via mail. The information sent contained an introduction letter providing a background to the project, what it involved, and its main objectives (Appendix D) and a copy of the information sheets and consent form (Appendix D). Approval was also sought and obtained from Barking and Havering Local Research Ethics Committee (Appendix D). Subsequently, the managers of possible centres were contacted via telephone within a week, inquiring about interest in participating in the project and suitability of the centre, and provided with any additional information required. If appropriate, a meeting was then arranged with the manager.
4.1.0.1 Selection of participants, sample 1

The inclusion criterion for the assessments and focus groups with people with dementia was meeting the DSM-IV (APA, 1994) criteria for dementia. In the initial meeting with the manager of the centre, a list of possible participants was compiled from residents or service users showing signs of dementia. These were then approached by their key worker with information about the project (Appendix D), and their relatives were contacted to ensure they were agreeable to their relative being included in the project. Subsequently, possible participants were screened, using the DSM-IV criteria. Before screening, informed consent was obtained in conjunction with the person’s key worker (Appendix D). Random allocation to focus groups and assessments (including Dementia Care Mapping) was then conducted, using sealed envelopes from a container. As the sample included people with all levels of dementia, some participants were unable to complete the assessments, and the interview was then discontinued in a sensitive manner. Additionally, some focus groups with people with dementia had to be discontinued, as the attendees found the task at hand too complex. Carers for the sample of people with dementia were invited to attend focus groups via mail from their contacts at the relevant centres, with information about the project and a consent form to return if interested in attending (Appendix D). Finally, details of health care professionals working with people with dementia were obtained from the participating centres, and questionnaires with covering letters containing information about the project was sent out to 100 people (Appendix D), including 5 managers, 5 psychiatrists, 5 psychologists, 10 assistant/trainee psychologists, 15 nurses, 10 nursing assistants, 15
care assistants, 5 occupational therapists, 5 occupational therapy assistants, 10 social workers, 10 members of the voluntary sector, and 5 people from other occupations working with people with dementia.

4.1.0.2 Assessment procedure, sample 1

The possible participants were reminded again on the day of the full assessment of the purpose and procedures of the project, and asked if they still consented to taking part. If they consented, an interview was conducted with one or two researcher(s) and the possible participants individually in a quiet room, lasting approximately 30 minutes. This interview consisted of the Quality of Life-Alzheimer’s Disease Scale (QOL-AD; Logsdon et al., 1999), Dementia Quality of Life (DQoL; Brod et al., 1999), and EQ-5D (EuroQoL Group, 1990). In the cases where two interviewers were present, one asked the questions while the other one sat quietly, completing the assessment scales. Some participants were interviewed again 7 days later by one researcher, using only the QOL-AD. These participants were reminded again on the day of the second assessment of the purpose and procedures of the project, and asked if they still consented to taking part. Data was also collected on the participants’ MMSE score, age, gender, level of education, living arrangements, and how long they had been living in the residential/nursing home or attended the day centre/hospital.
4.1.0.3 Dementia Care Mapping

Contemporaneously with the assessments, the participants were observed for 6 hours, with their behaviour and interactions being coded using DCM. This was done by a trained mapper, using ‘Evaluating Dementia Care – The DCM Method, 7th Ed. (Bradford Dementia Group, 1997). Mapping was conducted as far as possible during 3 hours in the morning and 3 hours in the afternoon. Interviewers were blind to the participants’ DCM scores, and the mapper to their assessment scores.

4.1.0.4 Focus groups

In total, five focus groups were run for 1 hour each, three of which consisted of carers for people with dementia, and two consisting of people with dementia. Each focus groups consisted of 10 participants and 2 group conductors. They all discussed the following issues: (1) What does QoL in dementia entail? (2) What elements of QoL in dementia are important? (3) Are all the 13 items of the QOL-AD important for QoL in dementia? (4) Are the items of equal importance? and (5) Does this scale cover all the important aspects of QoL for people with dementia? Before all focus groups, continued informed consent from all participants was ensured (Appendix D).

4.1.0.5 Questionnaires

The QOL-AD was sent to 100 health care professionals working with people with dementia as described above. They were asked to fill in a questionnaire regarding the scale, rating all the items on a four-point scale, ranging from not important to essential.
The questionnaire also asked respondents to answer the following three questions: (1) Do you think this scale covers all the important domains in a dementia sufferer's life? If no, please expand. (2) Do you think any of the items not relevant for the quality of life for a person with dementia? If yes, please expand. (3) Do you have any additional comments about the scale?

4.1.0.6 Recruitment of centres, sample 2
Described in Chapter 2 - 2.0.0.1, Recruitment of centres, page 84-85 of this thesis.

4.1.0.7 Selection of participants, sample 2
Described in Chapter 2 - 2.1.0.2, Selection of participants, page 85-86 of this thesis.

4.1.0.8 Assessment procedure, sample 2
Described in Chapter 2 - 2.1.0.3 Assessment procedure, page 86 of this thesis.

4.1.1 Diagnostic criteria

*DSM-IV.* As described in Chapter 2 - 2.1.1 Diagnostic criteria, p 86-87 of this thesis.

4.1.2 Measures

A) *Quality of Life – Alzheimer’s Disease (QOL-AD):* As described in Chapter 2 – 2.1.2, Measures, page 87-88 of this thesis.
B) Dementia Quality of Life: Dementia Quality of Life (DQoL; Brod et al., 1999) was administered along with the QOL-AD for the purpose of investigating concurrent validity. The DQoL is a 29-item scale, and was developed on the basis of domains identified as important to people with dementia by three focus groups consisting of caregivers for people with dementia, health care providers working with this client group, and people with mild to moderate dementia. These domains are: physical functioning, daily activities, discretionary activities, mobility, social interaction, interaction capacity, bodily well being, sense of well being, sense of aesthetics, and overall perceptions. The scores are given by the person with dementia on a 5-point Likert scale ranging from 'never' to 'very often'. The DQoL includes 3 sample questions to establish that the person understands the scale and the question format. Brod et al., (1999) found their scale to have good internal consistency, item and scale test-retest reliability, and construct validity.

C) EuroQoL-5D: To further investigate the criterion concurrent validity of the QOL-AD, the EuroQoL-5D (EQ-5D; EuroQoL Group, 1990) was administered. This well-established generic instrument, which measures health-related quality of life, has 5 domains: mobility, self-care, usual activities, pain/discomfort and anxiety/depression. The respondent also rates their own health today on a visual analogue scale (VAS) from 100 (best imaginable health state) to 0 (worst imaginable health state). The data can be presented descriptively as a health profile and a single index utility score can be calculated. The EQ-5D is designed for self-completion, but in the current study it was
D) **Dementia Care Mapping:** Dementia Care Mapping (DCM; Kitwood & Bredin, 1994) is an evaluation system of quality of care for people with dementia in formal settings, which was used as a further measure of criterion concurrent validity. During a DCM evaluation the recorder observes between five and ten participants continuously over a representative time period, and involves using three coding frames simultaneously:

1. The Behaviour Category Coding System codes the person’s behaviour, such as articulation, distress, and expression, into 24 categories. In addition, the degree of well being experienced by the person during the behaviour is recorded, utilising a 6-point Likert scale from +5 to −5.

2. The Personal Detractor Coding System aims to identify those staff behaviours that might reduce the person with dementia’s well being. A four-item Likert scale, from mild to very severe, is used to quantify the degree of personal detraction of 17 components, for example intimidation, disempowerment, and infantilisation.

3. The Positive Event Recording System is not a coding framework as such, but requires the recorder to provide a qualitative description of interactions with the person with dementia that constitutes good practice.

The DCM technique was developed to improve the quality of care for people with dementia, and has been found to be a useful tool for this purpose (Barnett 1995; Perrin,
1997), and also to be a highly appropriate audit tool to use in NHS formal dementia care settings (Brooker et al., 1998). It was used in the current study as an observable measure of QOL, and as such only the participants' well-being scores were utilised.

E)  *Mini Mental State Examination:* As described in Chapter 2 – 2.1.1 Measures, page 89 of this thesis.

F)  *Cornell Scale for Depression in Dementia:* As described in Chapter 2 – 2.1.1, Measures, page 89-90 of this thesis.

4.2 RESULTS

4.2.0 Descriptive characteristics of participants (sample 1)

A total of 82 people were screened. Of these, 60 were included. All exclusions were made on the basis of the three sample questions included in the DQoL, which aims to determine whether the person comprehends the assessment procedure. The ages of the participants ranged from 69 to 92 years, with a mean age of 81.3 (Table 13). The sample included 44 (73.3%) females, and 42 (70.0%) had an average education (i.e. leaving school at 14). 33 (55.0%) participants attended a day hospital, 9 (15.0%) were inpatients at a hospital ward, 8 (13.3%) lived in residential care, 7 (11.7%) lived in nursing care, and 3 (5.0%) were assessed at home. Of the 36 participants living in the community, 20 (56.0%) lived alone. The sample ranged from a score of 3 to 28 on the MMSE (mean 16.1), and the range of QoL measured by the QOL-AD was 17-49 (mean
Table 13. Descriptive characteristics of participants (sample 1)

<table>
<thead>
<tr>
<th></th>
<th>n = 60</th>
<th>mean (sd) [range]/value (percentage)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age</td>
<td>81.3 (6.0) [69-92]</td>
<td></td>
</tr>
<tr>
<td>MMSE</td>
<td>16.1 (6.5) [3-28]</td>
<td></td>
</tr>
<tr>
<td>QOL-AD</td>
<td>33.5 (6.3) [17-49]</td>
<td></td>
</tr>
<tr>
<td>DQoL Total (n = 46)</td>
<td>14.7 (4.4) [4.2-21.9]</td>
<td></td>
</tr>
<tr>
<td>EQ-5D Index Score</td>
<td>0.8 (.3) [-0.17-1.0]</td>
<td></td>
</tr>
<tr>
<td>EQ-5D Visual Analogue Scale</td>
<td>0.6 (0.2) [0-1.0]</td>
<td></td>
</tr>
<tr>
<td>Dementia Care Mapping (n = 25)</td>
<td>1.6 (0.7) [0.9-3.3]</td>
<td></td>
</tr>
<tr>
<td>Gender (female)</td>
<td>44 (73.3%)</td>
<td></td>
</tr>
<tr>
<td>Education (average)</td>
<td>42 (70.0%)</td>
<td></td>
</tr>
<tr>
<td>Living arrangements (alone)</td>
<td>20 (33.3%)</td>
<td></td>
</tr>
<tr>
<td>Day hospital/community</td>
<td>36 (60.0%)</td>
<td></td>
</tr>
<tr>
<td>In-patient</td>
<td>9 (15.0%)</td>
<td></td>
</tr>
<tr>
<td>Residential/nursing care</td>
<td>15 (25.0%)</td>
<td></td>
</tr>
</tbody>
</table>

QoL as measured by the DQoL ranged from 4.2 to 21.9 (mean 14.7) when totalling the 6 sub-scores. The range on the EQ-5D Index Score was −0.17 to 1.0 (mean 0.8) on the scale and 0.0 to 1.0 on the Visual Analogue Scale. QoL as measured by the well-being score of the DCM ranged from 0.9 to 3.3 (mean 1.6).
4.2.1  Face/Content validity (sample 1)

4.2.1.0  Focus groups with people with dementia (n = 20)

A definition of QoL emerging from the focus groups with people with dementia was “inward satisfaction”. They thought that having frequent contact with family members was essential in order to have a good QoL in dementia, particularly being around children and maybe even help in the childrens’ upbringing. Being involved in “negative relationships” was seen as having a detrimental effect on QoL. The members of these focus groups also emphasised the value of having good friendships, and saw loneliness as significantly reducing QoL in dementia. Having interests, hobbies and being stimulated were seen as important, as boredom could cause people with dementia to have a poor QoL. Physical health and having memory difficulties (“going potty”) were also thought to affect QoL in dementia. The members of these focus groups valued being able to reminisce about the past, and also manage to “make the best of it” and “take one day at the time”. Peace of mind and having freedom from worries was also seen as being essential for having a good QoL. Furthermore, the people with dementia attending the focus groups emphasised the detrimental effect on their QoL of not having a job anymore, losing your role in life and feeling useless. They saw having a direction in life, achieving what you want, and being able to give to society as essential in order to have good QoL in dementia, as well as being independent and having freedom to do what you want (“being one’s own”).
All the items of the QOL-AD were seen as being important for people with dementia's QoL, although 'friends' was thought to apply to some people more than others, as some people were seen as more self-sufficient. The items relating to finances ('money'), family and roles ('ability to do chores') were believed to not always elicit accurate responses, as these areas might be associated with privacy and self-respect. Furthermore, some of the people with dementia attending the focus groups thought that an item on food and drink should have been included in the QOL-AD, and also questions regarding what people perceived as important in their lives and what people need for their lives to be worthwhile.

4.2.1.1 Focus groups with carers (n = 30)

Some of the carers for people with dementia attending the focus groups thought that QoL in dementia was dependent on the same factors as for everybody else, while some felt that it was affected by different variables, as people with dementia were dependent on other people. Furthermore, some thought that people with dementia can not aim for happiness, but should "settle for being content", although other members of the carers' focus groups strongly disagreed with this statement. The carers emphasised the importance of having good family connections ("feeling that the family care") and contact with children, as well as having good friendships and a well-developed social network ("A smile has a great reaction"). They also thought that the QoL of the person with dementia was affected by the QoL of her/his carer. Enjoyment of life and food were seen as essential elements of a good QoL in dementia, as was being involved in
QUALITY OF LIFE IN DEMENTIA

VALIDITY AND RELIABILITY OF THE QUALITY OF LIFE – ALZHEIMER’S DISEASE SCALE 

Social events, leisure and creative activities, rather than sleeping or wandering around most of the time. The carers felt that if the person with dementia “regresses back to a childlike state”, s/he might enjoy more childlike activities, such as watching cartoons. They thought that physical health was central to QoL in dementia, but emphasised that the perception of being healthy and useful might be the most important. Having a feeling of security was stressed, as well as being able to relax, not being frustrated and having choice and variety in everyday life. Overall, the carers felt that QoL in dementia fluctuated a great deal, and that it was dependent on people’s personality. They also thought that the label of dementia was stigmatising, and while some saw having a clear diagnosis as being helpful in planning the future, other carers believed that a diagnosis was useless if there was not any cure available. The carers attending the focus groups thought that all items of the QOL-AD were important in order to determine people with dementia’s QoL, but that some items could benefit from being more specific, and that the scale was a bit too long. They thought that the item ‘friends’ assumed that the people with dementia were able to establish and/or maintain friendships, which might depend on the ability to recognise faces etc, and suggested contact with people as being more useful. As for ‘money’, the carers believed having cash was more important than finances in general. Furthermore, they felt that ‘marriage’ was not as important as “togetherness”, as was awareness of memory difficulties rather than ‘memory’ per se, and the feeling of being important rather than ‘ability to do chores’. The carers would have welcomed items on pain and availability of aids. They also feared that important elements of QoL could be missed out from a standardised scale such as the QOL-AD,
and thought that having the carer present would reduce the feeling of pressure for the person with dementia when being assessed by people seen as authority figures.

4.2.1.2 Questionnaires for health care professionals working with people with dementia (n = 70)

The results of the scores given to the thirteen items of the QOL-AD are shown in Table 14 below. The mean scores in this table shows that all items scored overall as being 'important to very important' for QoL in dementia. However, some items were seen as being more central than others by the majority of respondents, such as 'life', 'life situation', 'mood' and 'physical health'. 'Friends', 'energy', 'money' and 'marriage' were rated as being of lesser importance to people with dementia's QoL by the majority of health care professionals working with this client group. The majority, 45 (61.6%) of respondents, thought that the QOL-AD covered all the important elements of QoL in dementia, while 26 (35.6%) did not. When asked whether they thought that the QOL-AD included elements not important when assessing QoL for people with dementia, 59 (80.8%) answered no, and 12 (16.4%) answered yes.

In the qualitative responses received, some of the ratings above were expanded upon. Some respondents thought that social support in general would be more relevant than 'family', 'marriage' and 'friends'. These three items were also suggested to be of limited importance when evaluating interventions for people with dementia, as they were thought to be relatively static elements of QoL. Additionally, 'marriage' was
Table 14. Scores given to the items of the QOL-AD by health care professionals

<table>
<thead>
<tr>
<th>ITEM</th>
<th>not important</th>
<th>not very important</th>
<th>important</th>
<th>very important</th>
<th>essential</th>
<th>Mean (sd)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Life</td>
<td>0</td>
<td>3(4.1%)</td>
<td>27(37.0%)</td>
<td>19(26.0%)</td>
<td>23(31.5%)</td>
<td>3.86(.92)</td>
</tr>
<tr>
<td>Life Situation</td>
<td>0</td>
<td>0</td>
<td>22(30.1%)</td>
<td>40(54.8%)</td>
<td>9(12.3%)</td>
<td>3.82(.64)</td>
</tr>
<tr>
<td>Mood</td>
<td>0</td>
<td>0</td>
<td>31(42.5%)</td>
<td>23(31.5%)</td>
<td>18(24.7%)</td>
<td>3.82(.81)</td>
</tr>
<tr>
<td>Physical Health</td>
<td>0</td>
<td>0</td>
<td>30(41.1%)</td>
<td>27(37.0%)</td>
<td>15(20.5%)</td>
<td>3.79(.77)</td>
</tr>
<tr>
<td>Fun</td>
<td>0</td>
<td>0</td>
<td>31(42.5%)</td>
<td>31(42.5%)</td>
<td>10(13.7%)</td>
<td>3.71(.70)</td>
</tr>
<tr>
<td>Family</td>
<td>0</td>
<td>0</td>
<td>4(5.5%)</td>
<td>30(41.1%)</td>
<td>10(13.7%)</td>
<td>3.61(.80)</td>
</tr>
<tr>
<td>Energy</td>
<td>1(1.4%)</td>
<td>4(5.5%)</td>
<td>46(63.0%)</td>
<td>16(21.9%)</td>
<td>5(6.8%)</td>
<td>3.28(.74)</td>
</tr>
<tr>
<td>Friends</td>
<td>0</td>
<td>0</td>
<td>3(4.1%)</td>
<td>45(61.6%)</td>
<td>3(4.1%)</td>
<td>3.33(.63)</td>
</tr>
<tr>
<td>Money</td>
<td>2(2.7%)</td>
<td>9(12.3%)</td>
<td>47(64.4%)</td>
<td>8(11.0%)</td>
<td>6(8.2%)</td>
<td>3.10(.83)</td>
</tr>
<tr>
<td>Marriage</td>
<td>4(5.5%)</td>
<td>8(11.0%)</td>
<td>39(53.4%)</td>
<td>21(28.8%)</td>
<td>0</td>
<td>3.07(.79)</td>
</tr>
</tbody>
</table>
suggested as including a heterosexual bias. Some respondents highlighted the importance of being able to sustain previous interests and hobbies, and specified that people with dementia could have the ‘ability to do chores’, but not the opportunity. Self care, continence and independence were emphasised by many respondents as being essential in order to have a good QoL in dementia. Some of the health care professionals thought that the QOL-AD could benefit from items on medication, communication, insight, carers’ coping and sex (“...assumes that people with dementia may not enjoy sex, by the omission of [this] specific question”). The scale was seen by some as needing to be more self explanatory, particularly on items such as ‘energy’ (“Does this mean motivation?”) and ‘money’ (“Does this mean ability to handle money or possible concerns over money?”), and that some items were “oddly phrased”. It was also suggested that the people with dementia’s response to the item ‘money’ would depend on their attitude to money, “the sensitive administration of this item” was seen as essential. ‘Ability to do chores’ was thought to be more relevant to some than others. ‘Mood’ was not seen as being specific enough by some, and items on anxiety, agitation, fear and uncertainty would have been preferred. Overall, some respondents felt that the QoL for people with dementia was affected by the same elements as QoL for anybody else, while the question of whether QoL could be conceptualised as being the same for every person with dementia was asked by others: One person may judge good QoL by the level of family interaction, another may have no family and judge good QoL by being able to smoke at weekends”.

Thus, the majority of people with dementia, carers and health care professionals thought that all the items of the QOL-AD were important to assess QoL in dementia. Most of the people asked, also thought that the QOL-AD covered all the important aspects of QoL in dementia, although some thought that the measure could benefit from the inclusion of items on food and drink. When discussing what QoL in dementia entails, some patterns were apparent across the groups. These included an emphasis on having good social networks and family connections and being stimulated. Some items were thought to not always elicit accurate responses, such as those relating to finances ('money') and roles ('ability to do chores'), as these areas might be associated with privacy and self-respect, and these items were also among the items that could benefit from being more specific.

The question of whether QoL can be conceptualised as being the same for every person with dementia was also asked by some. However, some differences between the groups were also apparent. The people with dementia seemed to express a more positive outlook on their lives and roles than either carers or health care professionals, such as having a direction in life, achieving what you want, and being able to give to society.

4.2.2 Criterion concurrent validity (sample 1)

There was no 'gold standard' as such for measuring QoL in dementia. However, to investigate the criterion concurrent validity of the QOL-AD, the scores on the QOL-AD were correlated with the persons with dementia’s responses on the DQoL and the EQ-5D. The DCM Well-being (WIB) score was also correlated with the QOL-AD scale. In addition, the overall QOL-AD score was correlated with the scores on the QOL-AD
items ‘self as a whole’ and ‘life as a whole’, and how the person with dementia rated her/his own health today on the EQ-5D visual analogue scale (VAS). Pearson’s correlation coefficient was used for all correlations. The results are shown in Table 15. As can be seen in this table, total QOL-AD score correlated significantly with all other QoL indices measured, apart from DCM WIB score, which was bordering on statistical significance (0.39, p = 0.051).

Table 15. Correlations between total QOL-AD score and other QoL indices in dementia (n=60).

<table>
<thead>
<tr>
<th>QOL INDICES</th>
<th>Total QOL-AD Score</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total DQoL</td>
<td>0.69 (p &lt; 0.001)</td>
</tr>
<tr>
<td>EQ-5D</td>
<td>0.54 (p &lt; 0.001)</td>
</tr>
<tr>
<td>DCM WIB (n = 25)</td>
<td>0.39 (p = 0.051)</td>
</tr>
<tr>
<td>Self as a whole (QOL-AD)</td>
<td>0.68 (p &lt; 0.001)</td>
</tr>
<tr>
<td>Life as a whole (QOL-AD)</td>
<td>0.71 (p &lt; 0.001)</td>
</tr>
<tr>
<td>EQ-5D VAS</td>
<td>0.50 (p &lt; 0.01)</td>
</tr>
</tbody>
</table>

4.2.3 Inter-rater reliability (sample 1)
To assess inter-rater reliability, two assessors were be present for the interviews with 38 participants, conducting half of them each, and having the chance to ask questions in all for the purpose of clarification. Intraclass Correlation Coefficients and Cohen’s Kappa were conducted on the two assessors’ ratings of the 13 items and Intraclass Correlation Coefficients was conducted on the two assessors’ ratings of the total QOL-AD score
(Table 16). The results showed that all correlations between the two assessors' ratings on the QOL-AD were significant (people with dementia < 0.001 and p < 0.0001). Cohen's Kappa was good (0.60 -0.74) for one item ('memory'), and excellent (0.75-1.00) for the remaining 11, according to the cut-offs outlined by Bowling (2002).

Table 16. Inter-rater reliability for the QOL-AD (n=38).

<table>
<thead>
<tr>
<th>ITEM</th>
<th>Rater 1 mean (sd)</th>
<th>Rater 2 mean (sd)</th>
<th>Cohen's Kappa</th>
<th>Intraclass correlation</th>
</tr>
</thead>
<tbody>
<tr>
<td>(1) Physical health</td>
<td>2.68 (.82)</td>
<td>2.66 (.82)</td>
<td>0.95 (p&lt;0.001)</td>
<td>0.97 (p &lt; 0.0001)</td>
</tr>
<tr>
<td>(2) Energy</td>
<td>2.52 (.79)</td>
<td>2.52 (.79)</td>
<td>0.90 (p&lt;0.001)</td>
<td>0.94 (p &lt; 0.0001)</td>
</tr>
<tr>
<td>(3) Mood</td>
<td>2.52 (.83)</td>
<td>2.34 (.72)</td>
<td>0.79 (p&lt;0.001)</td>
<td>0.87 (p &lt; 0.0001)</td>
</tr>
<tr>
<td>(4) Life situation</td>
<td>2.85 (.93)</td>
<td>2.82 (.90)</td>
<td>0.95 (p&lt;0.001)</td>
<td>0.98 (p &lt; 0.0001)</td>
</tr>
<tr>
<td>(5) Memory</td>
<td>2.25 (.94)</td>
<td>2.07 (.83)</td>
<td>0.73 (p&lt;0.001)</td>
<td>0.75 (p &lt; 0.0001)</td>
</tr>
<tr>
<td>(6) Marriage</td>
<td>3.00 (1.07)</td>
<td>3.00 (1.07)</td>
<td>1.00 (p&lt;0.001)</td>
<td>1.00 (p &lt; 0.0001)</td>
</tr>
<tr>
<td>(7) Family</td>
<td>3.14 (1.00)</td>
<td>3.06 (.87)</td>
<td>0.76 (p&lt;0.001)</td>
<td>0.91 (p &lt; 0.0001)</td>
</tr>
<tr>
<td>(8) Friends</td>
<td>2.87 (.80)</td>
<td>2.80 (.79)</td>
<td>0.77 (p&lt;0.001)</td>
<td>0.88 (p &lt; 0.0001)</td>
</tr>
<tr>
<td>(9) Self</td>
<td>2.57 (.84)</td>
<td>2.63 (.80)</td>
<td>0.83 (p&lt;0.001)</td>
<td>0.91 (p &lt; 0.0001)</td>
</tr>
<tr>
<td>(10) Chores</td>
<td>2.54 (.92)</td>
<td>2.63 (.89)</td>
<td>0.90 (p&lt;0.001)</td>
<td>0.95 (p &lt; 0.0001)</td>
</tr>
<tr>
<td>(11) Fun</td>
<td>2.39 (.79)</td>
<td>2.38 (.75)</td>
<td>0.94 (p&lt;0.001)</td>
<td>0.96 (p &lt; 0.0001)</td>
</tr>
<tr>
<td>(12) Money</td>
<td>2.54 (.88)</td>
<td>2.52 (.88)</td>
<td>1.00 (p&lt;0.001)</td>
<td>0.99 (p &lt; 0.0001)</td>
</tr>
<tr>
<td>(13) Life</td>
<td>2.66 (.94)</td>
<td>2.64 (.90)</td>
<td>0.90 (p&lt;0.001)</td>
<td>0.97 (p &lt; 0.0001)</td>
</tr>
<tr>
<td>TOTAL QOL-AD</td>
<td>33.13 (7.50)</td>
<td>33.00 (7.8)</td>
<td>0.96 (p &lt; 0.0001)</td>
<td></td>
</tr>
</tbody>
</table>

4.2.4 Test-retest reliability (sample 1)

This was tested by the QOL-AD being repeated with the participants 7 days after the initial interview by the same assessor. Intraclass Correlation Coefficients and Cohen's Kappa were conducted on the baseline and follow-up data for all the items and Intraclass Correlation was conducted on the two assessors' ratings of the total QOL-AD scoree.
The results are shown in Table 17. As can be seen here, all correlations between the items and total QOL-AD score at baseline and follow up were significant (p < 0.001 and p < 0.0001). Cohen’s Kappa was poor (0.00 – 0.40) for one item (‘family’), and fair (0.40-0.59) or good (0.60 – 0.74) for all others (Bowling, 2002).

Table 17. Test-retest for the QOL-AD (n=38).

<table>
<thead>
<tr>
<th>ITEM</th>
<th>Baseline score mean (sd)</th>
<th>Follow-up score mean (sd)</th>
<th>Cohen's Kappa</th>
<th>Intraclass correlation</th>
</tr>
</thead>
<tbody>
<tr>
<td>(1) Physical health</td>
<td>2.65 (.80)</td>
<td>2.46 (.65)</td>
<td>0.64 (p &lt; 0.001)</td>
<td>0.77 (p &lt; 0.0001)</td>
</tr>
<tr>
<td>(2) Energy</td>
<td>2.48 (.75)</td>
<td>2.38 (.85)</td>
<td>0.51 (p &lt; 0.001)</td>
<td>0.66 (p &lt; 0.001)</td>
</tr>
<tr>
<td>(3) Mood</td>
<td>2.52 (.85)</td>
<td>2.38 (.90)</td>
<td>0.46 (p &lt; 0.001)</td>
<td>0.64 (p &lt; 0.001)</td>
</tr>
<tr>
<td>(4) Life situation</td>
<td>2.85 (.92)</td>
<td>2.69 (.88)</td>
<td>0.66 (p &lt; 0.001)</td>
<td>0.87 (p &lt; 0.0001)</td>
</tr>
<tr>
<td>(5) Memory</td>
<td>2.28 (.94)</td>
<td>2.32 (.90)</td>
<td>0.47 (p &lt; 0.001)</td>
<td>0.78 (p &lt; 0.0001)</td>
</tr>
<tr>
<td>(6) Marriage</td>
<td>3.00 (1.07)</td>
<td>2.95 (0.84)</td>
<td>0.57 (p &lt; 0.001)</td>
<td>0.77 (p &lt; 0.0001)</td>
</tr>
<tr>
<td>(7) Family</td>
<td>3.02 (1.09)</td>
<td>2.92 (.72)</td>
<td>0.37 (p &lt; 0.001)</td>
<td>0.62 (p &lt; 0.001)</td>
</tr>
<tr>
<td>(8) Friends</td>
<td>2.90 (.82)</td>
<td>2.88 (.73)</td>
<td>0.67 (p &lt; 0.001)</td>
<td>0.85 (p &lt; 0.0001)</td>
</tr>
<tr>
<td>(9) Self</td>
<td>2.58 (.86)</td>
<td>2.60 (.87)</td>
<td>0.55 (p &lt; 0.001)</td>
<td>0.77 (p &lt; 0.0001)</td>
</tr>
<tr>
<td>(10) Chores</td>
<td>2.56 (.87)</td>
<td>2.60 (.91)</td>
<td>0.54 (p &lt; 0.001)</td>
<td>0.77 (p &lt; 0.0001)</td>
</tr>
<tr>
<td>(11) Fun</td>
<td>2.42 (.81)</td>
<td>2.69 (.84)</td>
<td>0.49 (p &lt; 0.001)</td>
<td>0.61 (p &lt; 0.001)</td>
</tr>
<tr>
<td>(12) Money</td>
<td>2.54 (.90)</td>
<td>2.38 (.90)</td>
<td>0.82 (p &lt; 0.001)</td>
<td>0.82 (p &lt; 0.0001)</td>
</tr>
<tr>
<td>(13) Life</td>
<td>2.63 (.93)</td>
<td>2.73 (.92)</td>
<td>0.43 (p &lt; 0.001)</td>
<td>0.67 (p &lt; 0.001)</td>
</tr>
<tr>
<td>TOTAL QOL-AD</td>
<td>33.17 (7.41)</td>
<td>33.81 (7.11)</td>
<td></td>
<td>0.87 (p &lt; 0.0001)</td>
</tr>
</tbody>
</table>

4.2.5 Descriptive characteristics of participants, sample 2

In total, 291 people were screened. Of these, 201 were included (see Chapter 3 for reasons for exclusions). The ages of the participants ranged from 66 to 101, with a mean age of 85.3 (Table 18). The sample included 158 (78.6%) females, and 172 participants
(86.4%) lived in residential care. The sample scored on average as having moderate to severe dementia on the MMSE (14.4) and scored in the middle range on the QOL-AD (33.3). The descriptive statistics showed a range between centres of almost 10/52 on the QOL-AD, from a mean score of 26.45 to 36.00.

Table 18. Descriptive characteristics of participants, sample 2

<table>
<thead>
<tr>
<th></th>
<th>n = 201</th>
<th>mean (sd) [range]</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age</td>
<td>85.3 (7.0) [66-101]</td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>158 (78.6%)</td>
<td></td>
</tr>
<tr>
<td>Cognition (MMSE)</td>
<td>14.4 (3.8) [7-24]</td>
<td></td>
</tr>
<tr>
<td>Cognition (ADAS-Cog)</td>
<td>27.0 (7.5) [8.0-48.5]</td>
<td></td>
</tr>
<tr>
<td>Severity (CDR)</td>
<td>1.4 (0.5) [0.5-2.0]</td>
<td></td>
</tr>
<tr>
<td>QoL (QOL-AD)</td>
<td>33.3 (5.8) [17-47]</td>
<td></td>
</tr>
<tr>
<td>In residential care</td>
<td>172 (86.4%)</td>
<td></td>
</tr>
</tbody>
</table>

4.2.6 Construct validity (sample 2)

A Principal Component Analysis was performed on the data from sample 2, including all items of the QOL-AD to explore the factor structure and construct validity, and determine the eigenvalue and percentage of variance explained by each item (Table 19). This analysis was chosen over a factor analysis because it uses all of the variance of the variables through transforming them into a smaller set of linear combinations, rather
than using a mathematical model to only analyse the shared variance of the variables. A Principal Component Analysis avoids the difficulties associated with 'factor indeterminacy' associated with factor analysis, and it gives a better empirical summary of the data set, rather than a theoretical solution uncontaminated by unique and error variability.

The suitability of data for factor analysis was established before performing the principal component analysis by inspection of the correlation matrix. This revealed a large number of coefficients of 0.3 and above. The Bartlett's Test of Sphericity reached statistical significance (p < .001; Bartlett, 1954), and the Kaiser-Meyer-Olkin value was .74, which was above the recommended of .6 (Kaiser, 1974). This supported the factorability of the correlation matrix. The principal component analysis revealed the presence of four components with eigenvalues exceeding 1, explaining respectively 32.5%, 12.1%, 10.4 % and 7.7% of the variance. All 13 items of the QOL-AD loaded on component 1. Only 3 items loaded more strongly on other components, 'family' on component 3, and 'self as a whole' and 'ability to do chores' on component 2. As inspection of the screeplot revealed a clear break after the first component, rotation was not performed.
Table 19. Results from principal components analysis of QOL-AD items (n=201)

<table>
<thead>
<tr>
<th>QOL-AD ITEM</th>
<th>COMPONENT</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>1</td>
</tr>
<tr>
<td>Life situation</td>
<td>.68</td>
</tr>
<tr>
<td>Mood</td>
<td>.68</td>
</tr>
<tr>
<td>Energy</td>
<td>.67</td>
</tr>
<tr>
<td>Marriage</td>
<td>.61</td>
</tr>
<tr>
<td>Physical Health</td>
<td>.60</td>
</tr>
<tr>
<td>Money</td>
<td>.59</td>
</tr>
<tr>
<td>Friends</td>
<td>.55</td>
</tr>
<tr>
<td>Life</td>
<td>.55</td>
</tr>
<tr>
<td>Memory</td>
<td>.55</td>
</tr>
<tr>
<td>Fun</td>
<td>.54</td>
</tr>
<tr>
<td>Family</td>
<td>.51</td>
</tr>
<tr>
<td>Self</td>
<td>.44</td>
</tr>
<tr>
<td>Chores</td>
<td>.37</td>
</tr>
<tr>
<td>EIGENVALUES</td>
<td>4.23</td>
</tr>
<tr>
<td>% OF VARIANCE</td>
<td>32.51</td>
</tr>
<tr>
<td>Cumulative %</td>
<td>32.51</td>
</tr>
</tbody>
</table>

4.2.7 Convergent and divergent concurrent validity (sample 2)

Convergent and divergent concurrent validity were investigated by comparing the QOL-AD to the CSDD and the MMSE respectively. The hypothesis was that QoL should be expected to be more closely related to level of depression than cognitive abilities. For this, 1-tailed Pearson’s correlation coefficients were conducted. These revealed that depression was statistically significantly negatively correlated with QOL-AD score (-0.20, p < 0.01), while cognition was not (-0.09, p = 0.19).
4.2.8 Known group concurrent validity (sample 2)

In order to assess ‘known group concurrent validity’ (Prince, 1998), the correlation between QoL and depression detected above was utilised. The participants were divided into four levels of groups according to their scores on the CSDD, and a One-Way Anova conducted to establish whether there would be any significant difference in QOL-AD score between the groups (Table 20). The results showed that the mean QOL-AD score significantly decreased as CSDD increased (F = 2.75, p < 0.05). However, to further explore the differences between the groups, a post-hoc comparison was conducted, using the Tukey Honestly Significant Difference test. This is useful method to guard against the possibility of an increased Type 1 error being made when making a large number of comparisons, and sets a more stringent criteria for significance. This test revealed no statistically significant differences between the groups (1.26, p = 0.52; 3.81, p = 0.09; 5.14, p = 0.41; 2.54, p = 0.44; 3.88, p = 0.66; and 1.33, p = 0.98 respectively).

<table>
<thead>
<tr>
<th>QOL-AD mean (sd)</th>
<th>CSDD score 0-5 (n = 111)</th>
<th>CSDD score 6-12 (n = 57)</th>
<th>CSDD score 13-19 (n = 14)</th>
<th>CSDD score 20-25 (n = 3)</th>
<th>Sign.</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>33.8 (5.3)</td>
<td>32.5 (5.8)</td>
<td>30.0 (7.8)</td>
<td>28.67 (5.5)</td>
<td>F = 2.75</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>p &lt; 0.05</td>
</tr>
</tbody>
</table>
4.2.9 Internal consistency (sample 2)

The internal consistency of the QOL-AD was tested by using Cronbach’s Alpha Coefficient. The results are shown in Table 21. As can be seen here, Cronbach’s Alpha Coefficient of the scale was 0.82, which is above the recommended value of 0.7. All items correlated with the total scored at a value of above 0.3, with the exception of ‘ability to do chores’ (0.29), which, if deleted from the scale, would result in a minimal increase in the Alpha value of the QOL-AD from 0.820 to 0.822.

Table 21. Internal consistency of the QOL-AD (n=201).

<table>
<thead>
<tr>
<th>ITEM</th>
<th>Mean (sd)</th>
<th>Item-total correlation</th>
<th>Alpha if item is deleted</th>
</tr>
</thead>
<tbody>
<tr>
<td>(1) Physical health</td>
<td>2.56 (.83)</td>
<td>0.48</td>
<td>0.81</td>
</tr>
<tr>
<td>(2) Energy</td>
<td>2.43 (.86)</td>
<td>0.56</td>
<td>0.80</td>
</tr>
<tr>
<td>(3) Mood</td>
<td>2.61 (.76)</td>
<td>0.56</td>
<td>0.80</td>
</tr>
<tr>
<td>(4) Life situation</td>
<td>2.64 (.82)</td>
<td>0.57</td>
<td>0.80</td>
</tr>
<tr>
<td>(5) Memory</td>
<td>2.39 (.83)</td>
<td>0.43</td>
<td>0.81</td>
</tr>
<tr>
<td>(6) Marriage</td>
<td>2.71 (1.11)</td>
<td>0.50</td>
<td>0.81</td>
</tr>
<tr>
<td>(7) Family</td>
<td>2.97 (.72)</td>
<td>0.42</td>
<td>0.81</td>
</tr>
<tr>
<td>(8) Friends</td>
<td>2.79 (.70)</td>
<td>0.45</td>
<td>0.81</td>
</tr>
<tr>
<td>(9) Self</td>
<td>2.56 (.71)</td>
<td>0.36</td>
<td>0.81</td>
</tr>
<tr>
<td>(10) Chores</td>
<td>2.30 (.86)</td>
<td>0.29</td>
<td>0.82</td>
</tr>
<tr>
<td>(11) Fun</td>
<td>2.42 (.70)</td>
<td>0.46</td>
<td>0.81</td>
</tr>
<tr>
<td>(12) Money</td>
<td>2.40 (.73)</td>
<td>0.48</td>
<td>0.81</td>
</tr>
<tr>
<td>(13) Life</td>
<td>2.68 (.64)</td>
<td>0.46</td>
<td>0.81</td>
</tr>
</tbody>
</table>

Cronbach Alpha 0.82
4.3 DISCUSSION

4.3.0 Face/content validity

A definition of QoL arising from the focus groups conducted with people with dementia was ‘inward satisfaction’. These groups thought that the items of the QOL-AD were important for people with dementia’s QoL. The carers for people with dementia attending the focus groups also perceived all the items of the QOL-AD to be important in order to determine people with dementia’s QoL. Health care professionals completing a questionnaire rated all items of the QOL-AD as being ‘important’ to ‘very important’ for QoL in dementia, and the majority of respondents thought that the QOL-AD covered all the important elements of QoL in dementia and that the QOL-AD did not include any elements that were unimportant when assessing QoL for people with dementia. Hence, the QOL-AD was found to have good face/content validity.

From the focus groups with people with dementia, carers for people with dementia and the questionnaires completed by health care professionals working with this client group, certain themes emerged. One was the emphasis on social networks and good family connections, and both people with dementia and their carers thought that having contact with children was important for QoL in dementia. Another theme was the perceived importance of being stimulated and involved in activities. Physical health and memory difficulties were highlighted by most as having a significant effect on the QoL for people with dementia, although awareness and perception of these factors were though to be the most important by carers and health care professionals. The importance of feeling useful
was another theme that emerged from the focus groups, while the staff responding to the questionnaire highlighted the possibility of people with dementia being able to do chores independently, but not being given the opportunity to do them.

Another theme was level of dependence. People with dementia and staff agreed that being independent was important for QoL in dementia. People with dementia expressed a more positive outlook on their lives and roles, such as having a direction in life, achieving what you want, and being able to give to society. In contrast, the carers emphasised the role of the carer, as they seemed to perceive people with dementia as being more dependent and had a more restrained view of what people with dementia could expect, and some felt that the best they could aim for was contentment.

Similarly, the health care professionals, although emphasising the fact that QoL for people with dementia encompassed the same elements as QoL for other people, did not suggest the inclusion of items that they most likely would have seen as important for their own QoL, such as fulfilling one’s ambitions, experiencing beauty, and perfecting new skills. As such, the people with dementia seemed to relate more to higher levels of Maslow’s (1943) hierarchies of needs than the people around them thought they would.

All items of the QOL-AD were seen as being important to people with dementia’s QoL, although some items received criticism for not being self explanatory or specific enough. There was some ambivalence regarding the ability of people with dementia to sustain
friendships, and a more general wording such as ‘contact with people’ was suggested. The item relating to marriage also received some criticism, some felt that “togetherness” in general would be more useful to assess, and some thought that this item included a heterosexual bias. Additionally, items relating to money, family and roles were suggested as being too personal, and as such might not elicit an accurate response. Items on food, drink, medication, communication, insight and carers’ coping would have been welcomed by a minority. It was also suggested that the QOL-AD was too long and complex to understand for people with dementia, and that it might not be possible to capture the elements meaningful to the individual person with a standardised scale, and that as such some qualitative data was needed. Thus, there were several incompatible suggestions made as to how the QOL-AD could be improved. While the scale overall was criticised for being too vaguely worded, there were also suggestions made as to it being too specific in parts. Additionally, although it was thought by some that the QOL-AD was too long and complex, several suggestions were made as to items that ought to be included. Also the issue of individual differences was raised, which if addressed would result in a longer and more complex procedure in order to assess QoL in dementia, and might exclude people with more severe dementia from the assessment procedure.

In the questionnaires, in which health care professionals scored the 13 items of the QOL-AD in terms of importance to people with dementia’ QoL, some items were seen as being more central than others by the majority of respondents. However, all items
scored overall as being important to very important. The majority of respondents (61.6%) thought that the QOL-AD covered all the important elements of QoL in dementia, and that the QOL-AD did not include elements unimportant when assessing QoL for people with dementia (80.8%). Thus, in conclusion, the QOL-AD was found to have good face/content validity, no additional items were necessary and all the items were required.

4.3.1 Construct validity

The Principal Component Analysis on the items of the QOL-AD showed the presence of four components with eigenvalues exceeding 1, and all items loaded on the first component. This suggests that all the items of the QOL-AD assess the same underlying variable, namely QoL in dementia. In addition only three items loaded more strongly on other components, 'family' on component 3, and 'self as a whole' and 'ability to do chores' on component 2. Hence, the QOL-AD was found to have good construct validity as a multidimensional scale.

4.3.2 Criterion concurrent validity

There is no 'gold standard' as such for measuring QoL in dementia. Neither are there any well-established scales to assess the criterion concurrent validity of other scales against. Hence, in order to investigate this, the score on the QOL-AD were correlated with the person with dementia’s performance on the Dementia Quality of Life (DQoL; Brod et al., 1999) scale, the EQ-5D (EuroQoL Group, 1990), the person’s Well-being
(WIB) score from the Dementia Care Mapping (DCM; Kitwood & Bredin, 1994) conducted, the score on the QOL-AD items ‘self as a whole’ and ‘life as a whole’, and how the person with dementia rated her/his own health today on the EQ-5D visual analogue scale (VAS). The results showed that total QOL-AD score correlated significantly with all other QoL indices measured, apart from DCM WIB score, which was bordering on significance. However, bearing in mind the smaller numbers in the DCS-WIB group and the high correlation, there is a real possibility of a type II statistical error (Howell, 1999) with a significant results being found if a larger sample was used.

However, as there was no ‘gold standard’ for measuring QoL in dementia, or any well-established scales to assess the concurrent validity of other scales against, scales had to be used that appeared to be the best available. We aimed to include a range of levels of dementia, and as such people with a MMSE score as low as 3 were included. Although these participants were able to complete the QOL-AD, some found it too difficult to complete the DQoL, which in any case was developed for people with a minimum MMSE score of 11 (Brod et al., 1999). The DQoL also differs from the QOL-AD, in that it seems to focus more on internal states of the person, while the QOL-AD aims to assess the person with dementia’s perception of their relationships and ability to successfully engage with the world. Additionally, the 5 sub-scales of the DQoL were added up to produce a total score, which was not the scale designers’ intention. The EQ-5D (EuroQoL Group, 1990) was used as a generic well established QoL scale, but this has been shown to not be ideal when assessing QoL in dementia (Selai, 1997), and to be
lacking in content validity for this group (Silberfeld et al., 2002). This scale was found not to differentiate well between people with varying scores of QoL on the other measures, the majority of people did not report experiencing any problems in the 5 domains, and found the visual analogue scale too difficult to complete.

In order to assess QoL for people who did not have much remaining verbal language, Dementia Care Mapping (DCM; Kitwood & Bredin, 1994) was used. This is a method developed to establish quality of care, and only one element of the method, the person’s well-being (WIB) score, was used in this study. It was used due to the fact that it is the best established and validated structured observational method of this kind. The WIB score was the only QoL indicator not found to be highly significantly correlated with the total QOL-AD score. This might suggest that observational methods of QoL/well-being do not necessarily correspond with how the person perceives her/his QoL in dementia, which links in with the points made in the introduction of this thesis about ‘patient’ vs. proxy reports. It also offers some support to the emphasis placed here on the use of self-report measurement of QoL in dementia. However, the point has been made in the literature that the WIB score is not a substitute for DCM (Bruce, 2000). Furthermore, DCM is also dependent on quality of care input, and its time frame is very different from what is being assessed in interviews. Hence, within the limitations posed, the QOL-AD was found to have very good criterion concurrent validity.
4.3.3 Convergent and divergent concurrent validity

Convergent and divergent concurrent validity were investigated by comparing the scores on the QOL-AD to scores on the Cornell Scale for Depression in Dementia (CSDD; Alexopoulos et al., 1988) and the Mini Mental State Examination (MMSE; Folstein et al., 1975), hypothesising that QoL should be expected to be more closely related to level of depression than cognitive abilities. This was supported by the results, which revealed that depression was statistically significantly correlated with QOL-AD score while cognition was not. This is similar to findings by Logsdon et al. (1999), who found scores on the QOL-AD to be significantly correlated with ratings of depression. However, Logsdon et al. also found a modest correlation between QOL-AD score and the MMSE. This could be due to the fact that these authors included carers' ratings of the person with dementia's QoL into the total score. Thus, the QOL-AD was found to have good convergent and divergent validity.

4.3.4 Known group concurrent validity

In order to assess known group concurrent validity (Prince, 1998), the correlation between QoL and depression detected above was utilised. The participants were divided into four groups depending on their scores on the CSDD, and their QOL-AD scores were compared. Although the initial test indicated a significant difference between the groups, further analysis revealed no statistical significance. Thus, although the assumption made as to the links between QoL and depression in dementia has some support in the literature (Logsdon et al., 1999; Chapter 2 of this thesis), the relationship
might be more complex than assumed for the purpose of this study. Hence, the QOL-AD was not here found to have good known group concurrent validity.

4.3.5 Inter-rater reliability

Although the QOL-AD was designed for self-completion, it is more often the case that the scale has to be completed in conjunction with the interviewer, particularly with people with moderate to severe dementia. There will therefore be some degree of interpretation present, and the agreement between raters is a significant factor. The results showed that the two assessors' ratings were significantly correlated for total QOL-AD score and ratings of the 13 items, and Cohen's Kappa was very good for the 13 items. Therefore, the QOL-AD was found to have very good inter-rater reliability.

4.3.6 Test-retest reliability

Repeat assessments with the QOL-AD of the participants 7 days after the initial interview revealed that the 13 items as well as total QOL-AD score significantly correlated between these two occasions. Cohen's Kappa was found to be fair to good for all items, with the exception of the item relating to relationships with family. That the Kappa was not found to be good for all items might be due to QoL being a dynamic construct, and as such some variation might be expected. The item on relationship with family might be particularly affected by day-to-day variations, as the score given to this item might be dependent on when the last visit was made by relatives, and how this visit
was perceived. Hence, the QOL-AD was found to have fair to good test-retest reliability, as has also been found by Logsdon et al. (1999).

4.3.7 Internal consistency

The internal consistency of the QOL-AD was found to be high, as Cronbach’s Alpha Coefficient for the scale was .82. All items correlated with the total above the recommended value, and would decrease the Alpha value of the QOL-AD if deleted, with the exception of ‘ability to do chores’, which if deleted would have an extremely small effect increasing the Alpha. Most people with dementia in this sample were living in residential homes, and as such did not have the opportunity to do chores, as this was commonly not expected of them. Nevertheless, the finding was extremely marginal and is probably either not important or within the limits of error. Thus, the QOL-AD overall was found to have excellent internal consistency, suggesting that the items can be summated as a scale. These results are similar to those of Logsdon et al. (1999).

4.3.8 Limitations

Due to the recency of the methods used for assessing, and the challenges surrounding conceptualising QoL in dementia, several issues emerged when conducting this validation study. People with severe dementia were not being able to participate in the focus groups, and as such did not have much opportunity to convey their views about QoL in dementia and the QOL-AD as an assessment tool. Additionally, the analyses utilising sample 2 (n = 60) could have benefited from having a larger sample,
particularly as not everyone was able to complete all items of the DQoL. The difficulties with lack of available caregivers, as outlined in Chapter 2, applied also here, and as such these aspects were not included in the study. In relation to the correlation found between depression and QoL when investigating convergent and divergent validity, although statistically significant, it was below the suggested cut-off of 0.4 for clinical significance (Dunn & Everett, 1995). Therefore, how meaningful this is in clinical terms is unknown.

4.3.9 Conclusion

QoL is a highly subjective concept. Therefore, challenges do emerge when attempting to assess QoL, particularly for people who have difficulties with remembering and comprehending, such as those with dementia. Using dementia-specific scales to assess QoL in this group has only recently become widespread, and the methods are not yet well established. Thus, establishing the validity and reliability of these relatively new scales is important. One such scale is the Quality of Life- Alzheimer’s Disease (QOL-AD; Logsdon et al., 1999), for which there has been limited testing of its psychometric properties. Hence the need for the present study. The QOL-AD was found to have very good face/content validity, construct validity, and criterion concurrent validity. The indication found that the QOL-AD has good convergent and divergent concurrent validity must be considered with caution, and the known group concurrent validity of this scale remains unclear. The QOL-AD was further found to have excellent inter-rater reliability and internal consistency, and test-retest reliability was fair to good. Therefore,
the hypothesis that the QOL-AD is a valid and reliable scale has largely been supported. The present study shows that the QOL-AD is a reliable measure, also without the proxy input. Additionally, this study has demonstrated that also people with severe dementia can reliably report on their QoL, as the sample included participants with a MMSE score as low as 3. These results replicate the finding by Selai et al. (2001) that the QOL-AD can be used in the UK without any difficulties.
CHAPTER 5: DISCUSSION

5.0 OVERVIEW

The results from two studies have been presented in this thesis. Firstly, a single-blind randomised controlled trial of an evidence-based psychological group therapy programme for people with dementia was conducted, and the effects on quality of life (QoL) investigated. This trial additionally enabled an investigation into whether certain factors are associated with QoL in dementia, namely cognitive abilities, physical health and emotional functioning, and some aspects of the person’s social and physical environment. These factors were suggested as components of QoL in dementia in the conceptual model proposed in Chapter 1 – paragraph 1.2.6 of this thesis. These factors were investigated both at baseline and follow-up, and as such also associations between change on these variables established. Secondly, the validity, reliability and sensitivity to change of the shortest and most easily intelligible assessment scale of QoL in dementia currently available, the QOL-AD (Logsdon et al., 1999), was established. This was done in an attempt to add to the current debate regarding whether self-report assessment scales can be used to measure QoL for people with dementia. This study also allowed a further investigation into the nature of QoL in dementia, through the exploration of this as a valid construct. This chapter will aim to critically evaluate the results from these studies, and issues arising from these, in the context of the current literature.
5.1 CONCEPTUALISING QUALITY OF LIFE IN DEMENTIA

Throughout the findings of the studies presented in this thesis, one thing is clear: There is QoL in dementia! People with dementia attribute quality to their lives to a varying degree, and seem aware of this as a meaningful concept. Only a few aspects of the suggested conceptual model of QoL in dementia could be investigated directly in the studies presented in this thesis: cognitive abilities, physical health and emotional functioning. Additionally, some aspects of the factors thought to mediate the effect of these variables on people with dementia’s appraisal of their QoL, namely their social and physical environment, were also investigated. These elements are shown in Figure 2 below.

*Figure 3. The elements of the conceptual model of quality of life in dementia investigated.*
5.1.0 Associations between cognitive abilities and quality of life in dementia

QoL in dementia was not found in the results presented in this thesis to be correlated with cognitive function, which to some extent contrasts the findings by Gonzalez-Salvador et al. (2000), who found worse orientation to be associated with, and predicted by, lower QoL. However, the study reported in this thesis found QoL to be predicted by level of dementia (although little of the variance was explained by this variable). As such, people with more severe dementia appeared to have higher QoL.

The measure used to assess dementia level (CDR) encompasses more elements than cognitive abilities, and as such could be seen as a more holistic measure of severity of dementia than cognitive tests. However, in the present investigation the CDR was used as a dichotomous scale, as there were very few ‘severe’ cases. As such it is a fairly crude measure of dementia severity. Yet, consideration may be needed as to how dementia is currently being assessed, with measures of cognitive abilities and measures such as the CDR commonly being used interchangeably, with little discussion as to what implications the choice of measure might have.

Why people with more severe levels of dementia reported higher QoL is not clear. Some might argue that this supports the notion that people with dementia gradually lose ‘insight’. However, the question of insight is a thorny issue, as outlined in the introduction of this thesis, and there could be several other reasons for these findings. One is that the degree of acceptance might gradually increase and people to a lesser degree feel that they have to keep up a pretence of not experiencing difficulties, another that as people’s dementia progresses their environment becomes more adapted to their needs. Another suggestion could be that while people with mild to
moderate dementia feel more institutionalised, people with more severe dementia feel looked after and cared for. These findings could mean that 'dementia level' is a more meaningful variable in QoL in dementia than 'cognitive abilities'.

These results could also be suggesting that rather than QoL in dementia being independent of cognitive abilities (which sounds highly unlikely), it could be that cognitive abilities are linked to QoL via the person's social environment and the person's appraisal of these abilities, rather than cognition per se. This would support the proposed model of QoL in dementia. If so, this would mean that the people surrounding the person with dementia can have an influence on how these cognitive abilities, or lack thereof, are being perceived, through adaptation to the person's needs. This could offer a great degree of hopefulness to the field of dementia care, and also to the care for people with other degenerative disorders. This suggestion finds some support in the finding presented in this thesis, namely that the improvement in cognition found for people with dementia attending the psychological therapy groups (reported in Spector et al., 2001), was significantly correlated with, and significantly predicted, improved QoL, while the deterioration in cognition for controls was not associated with a decline in QoL. At the very least, it supports the notion that the association between cognition and QoL in dementia is of a complex nature.

5.1.1 Associations between physical functioning and quality of life in dementia

Significant associations between higher QoL and better physical functioning were found in the studies presented here. Higher levels of functioning could enable people
with dementia to more successfully engage with their environment. However, these
might not be simple, or direct, relationships. From the focus groups conducted with
people with dementia, reported in Chapter 4 – paragraph 4.2.2.0 of this thesis, a
consistent theme emerged regarding independence. In the focus groups the
detrimental effect on QoL of not having a job anymore, losing one’s role in life and
feeling useless was emphasised. Having a direction in life, achieving what you want,
being able to give to society, being independent and having freedom to do what you
want (“being one’s own”) were all seen as essential in order to have good QoL in
dementia. The differences between the bio-medical model of disability and the
social model of impairment (Makin, 1995) described in Chapter 1 – paragraph 1.2.4
seem relevant in this regard. According to the social model impairment only
becomes a disability when society fails to support the individual’s special needs.
The need for feeling useful, despite impaired physical functioning, does not seem to
currently be a priority in residential homes and day centres, where it may require
more resources to enable people to do what they can for themselves and others, than
just doing it for them (it is this author’s experience that people are commonly moved
around in wheelchairs rather than supported to walk because it is quicker, which has
a further detrimental effects on their mobility). Thus, it may not be the person with
dementia’s physical functioning per se that it important, but rather the way this is
accommodated by the person’s environment.
5.1.2 Associations between mood/emotional functioning and quality of life in dementia

Statistically significant correlations were detected between higher QoL and lower levels of depression in the studies presented in this thesis. These findings are similar to those of González-Salvador et al. (2000). Lower levels of depression may be important in order for the person with dementia to retain a positive perception of her/himself and her/his life. However, although these were statistically significant correlations, they were small in value and demonstrated there was relatively little overlap in variance between depression and QOL-AD. This may indicate a complex relationship between these variables. QoL has in the past been equated with 'happiness' (Frank-Stromborg, 1988), as well as consisting, amongst other elements, of positive and negative affect (Brod et al. (1999). Being in low mood, tearful or angry, would in this sense be seen as related to having low QoL. In contrast, Kitwood and Bredin (1992) suggest that one indicator of well being is the ability to experience and express a range of positive and negative emotions. Having dementia could possibly enable expression of a whole range of so-called negative emotions, which have in the past been denied expression, resulting in more labile emotional behaviour, but give a greater sense of QoL. In the studies conducted here self-report was used to assess QoL, whilst depression was assessed, as is most often the case, by proxy measures. Therefore, these expressions may have been perceived as a depressed mood by the proxy raters. This is supported by findings that measures assessing subjective complaints in dementia pick up less indicators of depression than ones measuring 'objective'/somatic aspects (Sultzer et al., 1992). Furthermore, as outlined in Chapter 1 – paragraph 1.2.5, Calman (1984) has proposed that we
consider QoL as the discrepancy between our expectations and our experience, and Carr et al. (2001) suggest that the reference value of people's expectations may change over time, labelled a 'response shift'. There is a possibility that most older people currently have low expectations of what their lives should entail. If this is true, older people, with or without dementia, could be experiencing low mood, or even clinical depression, but perceive this as a natural part of growing older. After all, this is a cohort with completely different value systems and expectations of life from young adults today.

5.1.3 Associations between social and physical environment and quality of life in dementia

Significant predictors of experiencing higher QoL in dementia were found to be living in a larger residential home or attending a larger day center, and for this to be set in a rural area. Some explanations for this include the possibility of these centres having more resources, or that the people living in/attending these centres were different in terms of socioeconomic status. This is something that could benefit from further investigation, as it could give us some idea as to what aspects of the setting benefit QoL in dementia, and how to aim the development of centres like these. Other variables studied relevant to people with dementia's social and physical environment, such as being in residential or day care, and being funded by private or public sources, were not found to have an effect on QoL in dementia. These are quite interesting findings, in that they are not what may have been expected. These results suggest that QoL might be influenced by some aspects of the person's social
and physical environment. Therefore, interventions aimed at improving QoL in dementia might benefit from targeting difficulties also in these areas.

Factors such as mood and cognition might additionally have an effect on how people in the person with dementia’s immediate environment perceive her/his interactions, and as such influence the way they interpret the person’s interactions. This is turn may affect the people with dementia’s social and physical environment in a reciprocal manner. The inclusion of staff members in the therapeutic groups conducted, and the interest the project evoked among staff in most centres, could have had a positive effect on the social environment of the people with dementia involved in the groups, and influenced their QoL as outlined in the proposed conceptual model of QoL in dementia. Additionally, as outlined in the introduction of this thesis, Innes (1998) found that what behaviour staff in a residential home perceived as ‘challenging’ varied according to their relationship to the person. Thus, this could have an effect on how this behaviour is being responded to, such as what medication, if any, is being prescribed in order to deal with these behaviours.

5.1.4 Quality of life as conceptualised by people with dementia

QoL was defined by people with dementia attending the focus groups conducted as ‘inward satisfaction’. Elements identified as important to having good QoL in dementia were well-developed social networks, good family connections, and being stimulated. The importance of feeling useful was another element thought to be important, as outlined above. These elements are included in the suggested conceptual model of QoL in dementia, as part of the person with dementia’s social
environment, affecting her/his appraisal of her/his situation, which according to this model constitutes the basis for QoL in dementia. This has rather encouraging implications for the ability of health care professionals to have a significant positive influence on the person with dementia’s QoL. For example, the possibility of people with dementia being able to do chores independently (or with a little help), but not being given the opportunity to do so, has been highlighted in this thesis. As mentioned before, this is important for the way residential homes are currently being run, with little or no opportunity for the residents to feel that they have something of value to contribute. This also applies to society as a whole. Older people in general, and people with dementia in particular, are often not valued as much as they should be for what they can contribute to a western society, something that might have an influence on their QoL, as outlined in the proposed conceptual model of QoL in dementia. When considering the wealth of experience, wisdom and compassion this group holds, it seems to be a great loss, for them and for us.

5.1.5 Quality of life in dementia as conceptualised by proxies

People with dementia attending focus groups expressed a positive outlook on their lives and roles, such as the importance of having a direction in life, achieving what you want, and being able to give to society. Their carers, however, seemed to hold a more muted view, and perceived people with dementia as being relatively dependent. Some carers even felt that the best they could aim for was ‘contentment’. Additionally, some carers felt that ‘contact with people’ was more important to assess as an aspect of QoL in dementia than meaningful friendships. This does not seem to reflect a particularly person-centered view. The carers also emphasised the
effect of the carer on the QoL of the people they cared for, and thought that the carers ideally should be present when assessing QoL for people with dementia. These views, however, must be considered in the light of the carers’ own needs in relation to the person with dementia. Health care professionals, although emphasising the fact that QoL for people with dementia encompassed the same elements as QoL for other people, did not suggest the inclusion of items that they might have seen as important for their own QoL, such as fulfilling one’s ambitions, experiencing beauty, and perfecting new skills. Thus, the people with dementia seemed to relate more to higher levels of Maslow's (1943) hierarchies of needs than their informal and formal carers. Traditionally, the conclusion drawn might be that the people with dementia have unrealistic expectations of the future, but is this necessarily so? As outlined in the introduction of this thesis, the perception of illness as a ‘contraction of life’ is being replaced by a more differentiated view in relation to other disorders (e.g. Sacks, 1985), and this shift is slowly taking place, also in relation to people with dementia (e.g. Russell, 1996; Allen, 2000).

These contrasting views of what QoL in dementia entails lends support to the argument posed in this thesis, namely that QoL in dementia is best assessed by using the people with dementia’s own reports as proxies cannot properly appreciate the subjective experience of other people, with or without dementia.

However, there is an important issue to consider in this regard. This relates to the fact that relying exclusively on the person with dementia’s own perception in the current ageist climate holds the possibility of being oppressive. As outlined in this
thesis, an important issue when conceptualising QoL is to recognise the impact of cultural and social factors. QoL will most probably be influenced by the individual’s frame of reference, and the individual’s perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals. Older people in general, and people with dementia specifically, belong to a particularly devalued group in our society, which commonly equates value with productivity. Therefore, if this group have internalised the negative attitudes and beliefs that surround them, they probably have particularly modest reference points when evaluating their QoL. This could in turn be used as an argument against dedicating resources to improve the situation for this group of people. As mentioned before, suggestions have been put forward that raising expectations of health is an essential part of the ‘critical consciousness’ of improving community health (Carr et al., 2001), and this is an important point to keep in mind. The fact that people with dementia may rate their own QoL higher than people around them would expect on the basis of their living situation or position in life, should never be used as an excuse for not taking responsibility for attempting to improve upon this situation.

5.1.6 Improvements in quality of life in dementia

The evidence-based psychological group therapy programme presented in this thesis was found to significantly improve the QoL for people with dementia in a single-blind randomised controlled trial. The main improvements were found on items relating to energy level, memory, relationship with spouse, partner or significant other, and ability to do chores. These could be said to relate to three aspects of QoL in dementia, namely cognitive functioning, physical health and ability to interact
with social and physical environment. It could be argued that these were the aspects that the programme was designed to improve, as it was intended to be cognitively stimulating in the context of social and enjoyable activities.

5.1.6.0 Possible mechanisms for improvements in quality of life in dementia

The groups provided a setting where people with dementia were respected and valued, which unfortunately is not a given in their everyday environments. Additionally, the groups included elements that could have influenced people's appraisal of their QoL, as outlined in the conceptual model proposed of QoL in dementia. The groups all involved what Kitwood called 'Positive Person Work' (Kitwood, 1997), including factors such as: (1) Recognition, i.e. acknowledgment of the person as an individual. An attempt was made for people to learn each others' names in the warm-up exercises used, and in the sessions people were encouraged to share unique stories from the past and present. (2) Negotiation, i.e. consulting people about their preferences. In naming the group, people were asked to make suggestions and a decision was made by vote, and emphasis in all sessions was on opinions rather than factual knowledge. (3) Collaboration/working together. This was exercised throughout the programme, for example in the creation of a map, the making of a cake and working in teams for the quiz. (4) Play, defined as an exercise in spontaneity and self-expression. All sessions were designed to be 'game-like', without rigid boundaries so that people could be unconstrained and expressive. (5) Relaxation. The aim of all sessions was that people were able to express and enjoy themselves in a relaxed, non-confrontational environment. These factors could at
least to some degree have curbed the 'Malignant Social Psychology' that Kitwood (1997) described.

In addition, the other psychological theories of dementia outlined in the introduction of this thesis, entail several possible mechanisms for change. The 'dementia spiral' (Barnes, Sack & Shore, 1973) might have been slowed down by reinforcing the people with dementia's sense of self-worth, and giving them an opportunity to give something of value to each other and us, the group leaders (which was one aspect of life seen as crucial for high QoL by the people with dementia attending the focus groups conducted). The people with dementia attending these groups may additionally have received reinforment of a more positive public self than in the past, and as such might have experienced a more positive 'social integration of the self' (Sabat & Harré, 1992). It is also possible that the groups functioned to lessen the people with dementia's sense of societal ageism as emphasised by Voss (1989), and their internalised ageism described by Bender and Wainwright (1998). The groups included a reminiscence element, in which the members’ ability to retain their 'transit ability' (Jones & Burns, 1992) between different realities was encouraged, the groups provided ample stimuli and opportunities for meaningful interactions with other people, and also aimed to provide choice and a sense of control over the group situation, all perceived as central to QoL by people with dementia attending focus groups. Furthermore, the groups aimed to create a safe environment for the people with dementia and provide available attachment figures in the present (the group leaders), and may therefore have lessened the need to display the 'attachment behaviour' described by Miesen (1992). Lastly, the groups provided the opportunity
to at least to some extent deal with unresolved conflicts and non-accepted events, and the people with dementia may have been able to gain some sense of resolution, as emphasised by Feil (1985).

5.1.6.1 Therapeutic properties of groups with people with dementia

As outlined in Chapter 1 – paragraph 1.1.4.4 of this thesis, conducting therapy in groups is thought to entail other therapeutic properties than therapy carried out on an individual basis, and Yalom (1985) has outlined 10 therapeutic factors thought to be important in this regard. However, with the cognitive and inter-personal deterioration commonly occurring in dementia, will these therapeutic factors be present to the same degree? After conducting a large number of groups for people with dementia, this author would say that some factors seem to apply more than others do. For example, 'instillation of hope' is most commonly used to refer to hope about being 'cured', which obviously does not apply in this context. For some group members, the opposite may have been the case, in that they were in the group with people who had deteriorated further than they had. Of the 115 people with dementia partaking in the groups, this was a problem for one participant, who was very early on in the progression of this disorder, and was greatly offended by being asked to take part in the groups with the other participants who were functioning at a lower level. Otherwise, it seemed that the group members took onboard the fact that they all had dementia to a degree that felt somewhat comfortable to them. In addition, does hope necessarily have to be of 'being cured'? It could be that hope may be of remaining continent throughout the day, or that deterioration will not prevent some grace to be ensured. In this vein, the groups could indeed have helped
instill some hope for their members, in that they contained activities which people were able to do successfully, highlighting their preserved abilities. Similarly, the disconfirmation of people's feelings of uniqueness might have been a powerful source of relief for people in the groups ('universality'). For example, jokes regarding memory loss were often made between group members. Furthermore, people's awareness of their symptoms as not being unique, may have reduced those symptoms that could be exaggerated by the awareness of their dementia, such as apathy. The group leaders offering of simple explanations about memory loss in old age ('impacting information') sometimes appeared to alleviate stress in individuals. This may have been as much because of the process of giving advice being useful, signaling respect and reinforcing the person's right to be concerned. Group members also sometimes offered their own interpretations or tips to each other, again reducing anxiety on both sides. Being part of a small group with regular meetings might have induced feelings of belonging ('group cohesiveness'), in contrast to the feeling of anonymity often felt in residential care. In many groups, individuals offered support to each other, perhaps giving them a sense of purpose ('altruism'). Whether other therapeutic factors, such as 'the corrective recapitulation of the primary family group', 'development of socialising techniques, 'imitative behaviour, or 'interpersonal learning', can occur in groups with people with dementia, seems more doubtful. Most participants seemed to remember the groups and the group leaders on some level, i.e. having vague recollections that this was something they enjoyed doing and these were people giving them time and respect. However, most did not have a clear idea of this, thus it was problematic to ensure the degree of trust and continuity necessary for these therapeutic factors to be present. Additionally, short-
term memory difficulties may have made it difficult for new insights to be maintained and consolidated.

Kitwood (1992) also highlighted ways in which people with dementia might benefit from groups: "People with dementia are often extremely sincere and open in expressing what they are feeling and needing, whereas many people who are cognitively intact hide behind conventional masks and pretences. People who have dementia are markedly sociable, and there are many who are positively relationship-seeking, whereas our culture often engenders withdrawal or self-isolation."

5.1.6.2 Gender differences in improvement of quality of life in dementia

Gender was found to be a significant factor in the improvement of QoL for people with dementia, with females improving more than males subsequent to participating in the groups, and males deteriorating more than females in the control group, specifically on items relating to ability to do chores and things for fun. This might reflect a general issue in residential and day care, where men are usually a minority, and their preferred activities are therefore more difficult to accommodate. This may also have been true for the groups. The issue of matching groups to participants was highlighted by the inclusion of a transsexual woman in one group. She tried her best to live as a man in a residential home, to which she met a lot of resistance, and as such she was particularly unwilling to engage in any activity she perceived as 'for women', which included quite a few of the sessions in the programme. This is a challenge that needs to be addressed, both in therapeutic groups such as the ones presented here, and in other activities offered to people with dementia.
5.2 MEASURING QUALITY OF LIFE IN DEMENTIA

In the results presented in this thesis, the Quality of Life- Alzheimer’s Disease scale (QOL-AD; Logsdon et al., 1999) was found to be valid and reliable as a self-report measure without carer input on all investigated aspects of reliability and most aspects of validity. This finding is particularly useful as research is starting to show that proxy reports of QoL for people with disability must only be used with caution (Andresen et al., 2001), as must proxy reports of QoL for people with dementia (Novella et al., 2001). Possibly the most meaningful finding was that the QOL-AD had good face/content validity, that is the people with dementia themselves, and the people around them, thought that the QOL-AD captured the aspects important to QoL in dementia. The use of the Dementia Quality of Life (DQoL; Brod et al., 1999) in this validation study to evaluate the concurrent validity of the QOL-AD, highlights the issues regarding whether the measurement of QoL must necessarily be multidimensional and creating a QoL profile, which the DQoL does, or whether it is possible to generate a single index value for QoL, as done by the QOL-AD. These findings suggest that it is possible to produce a meaningful single score. This is particularly important if QoL is going to be introduced as a routine part of assessments of people with dementia.

However, it might be that using a scale such as the QOL-AD is not the ideal for all people with dementia. This field is still in its early development, and as such no consensus has yet been made. It might be that for people with dementia, a QoL profile can also be meaningful, and that in some cases proxy reports should be taken into consideration. Lastly, although dementia-specific measures might be the
recommended assessment tools, in order to make comparisons across different disorders to make decisions about resource allocations, generic measures may still need to be considered. As such, these must not be ignored by professionals in the field, but instead must be properly validated for use with people with dementia, in order to ensure that they are sensitive to dementia-specific attributes. Research dealing with this issue is now starting to be conducted. However, the content validity of generic scales widely used for assessing QoL in dementia, such as the EQ-5D (EuroQoL Group, 1990), Health Utilities Index (Kerner et al., 1998) and Quality of Well Being Scale (Neuman et al., 1999) has been found to be poor (Silberfeld et al., 2002).

The results presented in this thesis also suggest that the QOL-AD is sensitive to change. This is, however, a complex issue. QoL is seen as a dynamic construct, and as such, scores on a QoL measure may change over time irrespective of change due to an intervention. Our results show that QOL-AD scores generally remained stable over a seven-day period, although little is known about the stability of QoL over longer periods of time. Additionally, it has been argued that due to fluctuations often present in dementia, it is even more difficult to determine whether change in QoL score is reflecting a genuine change in this group (Selai, personal communication, 2002). However, this could be argued also for the assessment of other variables in dementia, such as cognition and mood, which might measure not only these variables per se, but also the persons ability to adapt to, and cope with, difficulties.
5.3 LIMITATIONS

A number of limitations have been outlined relevant to the individual studies conducted, and there are other limitations to the empirical work undertaken of a more general nature. People with very severe dementia, learning disabilities, severe depression, or profound hearing difficulties or blindness had to be excluded from the therapeutic groups conducted. This was done to ensure reliable assessment, as well as maximising the possibility that people could utilise fully the prompts and tools available. It is difficult to consider different ways of doing this, which would enable also these groups to participate in this kind of research, unless improved criteria for establishing dual diagnosis are established, and better ways of interacting with people with little or no language developed. The criteria for participating in the group programme in clinical settings can be different when scientifically rigorous research is not being conducted, and this has been emphasised in the training being carried out. Another limitation from a clinical point of view is that, due to resource limitations, people in the control group did not receive the group intervention subsequent to the research being completed. Furthermore, participating in the groups seemed to be successful for some participants and not others. Maybe a greater differentiation could have been made, in order to investigate which people these were. No differentiation was made as to specific dementia diagnosis, which has been argued is not the most meaningful classification (Bender, personal communication, 2002). There may be other ways of differentiating, possibly on the basis of ability to successfully engage with the world, desire for social interactions, or other variables, which may have given some insight into for which people the intervention was beneficial. This could further have been aided by recording, transcribing and
analysing the group sessions. Overall, the data from the randomised controlled trial could have benefited from being supplemented with qualitative data throughout.

Throughout this thesis, the argument has been made that QoL in dementia needs to be assessed using self-report measures. However, whilst this was done, other variables studied, such as depression and anxiety, were assessed using proxy measures. If QoL in dementia can only be judged by the person her/himself, the same is probably true for measures of mood. The difficulty is that there are no validated instruments available for this to be done. This does not mean, however, that it should just be accepted as a necessary limitation. The perceptions of care staff and the researchers were a necessary component of assessing these variables, adding a degree of subjectivity from proxy reporters. This is problematic, and may be affected by the relationship between the person with dementia and the proxy, the proxy's own mood and attitudes including ageism. It is possible that the lack of strong associations detected between QoL and these variables could be due in part to this limitation.

Also in the selection process for the therapeutic groups, the perception of care staff was a factor. Although inclusion criteria were used, staff informed the researchers as to who would be suitable based on these. In particular, the criterion of not displaying behaviour such as constant wandering, shouting, or aggression was problematic. These could all be attempts to communicate and engage, and people displaying these types of behaviours could have been excluded whilst needing, and possibly benefiting from, the intervention the most. On a couple of occasions there were
debates regarding this criterion in relation to possible participants, and one person who occasionally displayed aggression and one person who never left his room were included in the project. They both appeared to benefit from participating the groups, and there may have been other exclusions made of people who could have benefited made on the basis of care staff’s perception. This is again a difficult issue to consider. All participants could have been observed directly by the researchers before screening, but this would have had huge resource implications. Besides, who is to say that the researchers’ judgments would have been any less biased than the care staff’s.

Not many carers were available for the sample studied here, as the majority of people with dementia lived alone, and as such the data obtained was so sparse that its inclusion did not seem meaningful. Thus nothing is known about the effects of the group intervention on the systems in which the participants function. This would have been a valuable addition to the data, and greater effort could probably have been made to include more variables involving how relatives and professional care staff were affected by the person with dementia partaking in the studies. A more equal split between residential care and day centers would have further facilitated this.

Throughout the data presented in this thesis, there is a consistent thread running; although results are statistically significant, this does not necessarily mean that they are clinically significant, which is the question of greater interest. This could have been a more central focus in the studies conducted, and a priori criteria for
meaningful clinical change should have been established. It can be difficult to find a
good balance between clinical- and research-orientated goals when conducting this
kind of empirical work. As outlined above, this issue affected the criteria for
inclusion in the studies, and also had an effect on the variables studied. Well-
validated, standardised measures were needed, which may have excluded the
inclusion of more meaningful variables that are more problematic to measure, such
as the ability to successfully engage with the world.

Only parts of the proposed conceptual model of QoL in dementia were investigated
in the studies presented in this thesis. Considering this in retrospect, it could have
been improved upon by investigating also the other variables in the model, such as
coping mechanisms and antecedent including attachment and personality
characteristics.

QoL is undoubtedly difficult to conceptualise and measure, particularly with people
with dementia, which is a disorder about which relatively little is known. Some
might even suggest that this is a task that is too complex altogether, and that the field
is better served by focussing on other variables altogether. Be that as it may, QoL
appears to be a variable of great, if not the most, clinical meaningfulness. However,
the work undertaken to validate the QOL-AD scale (Logsdon et al., 1999), involved
significant challenges to be considered.

In terms of construct validity, to what extent the construct of QoL, which the QOL-
AD aims to measure, is a real and concrete entity, as well as the salience of this scale
to that construct, cannot be demonstrated empirically. However, evidence can be sought to support it. Therefore, the evidence found through the use of focus groups and questionnaires must be seen as just that; evidence to support QoL in dementia as a unified construct and the QOL-AD as a salient scale to measure this, not an empirical demonstration of this. In relation to concurrent validity, there is no criterion measure or gold standard currently available for comparing assessment scales of QoL in dementia against. Consequently, the best available measures had to be used, although these were all less than ideal. The generic scale used (EQ-5D; EuroQoL Group, 1990) has, as outlined above, been shown to lack face validity for use with people with dementia. The dementia-specific scale used (DQoL; Brod et al., 1999), has been developed to establish five domains of QoL in dementia, not an overall rating. Additionally, this scale appears to measure internal states to a greater degree than the QOL-AD, which consists of items that are more relational. As an observational method to assess QoL in dementia, one element of Dementia Care Mapping (Kitwood & Bredin, 1994) was used. Although being the best observational method of the quality of dementia care currently available, it is not designed for this use. However, it seemed the best method detected in the literature. The value of both convergent and divergent validity and known group validity will necessarily depend on the rationale underlying the chosen constructs/criteria. What constructs are similar and dissimilar in relation to QoL in dementia is unclear, and the hypothesised links between QoL and depression and cognition must only be seen as good guesses under difficult circumstances. These types of validity were still included, however, in an attempt to provide an as comprehensive picture of the validity of the QOL-AD as possible. Due to the time-scale in question, predictive
validity was unfortunately not investigated in this validation study. Mortality and morbidity rates were low, and as such could not be meaningfully investigated. This is a further shortcoming of the research presented here.

In terms of test-retest reliability, this was tested using a seven-day interval. It could be argued that this time should have been longer. However, with the fluctuations often found in dementia, and the hypothesised dynamic nature of QoL, this is a difficult judgment to make. It has for these reasons been argued that this type of reliability may not necessarily be that meaningful. This is a complex issue, but it was still included in an attempt to provide as comprehensive a picture of the reliability of the QOL-AD as possible. Similarly, whether the goal of good internal consistency of an assessment scale is in disagreement with the goals of attaining construct validity and comprehensiveness is a complex issue, which was not dealt with in the validation study conducted here.

Finally, the fact that the QOL-AD showed a significant improvement for the participants in the experimental group relative to controls was used as an indication of the scale being sensitive to change. As this was the only QoL scale used in this regard, it can not be concluded as certain that this is the case. However, the QOL-AD appeared to be responsive to the changes attributed to the clinical intervention as well as deterioration, and not to include an inadequate range of responses leading to floor or ceiling effects. A challenge also in this regard is the question of what constitutes a clinically meaningful change in QoL in dementia, which should possibly have been given more thought when designing the validation study.
5.4 IMPLICATIONS FOR PRACTICE

The studies described in this thesis have found support for the value of QoL as an important aspect of dementia. As such, this may be a variable of importance to investigate when developing treatment plans for people with dementia, as it is an inclusive concept, reflecting a variety of elements of the everyday lives of these clients. The QOL-AD was found to be a valid, reliable and responsive scale, and its use in clinical practice can as such be supported. The evidence-based psychological group therapy programme studied here, was shown to make a significant difference in improving quality of life for people with dementia. Furthermore, stimulation was emphasised by people with dementia as an important element of their QoL. Another important implication is the hopefulness underlying the proposed conceptual model of QoL in dementia outlined in this thesis. This would imply that health care professionals have an important effect on QoL for people with dementia, particularly on the way in which cognitive abilities; physical health and emotional functioning are appraised to form a person with dementia's sense of her/his QoL.

The programme was developed with the aim of providing a structured guideline as to how to conduct groups with people with dementia, for professionals working with this group without much previous training in or experience with groupwork. A training package is currently being piloted to enable people to do just that. However, in order to conduct these groups in residential homes and day centres, resources have to be available. Fortunately, there seems to be a shift away from addressing exclusively people with dementia's physical needs, and as such the future of dementia care seems increasingly more hopeful. This was recently expressed in the
National Service Framework for Older People (Department of Health, 2001), where the need for delivering person-centred care was emphasised. The programme presented here has also been shown to be cost-effective (Appendix E), and had no known adverse effects. Therefore, there is now a strong argument for prioritising this kind of therapeutic input in service development based on very modest costs and scientifically rigorous evidence.

5.5 IMPLICATIONS FOR RESEARCH

The results presented in this thesis show that psychological interventions for dementia can be evaluated in a scientifically rigorous way to methodological standards that are on par with evidence to support the use of drug treatments. It is to be hoped that other types of psychological therapies for people with dementia will be researched in similar ways, as the need for this still is great (Spector et al., 1998b, De Vreese et al., 2001; Neal and Briggs, 2002). Additionally, participating in the groups seemed to have a more positive effect on some people with dementia than others, and future research might benefit from identifying which participants benefited most from this kind of intervention. Long-term effects of this intervention are still unknown, but a pilot study of a maintenance trial over 6 months suggested that participating in such groups continued to be beneficial, particularly to help sustain the improvements (Spector, personal communication, 2002). This thesis has highlighted some of the challenges of conducting this kind of research, and also some of the issues in need of consideration when conducting research into QoL in dementia. The studies presented here found only some factors associated with QoL in dementia, and as such there is much work yet to be done in this field. A
naturalistic one year follow-up study is planned to look at how QoL changes over time (Selwood, personal communication, 2002). Additionally, further investigation is needed to address the issues surrounding assessment of QoL in dementia, some of which have been highlighted in this thesis. This includes the need for comprehensively validating the assessment scales currently being used, doing further work into attempting to conceptualise QoL in dementia, and might also involve investigating the effects of non-specific variables in QoL assessment of people with dementia, such as how the assessor introduces the task at hand, and how responses are received.

5.6 CONCLUSIONS

(1) The results presented in this thesis showed a significant correlation between better perceived QoL and higher levels of functioning in dementia. They also showed a significant correlation between better perceived QoL and lower levels of depression in dementia. Anxiety or cognitive functioning were not found to be significantly correlated with QoL in dementia. However, at baseline higher QoL was found to be predicted by having more severe dementia. Thus, the hypothesis that there would be a significant relationship between higher QoL and better physical functioning; cognitive functioning; and better mood found some support in these results, but the relationships between these variables seem to be more complex than hypothesised.

(2) Improved QoL in dementia was found to be predicted by being in a larger residential home or day centre and not living in an inner city area. Other variables
studied, such as whether in residential or day care, and whether funded by private or public sources, were not found to have an effect on QoL in dementia. Therefore, the hypothesis that environmental factors such as size and location of residential homes and day centres would be associated with QoL in dementia was partially supported by the findings presented here.

(3) Gender was found to be a significant factor in the improvement of QoL for people with dementia. Females improved more than males subsequent to participating in the groups, and males deteriorated more than females in the control group, specifically on items relating to ability to do chores and things for fun. Other demographic factors such as age and education were not found to be significantly associated with QoL in dementia. Therefore, the hypothesis that demographic factors such as age, education, and gender would be associated with QoL for people with dementia was partially supported by the results presented in this thesis.

(4) An evidence-based psychological group therapy programme was found to significantly improve the QoL for people with dementia in a single-blind randomised controlled trial. The main improvements were found on items relating to energy level, memory, relationship with spouse, partner or significant other, and ability to do chores. As such, the hypothesis that an evidence-based psychological programme would have a significant positive effect on QoL in dementia was supported by these results.
(5) Significant correlations were found between a positive change in QoL score and improvement of cognition. Improvement in QoL in dementia was additionally found to be significantly correlated with a reduction of symptoms of depression, and improvement of communication abilities. Hence, the hypothesis that there would be a significant relationship between improvement of QoL and a positive change on other factors, such as functioning, cognition and mood was partially supported by the results presented in this thesis.

(6) The Quality Of Life –Alzheimer’s Disease scale was found to have good face/content validity, construct validity, concurrent validity, and convergent and divergent validity. It was also found to have good test-retest reliability, internal consistency and inter-rater reliability, and to be sensitive to change. The hypothesis that the QOL-AD is valid, reliable and sensitive to change can be therefore be supported by the findings reported here. Although the QOL-AD was originally intended to be completed both by the person with dementia and their carer, in this study, only the person with dementia completed the QOL-AD. Thus, the present study shows that the QOL-AD is reliable and valid also without the proxy input. Additionally, this study has demonstrated also that people with moderate/severe dementia can reliably report on their QoL, and further that the QOL-AD can be used with a UK population without any difficulties.

In short, the results presented in this thesis show that there is QoL in dementia, and that it varies between people relatively independently of cognitive abilities and mood. They also show that it is possible to make an improvement to people with
dementia's QoL through therapeutic intervention. Lastly, the results presented here show that the QOL-AD (Logsdon et al., 1999) is a valid, reliable and responsive scale for assessment of QoL in dementia in an interview-assisted, self-report format, also with people in the severe end of the spectrum.
instillation of hope

deeple dark winter gives way
to a golden sky
and not until this moment
did i know
just how cold it was

and through my exhilaration
and disbelief
i wonder of the power
of the present
to blur our vision of the future

still
undeservedly it comes to us
with sunny mornings
warm nights
and marvellous colours
REFERENCE LIST

Aksoy S (2000): Can the "quality of life" be used as a criterion in health care services?  
*Bulletin of Medical Ethics,* 162:19-22.

Albert SM, Castillo-Castaneda C, Sano M, Jacobs DM, Marder K, Bell K, Bylsma F,  
Alzheimer’s disease as reported by patient proxies. *Journal of American Geriatric  
Society,* 44:1342-1347.

Albert SM, Jacobs DM, Sano M, Marder K, Bell K, Devanand D, Brandt J, Albert M,  
and Stern Y (2001): Longitudinal study of quality of life in people with advance  

Albrecht GL and Devlieger PJ (1999): The disability paradox: high quality of life  


Alexopoulos GS, Abrams RC, Young RC, and Shamonian CA (1988): Cornell scale for  

Alzheimer A (1977): A unique illness involving the cerebral cortex. In: *Neurological  


Brooker D, Foster N, Banner A, Payner M, and Jackson L (1998): The efficacy of
dementia care mapping as an audit tool: report of a 3-year British NHS evaluation.
*Aging and Mental Health*, 2:60-70.

Browne JP, O'Boyle CA, McGee HM, McDonald NJ, and Joyce CRB (1997):
Development of a direct weighting procedure for quality of life domains. *Quality of

Buchanan AE and Brock DW (1989): *Deciding for Others: The Ethics of Surrogate

159:609-614.

Disease and Associated Disorders*, 6:138-144.

Canam C and Acorn S (1999): Quality of life for family caregivers of people with


Department of Health, London.


Diagnosing dementia: Do we get it right? \textit{British Medical Journal}, 297:894-896.


Agreement between patients’ and proxies’ reports of quality of life in Alzheimer’s

*SEIQoL-DW.* Department of Psychology, Royal College of Surgeons in Ireland,
Dublin.


Parmelee PA, Katz IR, and Lawton MP (1989): Depression among institutionalized


Pattie A and Gilleard C (1979): *Manual for the Clifton Assessment Procedures for the*
*Elderly.* Hodder & Stoughton, Sevenoaks, Kent.

*Advanced Nursing,* 25:934-941.

Pickard L (2000): The decline of intensive intergenerational care in Great Britain? The
contribution of children towards informal care of elderly parents, 1985-1995. *Old*


Sprangers MAG and Aaronson NK (1992): The role of health care providers and significant others in evaluating the quality of life of patients with chronic disease: a review. *Journal Clinical Epidemiology*, 45:743-760.
QUALITY OF LIFE IN DEMENTIA
Reference list...213


Appendix A:

Protocol
INTRODUCTION

Background. With the growing number of old and very old people, dementia is becoming ever more common, and it is estimated that the number of people with dementia in the UK alone will increase from the present 665,000 to 855,000 by the year 2020 (DoH, 1997). The process of dementia affects a wide range of cognitive and functional abilities, and the capacity to improve the well being of the sufferer is far greater than the capacity to affect the course of the disease. There is therefore increasing emphasis on including a measure of quality of life (QOL) when evaluating interventions with people with dementia. This might also be a consequence of increasing recognition that assessment scales such as those of cognition or behaviour might not be only significant measures of change, and that QOL might be a more useful guide to potential benefits.

Assessing QOL in dementia QOL should be regarded as a multidimensional construct comprising physical, psychological, and social well being (Selai & Trimble, 1999). It is difficult to measure and validate QOL with people with dementia. QOL assessments comprise a highly complex procedure of introspection and evaluation, involving several components of cognition including implicit and explicit memory (Barofsky, 1996), and so after a certain level of cognitive decline, self-assessment of QOL becomes too difficult. At what stage this is, is not known as yet (Fletcher et al., 1992), although a cut-off point of 9/10 on the Mini Mental State Examination
QUALITY OF LIFE IN DEMENTIA
Appendix A: Protocol ...219

(MMSE; Folstein et al., 1975) has been suggested (Mozley et al., 1999). There is also the dilemma of how to address the different stages of dementia, and compare small improvements late in the disease progression with small differences early on, which might not be particularly beneficial or noteworthy (Selai & Trimble, 1999). Among the ethical issues in need of consideration when assessing QOL in dementia are those concerning personhood, the self, and the value of life (Harris, 1988; Post, 1995).

When assessing QOL almost inevitably language has to be used, which also poses a problem for people with dementia, since language impairment is an early symptom of this condition, as is some loss of insight or awareness (Markova & Berrios, 1992). Whether people with dementia can evaluate their own QOL has been a much debated issue, which has evolved around the use of subjective versus objective entities (e.g. Lawton, 1994, 1997), and whether to use patient or proxy ratings or both. Although it is also generally agreed that due to the highly subjective nature of this concept, any appraisal of QOL should rely where possible on the perception of the individual patient, Albert (1998) has stated that people with Alzheimer's Disease (AD) 'cannot comprehend questions or report on subjective states', and direct respondent assessment has seldom been done due to the presumed logistical and methodological issues, such as concerns about comprehension and reliability (Steward et al., 1996).

However, inferring subjective QOL from external circumstances or relatively objective domains does not fully take into account the values, needs, and adaptations of individuals to various life circumstances (Flanagan, 1982, Sanifort et al., 1996). The use of proxies to measure QOL with people with dementia also creates difficulties, as characteristics of the proxy such as the nature of the relationship and time spent with the person with dementia, the degree of objectiveness of the
questions, and the level of impairment may influence the degree of correspondence between proxy and client responses (Magaziner et al., 1988; Zimmerman & Magaziner, 1994).

Research on quality of life in dementia. Research has shown that the effects of therapeutic interventions to improve QOL in any condition is best measured with sensitivity by disease-specific instruments that focus on the domains most relevant to the disease under investigation (e.g. Epstein et al., 1992; Testa & Simonson, 1996) and have an increased likelihood of capturing change over time (Guyatt et al., 1987; Howards & Rockwood, 1995). To date, few studies have empirically investigated QOL in dementia. Albert et al. (1996) found good agreement on ratings of patient QOL by family and institutional caregivers of people with AD living in nursing homes, but did not include patient ratings of their own QOL. Logsdon et al. (1999) found high QOL in AD to be predicted by low levels of depressive symptoms, more independent functioning in activities of daily living, and more years of education. Their results also suggested good agreement between patient and caregiver report versions of their measure Quality of Life - Alzheimer's Disease (QOL-AD). This contrasts with the findings by Selai et al. (1999), which indicated discrepancy between patient and proxy ratings on their measure The Quality of Life Assessment Schedule (QOLAS). However, the QOL-AD differs greatly from the QOLAS, the latter being an individualised and patient-centred assessment technique, while the QOL-AD is of a standardised format, placing equal emphasis on each QOL component. The difference between these two scales illustrates the tension in the measurement of QOL between the acknowledgement that this is a subjective and
idiosyncratic concept and the need for data-collection to be reliable and valid. The suggestion has been put forward that qualitative methods of assessing QOL are more valid whilst quantitative methods are more reliable (Mays & Pope, 1996). However, Brod et al. (1996) have developed the Dementia QOL (DQOL) based on a comprehensive dementia-specific definition of QOL based on focus groups consisting of caregivers for people with dementia, health care provider working with this client group, and people with mild to moderate dementia, which they found to be valid and reliable. This method might offer a quantitative method of measuring QOL which is meaningful to people with dementia.

**Economic evaluations.** While QOL is one outcome variable informing health economic decisions about the allocation of scarce resources, cost and effectiveness are other. Historically, services for people with dementia have suffered in comparison with younger adults' and children's acute hospital services. This leads to questions about the relative value of the services currently provided for people with dementia. If dementia services are to be developed, coherent arguments based on measurable benefit have to be put forward for diverting resources from elsewhere. An economic evaluation is a way of establishing the value for money of health care techniques, in which the cost of health care interventions is compared with their consequences in terms of improvement in the length or quality of life and savings in other health care resources. At the moment, there is far less evidence on cost and effectiveness of services for people with dementia than for elderly people in general (Keen, 1993).
Economic evaluations in dementia. There are always methodological challenges to consider when conducting an economic evaluation of any intervention, including the choice regarding the type and perspective of the study. When conducting an economic evaluation of an intervention for people with dementia, there are additional issues in need of consideration. For example, informal care is one of the most important resources in dementia care (Karlsson et al., 1998), and difficulties arise when considering how to include this into the equation, and how to put a monetary value on a caregiver's time and use of emotional resources. Furthermore, if comparing a new intervention with current services which are inadequate, as can often be argued is the case with those for people with dementia, problems emerge. Many cost of illness studies have been carried out within the field of dementia (e.g. Huang et al., 1988; Ernst & Hay, 1994; Kavanagh et al., 1995), and the direct annual cost of dementia has been estimated in the Netherlands to have been 3309 billion guilders in 1994 which is 5.6% of their total health care costs (Koopmanschap et al., 1998), and in Canada to be 3.3 billion CAN$, 4.9% of total health care costs in 1994 (Oestbye & Crosse, 1994). When evaluating the economic consequences of interventions for people with dementia, there has not been the same amount of work done, and most economic evaluations conducted have been of medication for AD. One example is a cost-effectiveness analysis conducted by Neumann et al. (1997), which aimed to estimate the incremental cost per quality-adjusted life year (QALY) gained for people with mild to moderate AD by using donepezil. Their results, although inconclusive about the effects of the medication in question, suggested that patient values were sensitive to AD stages and settings of care, whilst caregiver
values were not. Quality-adjusted life-years (QALYs) have introduced the concept of QOL into economic evaluations. QALYs reflect individual values for different health outcomes and permit comparisons across diverse interventions, and are therefore useful as a measure of health benefit, capturing both quantity- and quality-of life effects. It has become increasingly common for cost-effectiveness analyses (CEAs) in health and medicine to measure effectiveness by using QALYs as an outcome measure. However, when comparing QALYs across client groups, difficulties arise for people suffering from degenerative disorders, such as dementia. A relatively small improvement in their situation will be much more costly than a cheaper, relatively effective intervention for people who suffer from less severe, short-lived diseases or the prevention of accidents among the general population. It is therefore unwise to use QALYs because it discriminates against people suffering from disorders such as dementia resulting in them being given a low priority for health care.

**Aims.** This study will aim to investigate the measurement of QOL in relation to cost of care in dementia in the context of an evidence-based psychological group therapy package (Spector et al., 1999) with dementia. It will also consider the relationships between QOL and other factors in dementia. Lastly it will evaluate the QOL-AD (Logsdon et al., 1999) in terms of its reliability, validity, and sensitivity to change.

**Aim 1:** To investigate the impact of an evidence-based psychological group therapy package on QOL for people with dementia.
**Aim 2:** To investigate the impact of an evidence-based psychological group therapy package on cost of care for people with dementia.

**Aim 3:** To determine how far change in QOL is associated with change in cost of care for people suffering from dementia.

**Aim 4:** To investigate the reliability and validity of the QOL-AD scale (Logsdon et al., 1999), and its sensitivity to change.

**Aim 5:** To investigate the relationship between QOL and: cognition; dementia severity; depression; and anxiety.

**Aim 6:** To investigate the relationship between cost of care for people with dementia, level of cognition, and dementia severity.

**Aim 7:** To establish whether demographic factors such as age, education, and gender have an effect on QOL for people with dementia.

**Hypothesis 1:**
An evidence-based psychological therapy package will result in a significant improvement in QOL for people with dementia and their carers.

**Hypothesis 2:**
An evidence-based psychological therapy package will significantly reduce the cost of care for people with dementia.

**Hypothesis 3:**
There will be no direct relationship between QOL and cost of care.

**Hypothesis 4:**
The QOL-AD is reliable, valid and sensitive to change.

METHOD

STUDY 1

Aims: 1. To investigate the impact of an evidence-based psychological group therapy package on QOL for people with dementia.

2. To investigate the impact of an evidence-based psychological group therapy package on cost of care for people with dementia.

3. To determine how far change in QOL is associated with change in cost of care for people suffering from dementia.

4. To investigate the relationship between QOL and: cognition; dementia severity; depression; and anxiety.

5. To investigate the relationship between cost of care for people with dementia, level of cognition, and dementia severity.

6. To establish whether demographic factors such as age, education, and gender have an effect on QOL for people with dementia.
**Participants:** The sample will consist of an experimental population of 120 people of 65 years of age or more scoring between 10 and 26 on the Mini Mental State Examination (MMSE; Folstein et al., 1975), drawn from people with dementia attending day centres/hospitals and living in residential homes. The control group will comprise of further 100 65+ year old people scoring 10-26 on the MMSE from the same sources, not exposed to the psychological therapies package. In addition, all participants will need to meet the DSM-IV (APA, 1994) criteria for dementia, have some visual, auditory, and communication ability, be able to stay in the room where the group is held for the duration of the sessions, and not suffer from any disorder likely to significantly affect their cognitive functioning.

**Design:** The study will be of a randomised single blind controlled design, where the measures will be administered by one researcher the week before and the week after the group is conducted. This researcher will be blind to the results of the randomisation. The group will consist of 45 minutes, twice weekly session for 7 weeks, and be conducted by another researcher with the assistance of a member of staff where the group is run. The control group will participate in usual activities in the day centre/hospital or residential home for the 45 minute period.

**Outcome measures:**

**Quality of Life – AD (QOL-AD):** The QOL measure used in this study will be the Quality of Life-AD (QOL-AD; Logsdon et al., 1999). This obtains a rating of the patient’s QOL from both the patient and the caregiver, and is based on a literature review of QOL in older people and on the assessment of QOL in other chronically ill
populations. It has 13 items covering the domains of physical health, energy, mood, living situation, memory, family, marriage, friends, chores, fun, money, self and life as a whole. This scale has the advantage of being brief, which is essential to the present study, as the total assessment time is approximately 45 minutes, which is approaching the limit for what is feasible with this client group. The QOL-AD also has the advantage of being of a self-report format, and incorporating both patient and caregivers' ratings. Early studies by Logsdon et al. (1999) suggest it to have good internal consistency, construct and test-retest reliability.

**Client Service Receipt Inventory:** The instruments used to measure cost, will be two versions of the Client Service Receipt Inventory (CSRI; Beecham and Knapp, 1992), adapted for this study by Martin Knapp and Angela Hallam from London School of Economics and Political Science. One of the measures is aimed at people living in residential homes, and requests information about the service user’s background, and details about their accommodation, medication profile, what informal care support they receive, and the formal services they use. The other measure is appropriate for people attending day centres/hospitals, and include in addition to the above the carer’s background, accommodation details, and income.

**Clinical Dementia Rating:** Dementia severity will be measured using the Clinical Dementia Rating (CDR; Hughes et al., 1982), which is a global scale and describes performance in six areas of cognitive functioning; memory, orientation, judgement and problem solving, communication skills, domestic skills, and personal care. Good reliability and validity has been demonstrated for this scale.
Mini Mental State Examination: Cognitive function will be measured using the Mini Mental State Examination (MMSE; Folstein et al., 1975), which is a brief and well-established test of cognitive function. Good reliability and validity has been demonstrated for this scale.

Alzheimer’s Disease Assessment Scale – Cognition: A second measure of cognitive level will be the Alzheimer’s Disease Assessment Scale – Cognition (ADAS-Cog; Rosen et al., 1984), which is more sensitive to change than the MMSE and includes more items which assess short term memory. Good reliability and validity have been demonstrated for this scale.

Cornell Scale for Depression in Dementia: For measuring depression, the Cornell Scale for Depression in Dementia (CSDD; Alexopoulos et al., 1988) will be used which includes 19 items under 5 categories, which use information from clinician’s interview with carer and patient, and for which good reliability and validity has been shown.

Rating Anxiety in Dementia: The Rating Anxiety in Dementia (RAID; Shankar et al., 1999) will be used for measuring anxiety, in which 18 items are included under 6 categories. This scale also uses information from clinician’s interview with carer and patient, and for which good reliability and validity have been shown.

General Health Questionnaire: The General Health Questionnaire: (GHQ-12; Goldberg et al., 1972) will be use, which is a standard measure of psychological
distress and has been widely used to evaluate carers’ psychological health and the impact of caring upon it.

**Relatives Stress Scale:** Relatives Stress Scale (Greene et al., 1982) will be used to evaluate the distress arising specifically from caring.

**Analyses:**

**Power Analyses:** The sample used is resulting from a power analysis conducted by Professor Stephen Senn, Professor of Statistics at UCL.

**Data Analyses:** The analysis will be done on an intent to treat basis. The difference between groups will be analysed using analysis of covariance in which the baseline has been fitted as an explanatory factor. There will be no adjustment for multiplicity. Significance level used will be 5% two-sided.

**Economic Analysis:** The economic evaluation will be a cost-effectiveness analysis (comprehensive costs and the primary outcome measure, QOL-AD) and a cost-consequence analysis (cost and all of the outcome measures). The cost measures will range over all health and social services, plus other services used, and an estimate of caregiver cost. Cost will be built up from the CSRI, unit costs will be estimated so as to be nationally generalisable. The economic evaluation will be fully integrated in the main outcome evaluation. The analyses of the economic data will be undertaken in cognisance of the possibility of skewed distributions.
STUDY 2

Aim: To investigate the reliability and validity of the QOL-AD scale (Logsdon et al. 1999), and its sensitivity to change.

Participants: The sample will consist of 80 people of 65 years of age or more fulfilling the DSM-IV (APA, 1994) and the Mini Mental State Examination (MMSE; Folstein et al., 1975) criteria for dementia, drawn from people with dementia attending day centres/hospitals, living in residential homes, and living in nursing homes. 100 health care professionals working within the field of dementia in the NHS will be asked to fill in a questionnaire, and four focus groups will be conducted; two consisting of 10 people with dementia, the other two consisting of 10 carers for people with dementia. Participants for these focus groups will be recruited from an NHS day care facility.

Instruments:

Quality of Life – AD (QOL-AD; Logsdon et al., 1999).

Dementia Quality of Life: Dementia Quality of Life (DQoL; Brod et al., 1999) will be administered along with the QOL-AD for the purpose of investigating concurrent validity. The DQoL is a 29-item scale, and was developed on the basis of domains identified as important to people with dementia by three focus groups consisting of caregivers for people with dementia, health care provider working with this client group, and people with mild to moderate dementia. These domains are: physical functioning, daily activities, discretionary activities, mobility, social interaction, interaction capacity, bodily well being, sense of well being, sense of
aesthetics, and overall perceptions. The scores are given by the person with dementia on a 5-point Likert scale ranging from 'never' to 'very often'. Brod et al., (1999) found their scale to have good internal consistency, item and scale test-retest, and construct validity.

**EQ-5D:** To further investigate the concurrent validity of the QOL-AD, the EQ-5D (EuroQoL Group, 1990) will be administered. This well-established generic instrument, which measures health-related quality of life, has 5 domains: mobility, self-care, usual activities, pain/discomfort and anxiety/depression. The respondent also rates their own health today on a visual analogue scale (VAS) from 100 (best imaginable health state) to 0 (worst imaginable health state). The data can be presented descriptively as a health profile and a single index utility score can be calculated. The EQ-5D is designed for self-completion, but in the current study it will be interviewer-assisted i.e. copy given to person assessed but wording also read out to the person.

**Dementia Care Mapping:** Dementia Care Mapping (DCM; Kitwood & Bredin, 1994) is an evaluation system of quality of care for people with dementia in formal settings, and will be used as a further measure of criterion validity. During a DCM evaluation the recorder observes between five and ten participants continuously over a representative time period, and involves using three coding frames simultaneously: (1) The Behaviour Category Coding System codes the person’s behaviour, such as articulation, distress, and expression, into 24 categories. In addition, the degree of well being experienced by the person during the behaviour is recorded, utilising a 7-point Likert scale from +1 to −5.
(2) The Personal Detractor Coding System aims to identify those staff behaviours that might reduce the person with dementia's well-being. A four-item Likert scale, from mild to very severe, is used to quantify the degree of personal detraction of 17 components, for example intimidation, disempowerment, and infantilisation.

(3) The Positive Event Recording System is not a coding framework as such, but requires the recorder to provide a qualitative description with the person with dementia which constitutes good practice.

The DCM technique was developed to improve the quality of care for people with dementia, and has been found to be a useful tool in doing so (Barnett 1995; Perrin, 1997), and also to be a highly appropriate audit tool to use in NHS formal dementia care settings (Brooker et al., 1998). It will be used in the current study as an observable measure of QOL, and will be conducted with one group of 10 people with dementia attending a day centre/hospital, one group of 10 people in a nursing home, and two groups of 10 people living in residential care.

Cornell Scale for Depression in Dementia (CSDD; Alexopoulos et al., 1988).

Mini Mental State Examination (MMSE; Folstein et al., 1975),

Design

A pilot study will be conducted with 10 additional participants prior to the main study being carried out to ensure the appropriateness of the planned procedures.

Sensitivity to change: This will be investigated through administering the QOL-AD the week before and the week after the group is run, consisting of 45 minutes, twice weekly session for 7 weeks period, which will be including half of the participants.
Face/Content validity: The QOL-AD will be sent to 100 health care professionals working with people with dementia. They will be asked to fill in a questionnaire regarding the scale, consisting of the following three questions: (1) Do you think this scale covers all the important domains in a dementia sufferer’s life? If no, please expand. (2) Do you think any of the items not relevant for the quality of life for a person with dementia? If yes, please expand. (3) Do you have any additional comments about the scale? In addition, four focus groups will be run for 1 hour each, two consisting of 10 carers for people with dementia, and two consisting of 10 people with dementia each, both discussing the above 3 questions.

Construct validity: A principle component analysis will be performed including all items of the QOL-AD to explore the factor structure and construct validity, and determine the eigenvalue and percentage of variance explained by each item. The questionnaire and focus groups described above will also be asked to comment on QOL as an entity, and to what extent it is captured by the QOL-AD.

Concurrent validity: There is no ‘gold standard’ as such for measuring QOL in dementia. However, to investigate the criterion validity of the QOL-AD, the scores on the QOL-AD will be compared with the persons performance on the DQoL (disease-specific) and the EQ-5D (generic, well established). The EQ-5D will also be administered to the person’s main carer/closest relative and her or his key worker. In addition, the overall QOL-AD score with (1) the scores on the items "Self as a whole" and "Life as a whole", and (2) how the person with dementia rates her or his own health today on the visual analogue scale (VAS) from 100 (best imaginable health state) to 0 (worst imaginable health state) which is a part of the EQ-5D. 40 participants will also be observed for 6 hours, with their behaviour and interactions
being coded using DCM. 10 of these will be in a day care NHS day care facility, 10 in a nursing home, and 20 will be in residential care. The assessor conducting the DQoL, EQ-5D, and DCM will be blind to scores on the QOL-AD which will be conducted by another assessor.

**Convergent and divergent validity** will be investigated by comparing the QOL-AD to the CSDD and the MMSE, hypothesising that quality of life should be expected to be more closely related to level of depression than cognitive abilities.

**Known group validity** is again difficult to assess, as QOL is highly subjective and reliably identifying people with high or low QOL is problematic. However, the hypothesised link between QOL and depression will be utilised. The participants will be divided into low, moderate, and high levels of depression based on their scores on the CSDD, and their QOL scores will be investigated.

**Predictive validity:** A high score on the QOL-AD will be expected to predict a high score on the DCM, and low QOL score with low DCM score. In addition, low QOL score on the initial assessment will be expected to predict high morbidity, which is assessed by the CSRI in the follow-up interview, and mortality, which will be recorded.

**Test-retest reliability:** This will be tested by the QOL-AD being repeated with the participants 7 days after the initial interview by the same assessor.

**Internal consistency:** This will be tested including all items in the QOL-AD.

**Inter-rater reliability:** Although the QOL-AD is designed for self-completion it will in the current study be interviewer-assisted, which most often will be the case with people with moderate to severe dementia. There will therefore be some degree of interpretation present, and the agreement between raters is a significant factor.
Thus, two assessors will be present for the interview with the 50 participants, conducting half of them each, and having the chance to ask questions in all for the purpose of clarification.

**Statistical Analyses:** The statistical analyses will be conducted using the SPSS software package (version 6.1). The test-retest and inter-rater reliability will be calculated using intra-class correlation, and overall agreement calculated by the percentage of agreement. Cronbach's coefficient alpha will be calculated to assess internal consistency, and a principle component analysis will be performed exploring the factor structure and construct validity. Spearman's correlation coefficient will be calculated between QOL-AD score, the score on the visual analogue scale, and mean of the two items Life and Self as a whole, and Pearson's correlation coefficient will be carried out for the total measure and the other correlations.
References:


Thornicroft, C. Brewin & J. Wing (Eds.) *Measuring Mental Health Needs.*
London: Gaskell.


*Dementia, 6*, 113-116.


I like’: Cognitive impairment and quality of life responses in elderly people.


Appendix B:

Assessment Scales
### Aging and Dementia: Quality of Life in AD

#### Quality of Life: AD

(Participant Version)

<table>
<thead>
<tr>
<th>Subject Number</th>
<th>Assessment Number</th>
<th>Interview Date</th>
</tr>
</thead>
</table>

Interviewer administer according to standard instructions. Circle responses.

1. Physical health. | Poor | Fair | Good | Excellent |
2. Energy.          | Poor | Fair | Good | Excellent |
3. Mood.            | Poor | Fair | Good | Excellent |
4. Living situation.| Poor | Fair | Good | Excellent |
5. Memory.          | Poor | Fair | Good | Excellent |
6. Family.          | Poor | Fair | Good | Excellent |
7. Marriage.        | Poor | Fair | Good | Excellent |
8. Friends.         | Poor | Fair | Good | Excellent |
9. Self as a whole. | Poor | Fair | Good | Excellent |
10. Ability to do chores around the house. | Poor | Fair | Good | Excellent |
11. Ability to do things for fun. | Poor | Fair | Good | Excellent |
12. Money.          | Poor | Fair | Good | Excellent |
13. Life as a whole. | Poor | Fair | Good | Excellent |

Comments: ____________________________________________

© 1996, Rebecca Logsdon, PhD; University of Washington
QOL.doc 15/06/02
### Aging and Dementia: Quality of Life in AD

#### Quality of Life: AD

(Family Version)

<table>
<thead>
<tr>
<th>Subject Number</th>
<th>Assessment Number</th>
<th>Interview Date</th>
<th>Month</th>
<th>Day</th>
<th>Year</th>
</tr>
</thead>
</table>

The following questions are about your relative's quality of life. When you think about your relative's life, there are different aspects, some of which are listed below. Please think about each item, and rate your relative's current quality of life in each area using one of four words: poor, fair, good, or excellent. Please rate these items based on your relative's life at the present time (e.g., within the past few weeks). If you have questions about any item, please ask the person who gave you this form for assistance. **Circle your responses.**

1. Physical health. | Poor | Fair | Good | Excellent |
2. Energy. | Poor | Fair | Good | Excellent |
3. Mood. | Poor | Fair | Good | Excellent |
4. Living situation. | Poor | Fair | Good | Excellent |
5. Memory. | Poor | Fair | Good | Excellent |
6. Family. | Poor | Fair | Good | Excellent |
7. Marriage. | Poor | Fair | Good | Excellent |
8. Friends. | Poor | Fair | Good | Excellent |
9. Self as a whole. | Poor | Fair | Good | Excellent |
10. Ability to do chores around the house. | Poor | Fair | Good | Excellent |
11. Ability to do things for fun. | Poor | Fair | Good | Excellent |
12. Money. | Poor | Fair | Good | Excellent |
13. Life as a whole. | Poor | Fair | Good | Excellent |

Comments: ____________________________

© 1996, Rebecca Logsdon, PhD; University of Washington
QOL.doc 15/06/02
Dementia Quality of Life Instrument
(DQOL)

TEST QUESTIONS

NOTE: It is acceptable for the patient to engage in conversation around the question. More repetition and discussion can be expected when assessing people without dementia. An effort should be made to make the patient feel relaxed and comfortable before beginning questions.

Use scale #1 to ask test questions and questions 1-5.

DIRECTIONS (TO BE READ TO PATIENT)
I am going to ask you some questions about how you have been doing recently. I would like you to use this scale to answer the questions that I'm going to ask (Hand patient a full-page copy of scale #1 for them to hold.). Before we start, I'd like to ask you a couple of practice questions, so that I can explain to you how to use the scale. This first scale is about enjoying things. The scale goes from not at all enjoying something, enjoying it a little, enjoying it some, enjoying it quite a bit, or enjoying something a lot.

NOTE: Point to each point as you read it out loud. Additionally, after each question you may repeat the choice option of necessary (e.g. for test question #1, please say: “would the person not enjoy the meal at all, enjoy the meal a little, enjoy the meal some, enjoy the meal quite a bit, or enjoy the meal a lot?”).

Test 1.
If I (interviewer point to self) did not enjoy a meal, which choice would I pick to describe how much I enjoyed it?

correct incorrect

Test 2.
If I (interviewer point to self) enjoyed a meal a lot, which choice would I pick to describe how much I enjoyed it?

correct incorrect

Test 3.
If YOU (point to patient) really enjoyed a meal, which choice would you pick to describe how much you enjoyed it? (NOTE: either option 4 or 5 is acceptable)

correct incorrect

*****************************************************************************
NOTE: Do not proceed unless the patient gets at least 2 out of 3 test questions correct.
*****************************************************************************
DIRECTIONS TO INTERVIEWER: Present the patient with the appropriate... before asking the group of questions for that scale. Ask the first question in the group and then read off (and point to) the answer choices for that question. Repeat the scale choices as necessary for subsequent procedures. Repeat the item stem for each question.

SCALE #1

NOTE: Continue with scale #1, and read the following: "Do you have any questions about how to use this scale? ...now I am going to ask you some questions about YOU."

Recently, how much have you enjoyed:

_____ 1. Listening to music
_____ 2. Listening to the sounds of nature (birds, wind, rain)
_____ 3. Watching animals or birds
_____ 4. Looking at colourful things
_____ 5. Watching the clouds, sky, or a storm

SCALE #2

NOTE: Read the following: "This next scale is about how often YOU have had certain feelings. The scale goes from never to seldom, to sometimes to often, to very often (point to each choice on the scale as you read it off)... do you have any questions about how to use the scale?"

Recently, how often have you felt:

_____ 6. Useful
_____ 7. Embarrassed
_____ 8. Loveable
_____ 9. Confident
_____ 10. Satisfied with yourself
_____ 11. That people liked you
_____ 12. That you’ve accomplished something
Recently, how often have you:

_____ 13. Found something that made you laugh

Recently, how often have you felt:

_____ 14. Afraid
_____ 15. Happy
_____ 16. Lonely
_____ 17. Frustrated
_____ 18. Cheerful
_____ 19. Angry
_____ 20. Worried
_____ 21. Content
_____ 22. Depressed
_____ 23. Hopeful
_____ 24. Nervous
_____ 25. Sad
_____ 26. Irritable
_____ 27. Anxious
_____ 28. How often do you joke or laugh with other people?
_____ 29. How often are you able to make your own decisions?

---

Optional Overall Item

SCALE #3

NOTE: Read the following: "This is a scale to rate what YOU think quality of life is, it goes from bad to fair, to good, to very good, to excellent."

_____ Overall, how would you rate your quality of life?

Thank you for your time.
Appendix B: Assessment Scales

Scale #2

HOW OFTEN

1 NEVER

2 Seldom

3 Sometimes

4 Often

5 Very Often
QUALITY OF LIFE IN DEMENTIA
Appendix B: Assessment Scales...

OVERALL

1  2  3  4  5
BAD  FAIR  GOOD  VERY GOOD  EXCELLENT

Scale #3
By placing a tick in one box in each group below, please indicate which statements best describe your own health state today.

**Mobility**
- I have no problems in walking about
- I have some problems in walking about
- I am confined to bed

**Self-Care**
- I have no problems with self-care
- I have some problems washing or dressing myself
- I am unable to wash or dress myself

**Usual Activities** (e.g. work, study, housework, family or leisure activities)
- I have no problems with performing my usual activities
- I have some problems with performing my usual activities
- I am unable to perform my usual activities

**Pain/Discomfort**
- I have no pain or discomfort
- I have moderate pain or discomfort
- I have extreme pain or discomfort

**Anxiety/Depression**
- I am not anxious or depressed
- I am moderately anxious or depressed
- I am extremely anxious or depressed
To help people say how good or bad a health state is, we have drawn a scale (rather like a thermometer) on which the best state you can imagine is marked 100 and the worst state you can imagine is marked 0.

We would like you to indicate on this scale how good or bad your own health is today, in your opinion. Please do this by drawing a line from the box below to whichever point on the scale indicates how good or bad your health state is today.
<table>
<thead>
<tr>
<th>Participant Name</th>
<th>Time</th>
<th>#WIB</th>
<th>#Time Frames</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>DCC</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>WIB</td>
<td></td>
<td></td>
</tr>
<tr>
<td>DCC</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>WIB</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>DCC</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>WIB</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>DCC</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>WIB</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>DCC</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>WIB</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

ΣWIB means the sum of the WIB values
ΣTF means the sum of the relevant time frames

Notes:
## CLIENT SERVICE RECEIPT INVENTORY

**ADAPTED FOR**

*Psychological Therapies for Dementia*

Version 2: Service users living in residential homes (baseline)

### 1. BACKGROUND INFORMATION ABOUT THE SERVICE USER

<p>| | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>1.1</td>
<td>Service user’s name</td>
</tr>
<tr>
<td>1.2</td>
<td>Interview</td>
</tr>
<tr>
<td>1.3</td>
<td>Title of informant’s job</td>
</tr>
<tr>
<td>1.4</td>
<td>Interview date</td>
</tr>
<tr>
<td>1.5</td>
<td>Service user’s age</td>
</tr>
<tr>
<td>1.6</td>
<td>Service user’s sex</td>
</tr>
<tr>
<td>1.7</td>
<td>Marital status of service user</td>
</tr>
<tr>
<td>1.8</td>
<td>At what age did he/she leave full-time education?</td>
</tr>
</tbody>
</table>

### 2. SERVICE USER ACCOMMODATION DETAILS

<p>| | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>2.6</td>
<td>What is the <strong>total</strong> charge per week for this resident, including any top up?</td>
</tr>
<tr>
<td>2.7</td>
<td>Who contributes towards the cost of this placement? <em>(Tick all boxes that apply)</em></td>
</tr>
<tr>
<td></td>
<td>DSS (preserved rights)</td>
</tr>
<tr>
<td></td>
<td>National health service</td>
</tr>
<tr>
<td></td>
<td>Local authority</td>
</tr>
<tr>
<td></td>
<td>Voluntary organisation</td>
</tr>
<tr>
<td></td>
<td>Service user</td>
</tr>
<tr>
<td></td>
<td>Service user’s family</td>
</tr>
</tbody>
</table>
2.8 How long has the service user been a resident (months)?

2.9 Has the service user lived anywhere else during the last two months?
(Please include respite arrangements.)

If yes, please complete table
Yes = 1, No = 2

<table>
<thead>
<tr>
<th>Accommodation type</th>
<th>Number of days in last 2 months</th>
</tr>
</thead>
<tbody>
<tr>
<td>(See below for code)</td>
<td></td>
</tr>
<tr>
<td>Owner-occupied house/flat</td>
<td></td>
</tr>
<tr>
<td>Privately rented house/flat</td>
<td></td>
</tr>
<tr>
<td>House/flat rented from housing association/local authority</td>
<td></td>
</tr>
<tr>
<td>Residential home</td>
<td>8 Acute psychiatric ward</td>
</tr>
<tr>
<td>Nursing home</td>
<td>9 Rehabilitation ward</td>
</tr>
<tr>
<td>Dual registered home</td>
<td>10 General medical ward</td>
</tr>
<tr>
<td>Sheltered housing</td>
<td>11 Other (please specify)</td>
</tr>
</tbody>
</table>

3. MEDICATION PROFILE

3.1 Please list below any drugs the service user is currently taking.

<table>
<thead>
<tr>
<th>Preparation</th>
<th>Dosage</th>
<th>Dosage frequency</th>
<th>Duration of treatment (months)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

CSRIVER2.DOC
5 SERVICE RECEIPT

4.1 Please list any use of the following hospital services over the last 2 months

<table>
<thead>
<tr>
<th>Service</th>
<th>Name of ward, clinic/hospital</th>
<th>Reason for using service (eg fall, regular respite arrangement)</th>
<th>Unit of measurement</th>
<th>Total number of units received</th>
</tr>
</thead>
<tbody>
<tr>
<td>Assessment/rehab, ward</td>
<td></td>
<td></td>
<td>Inpatient day</td>
<td></td>
</tr>
<tr>
<td>Continuing care/respite</td>
<td></td>
<td></td>
<td>Inpatient day</td>
<td></td>
</tr>
<tr>
<td>Medical ward</td>
<td></td>
<td></td>
<td>Inpatient day</td>
<td></td>
</tr>
<tr>
<td>Other hospital ward</td>
<td></td>
<td></td>
<td>Inpatient day</td>
<td></td>
</tr>
<tr>
<td>Outpatient services</td>
<td></td>
<td></td>
<td>Appointment</td>
<td></td>
</tr>
<tr>
<td>Accident &amp; Emergency</td>
<td></td>
<td></td>
<td>Attendance</td>
<td></td>
</tr>
<tr>
<td>Day hospital</td>
<td></td>
<td></td>
<td>Day attendance</td>
<td></td>
</tr>
<tr>
<td>Other:</td>
<td></td>
<td></td>
<td>(Please specify)</td>
<td></td>
</tr>
</tbody>
</table>

4.2 Please list any use of the following day services over the last 2 months

*(NB: do not include any day service provided by the home itself)*

<table>
<thead>
<tr>
<th>Service</th>
<th>Name of centre/service</th>
<th>Unit of measurement</th>
<th>Number of units received per week</th>
<th>Total number of units received over last 2 months</th>
</tr>
</thead>
<tbody>
<tr>
<td>Day care – local authority</td>
<td></td>
<td>Days</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Social services department</td>
<td></td>
<td>Days</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Day care – voluntary organisation.</td>
<td></td>
<td>Days</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Day care – NHS (not hospital)</td>
<td></td>
<td>Days</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Lunch club</td>
<td></td>
<td>Visits</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Social club</td>
<td></td>
<td>Visits</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other</td>
<td></td>
<td>State:</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

4.3 How does the service user travel to day care?

1. Private car
2. Taxi
3. Transport arranged by day service
4. Other (please specify) ________________________

4.4 Does a member of staff from the home travel with the service user to day care?
Please list any use the service user has made of community-based services over the last 2 months (do not include services provided by people employed directly by the home itself).

*code outpatient services at 4.1*

<table>
<thead>
<tr>
<th>Service</th>
<th>Domiciliary visit (DV) or office visit (OV)</th>
<th>Provider agency: 1 = health service, 2 = local authority, 3 = voluntary org, 4 = private org</th>
<th>Total number of contacts</th>
<th>Average duration of contact (mins)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Care manager</td>
<td>DV</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Social worker</td>
<td>DV</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Home care worker</td>
<td>DV</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Care attendant</td>
<td>DV</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sitting scheme</td>
<td>DV</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Carer's support worker</td>
<td>DV</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>District nurse</td>
<td>DV</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Occupational therapist</td>
<td>DV</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Meals on wheels</td>
<td>DV</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Laundry service</td>
<td>DV</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>General practitioner</td>
<td>DV</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Community psychiatrist</td>
<td>DV</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Geriatrician</td>
<td>DV</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Psychologist</td>
<td>DV</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>CPN</td>
<td>DV</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Health visitor</td>
<td>DV</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Occupational therapist</td>
<td>DV</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Physiotherapist</td>
<td>DV</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Chiropodist</td>
<td>DV</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other: e.g. complementary therapies, police, dentist</td>
<td>DV</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1.</td>
<td>DV</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2.</td>
<td>DV</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3.</td>
<td>DV</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4.</td>
<td>DV</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

THANK YOU
### BACKGROUND INFORMATION ABOUT THE SERVICE USER

1. **Service user's name**
   - Study number

2. **Interview**
   - Baseline = 1, Follow-up = 2

3. **Relationship of person being interviewed to service user**
   - 1 Carer
   - 2 Keyworker
   - 3 Other (please specify)

4. **Interview date**
   - Day (dd), Month (mm), Year (yyyy)

5. **Service user's age**

6. **Service user's sex**
   - Female = 1, Male = 2

7. **Marital status of service user**
   - 1 Single/unmarried
   - 2 Married/living with partner
   - 3 Separated
   - 4 Divorced
   - 5 Widow/widower
   - 6 Not known

8. **At what age did s/he leave full-time education?**

9. **Does he/she receive any of the following benefits? (Please tick all boxes that apply)**
   - Income support, income-based jobseeker's allowance
   - Housing benefit
   - Council-tax benefit
   - Incapacity benefit
   - Severe disablement allowance
   - Invalid care allowance
   - Attendance allowance
   - Disability living allowance
   - Retirement pension
   - Other
2. **SERVICE USER ACCOMMODATION DETAILS**

2.1 What type of accommodation does the service user normally live in?

1. Owner-occupied house/flat
2. Privately rented house/flat
3. House/flat rented from housing association/local authority
4. Residential home
5. Nursing home
6. Dual registered home
7. Sheltered housing
8. Acute psychiatric ward
9. Rehabilitation ward
10. General medical ward
11. Other (please specify)

2.2 How many adults live in the service user’s household?

How many children (under the age of 16) live there?

2.9 Has the service user lived anywhere else during the last two months?

(Please include respite arrangements.)

If yes, please complete table

<table>
<thead>
<tr>
<th>Accommodation type</th>
<th>Number of days in last 2 months</th>
</tr>
</thead>
<tbody>
<tr>
<td>Owner-occupied house/flat</td>
<td></td>
</tr>
<tr>
<td>Privately rented house/flat</td>
<td></td>
</tr>
<tr>
<td>House/flat rented from housing association/local authority</td>
<td></td>
</tr>
<tr>
<td>Residential home</td>
<td></td>
</tr>
<tr>
<td>Nursing home</td>
<td></td>
</tr>
<tr>
<td>Dual registered home</td>
<td></td>
</tr>
<tr>
<td>Sheltered housing</td>
<td></td>
</tr>
<tr>
<td>Acute psychiatric ward</td>
<td></td>
</tr>
<tr>
<td>Rehabilitation ward</td>
<td></td>
</tr>
<tr>
<td>General medical ward</td>
<td></td>
</tr>
<tr>
<td>Other (please specify)</td>
<td></td>
</tr>
</tbody>
</table>

3. **MEDICATION PROFILE**

3.1 Please list below any drugs the service user is currently taking.
<table>
<thead>
<tr>
<th>Preparation</th>
<th>Dosage</th>
<th>Dosage Frequency</th>
<th>Duration of Treatment (months)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

4.
### 5. SERVICE RECEIPT

#### 4.1 Please list any use of the following hospital services over the last 2 months:

<table>
<thead>
<tr>
<th>Service</th>
<th>Name of ward, clinic, hospital or centre</th>
<th>Reason for using service (eg fall, regular respite arrangement)</th>
<th>Unit of measurement</th>
<th>Total number of units received</th>
</tr>
</thead>
<tbody>
<tr>
<td>Assessment/rehab. ward</td>
<td></td>
<td></td>
<td>Inpatient day</td>
<td></td>
</tr>
<tr>
<td>Continuing care/respite</td>
<td></td>
<td></td>
<td>Inpatient day</td>
<td></td>
</tr>
<tr>
<td>Medical ward</td>
<td></td>
<td></td>
<td>Inpatient day</td>
<td></td>
</tr>
<tr>
<td>Other hospital ward</td>
<td></td>
<td></td>
<td>Inpatient day</td>
<td></td>
</tr>
<tr>
<td>Outpatient services</td>
<td></td>
<td></td>
<td>Appointment</td>
<td></td>
</tr>
<tr>
<td>Accident &amp; Emergency</td>
<td></td>
<td></td>
<td>Attendance</td>
<td></td>
</tr>
<tr>
<td>Day hospital</td>
<td></td>
<td></td>
<td>Day attendance</td>
<td></td>
</tr>
<tr>
<td>Other:</td>
<td></td>
<td></td>
<td>(Please specify)</td>
<td></td>
</tr>
</tbody>
</table>

#### 5.2 Please list any use of the following day services over the last 2 months:

<table>
<thead>
<tr>
<th>Service</th>
<th>Name of centre/service</th>
<th>Unit of measurement</th>
<th>Total number of units received over last 2 months</th>
</tr>
</thead>
<tbody>
<tr>
<td>Local authority services department</td>
<td>Days</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Voluntary organisation</td>
<td>Days</td>
<td></td>
<td></td>
</tr>
<tr>
<td>NHS (not hospital)</td>
<td>Days</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Club</td>
<td>Visits</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Club</td>
<td>Visits</td>
<td></td>
<td></td>
</tr>
<tr>
<td>State:</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

#### 4.3 How does the service user travel to day care?

1 Private car
2 Taxi
3 Transport arranged by day service
4 Other (please specify) ____________

#### 4.4 Does the carer travel with the service user to day care? Yes = 1, No = 2

Yes = 1, No = 2

4
4.5 Please list any use the service user has made of community-based services over the last 2 months

*code outpatient services at 4.1

<table>
<thead>
<tr>
<th>Service*</th>
<th>Domiciliary visit/office visit (circle one)</th>
<th>Provider agency</th>
<th>Total number of contacts</th>
<th>Average duration of contact (mins)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Care manager</td>
<td>DV</td>
<td>1</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Social worker</td>
<td>DV</td>
<td>2</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Home care worker</td>
<td>DV</td>
<td>3</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Care attendant</td>
<td>DV</td>
<td>4</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sitting scheme</td>
<td>DV</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Carer’s support worker</td>
<td>DV</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>District nurse</td>
<td>DV</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Occupational therapist</td>
<td>DV</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Meals on wheels</td>
<td>DV</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Laundry service</td>
<td>DV</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>General practitioner</td>
<td>DV</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Community psychiatrist</td>
<td>DV</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Geriatrician</td>
<td>DV</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Psychologist</td>
<td>DV</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>CPN</td>
<td>DV</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Health visitor</td>
<td>DV</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Occupational therapist</td>
<td>DV</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Physiotherapist</td>
<td>DV</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Chiropodist</td>
<td>DV</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other; e.g. complementary therapies, police, dentist</td>
<td>DV</td>
<td>1</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>DV</td>
<td>2</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>DV</td>
<td>3</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>DV</td>
<td>4</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
4.6 Please list any use of privately arranged services paid for by the service user over the last 2 months (e.g. gardening, cleaning)

<table>
<thead>
<tr>
<th>Specify service</th>
<th>Unit of measurement (e.g. hour, minute)</th>
<th>Number of units received (over the last 2 months)</th>
<th>Total cost</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

4.7 Please list any use of the following voluntary services provided without charge to the service user over the last 2 months

<table>
<thead>
<tr>
<th>Service</th>
<th>Specify</th>
<th>Unit of measurement (e.g. hour, minute)</th>
<th>Number of units received (over the last 2 months)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Volunteers or befriending</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Telephone care link call out</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Alarm system</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other:</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

6. BACKGROUND INFORMATION ABOUT THE CARER

5.1 Interview date

5.2 Carer's age

5.3 Carer's sex

5.4 Relationship to service user

1. Spouse
2. Son/Daughter
3. Son/Daughter-in-law
4. Sibling
5. Other relative
6. Friend
7. Neighbour
8. Other (please specify)

5.5 Marital status of carer

1. Single/unmarried
2. Married/living with partner
3. Separated
4. Divorced
5. Widow/widower
6. Not known

Female = 1, Male = 2

DATE mm/dd/yyyy

Day
Month
Year
5.6 Is the carer providing care for anyone other than the service user?  
Yes = 1, No = 2

5.7 If yes, please give details ________________________________________

6. CARER ACCOMMODATION DETAILS

6.1 Does the carer normally live with the service user?  Yes = 1, No = 2

6.2 If no: What kind of accommodation does the carer have?

1 Owner occupied house/flat
2 Privately rented house/flat
3 House/flat rented from housing association/local authority
4 Other (please specify)

6.3 How many adults live in the carer's household?  
How many children (under the age of 16) live there?

7. CARER EMPLOYMENT AND INCOME

7.1 What is the carer's employment status?  (Tick one box)

1 Paid employment  (Please go to 7.2)
2 Unemployed  (Please go to 7.5)
3 Housewife/husband  (Please go to 7.6)
4 Retired  (Please go to 8.1)

7.2 If employed: Please state occupation type

1 Manager/administrator
2 Professional (e.g. health, teaching, financial)
3 Associate professional (e.g. technical, nursing)
4 Clerical worker/secretary
5 Skilled labourer (e.g. building)
6 Services/sales (e.g. retail)
7 Factory worker
8 Other

7.3 Number of hours worked per week
8. OTHER INFORMAL CARERS

8.1 Do any other friends or relatives regularly provide help for the service user?
   Yes = 1, No = 2

8.2 If yes: Thinking about an average or typical week, for how many hours do they substitute for/or assist the carer?
   Hours

8.3 Have any friends and relatives stayed off work over the last 3 months to help with caregiving?
   Yes = 1, No = 2

8.4 If yes: For how long have they stayed off work? Total weeks

What is the person’s occupation?
1 Manager/administrator
2 Professional (e.g. health, teaching, financial)
3 Associate professional (e.g. technical, nursing)
4 Clerical worker/secretary
5 Skilled labourer (e.g. building)
6 Services/sales (e.g. retail)
7 Factory worker
8 Other

THANK YOU
<table>
<thead>
<tr>
<th>Orientation</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>What is the (year) (season) (date) (day) (month)?</td>
<td>5</td>
</tr>
<tr>
<td>Where are we (country) (state) (county) (city) (clinic)?</td>
<td>5</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Registration</th>
<th>3</th>
</tr>
</thead>
<tbody>
<tr>
<td>Name three objects, allowing one second to say each one. Then ask the patient to name all three objects after you have said them. Give one point for each answer. Repeat them until he hears all three. Count trials and record number.</td>
<td></td>
</tr>
</tbody>
</table>

**APPLE TABLE PENNY** Number of trials __________

<table>
<thead>
<tr>
<th>Attention and Calculation</th>
<th>5</th>
</tr>
</thead>
<tbody>
<tr>
<td>Begin with 100 and count backward by 7 (stop after five answers): 93, 86, 79, 72, 65. Score one point for each correct answer.</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Recall</th>
<th>3</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ask the patient to repeat the objects above (See Registration). Give one point for each correct answer.</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Language</th>
<th>2</th>
</tr>
</thead>
<tbody>
<tr>
<td>Naming: Show a pencil and a watch and ask the patient to name them.</td>
<td></td>
</tr>
<tr>
<td>Repetition: Repeat the following: &quot;No ifs, ands, or buts.&quot;</td>
<td>1</td>
</tr>
<tr>
<td>Three-Stage Command: Follow the three-stage command, &quot;Take a paper in your right hand, fold it in half, and put it on the table.&quot;</td>
<td>3</td>
</tr>
<tr>
<td>Reading: Read and obey the following. &quot;Close your eyes&quot; (show the patient the item written on reverse side).</td>
<td>1</td>
</tr>
<tr>
<td>Writing: Write a sentence (on reverse side).</td>
<td>1</td>
</tr>
<tr>
<td>Copying: Copy the design of the intersecting pentagons (on reverse side).</td>
<td>1</td>
</tr>
</tbody>
</table>

**Total Score Possible**

---

### 1. Word Recall Task

The patient reads 10 high imagery words on cards exposed successively for 2 seconds each. The patient then recalls the words aloud in any order. Three trials of reading and recall are given. Place a check in the box of each word recalled correctly.

<table>
<thead>
<tr>
<th>TRIAL 1</th>
<th>TRIAL 2</th>
<th>TRIAL 3</th>
</tr>
</thead>
<tbody>
<tr>
<td>BUTTER</td>
<td>POLE</td>
<td>SHORE</td>
</tr>
<tr>
<td>ARM</td>
<td>LETTER</td>
<td>LETTER</td>
</tr>
<tr>
<td>SHORE</td>
<td>BUTTER</td>
<td>ARM</td>
</tr>
<tr>
<td>LETTER</td>
<td>QUEEN</td>
<td>CABIN</td>
</tr>
<tr>
<td>QUEEN</td>
<td>ARM</td>
<td>POLE</td>
</tr>
<tr>
<td>CABIN</td>
<td>SHORE</td>
<td>TICKET</td>
</tr>
<tr>
<td>POLE</td>
<td>GRASS</td>
<td>ENGINE</td>
</tr>
<tr>
<td>TICKET</td>
<td>CABIN</td>
<td>GRASS</td>
</tr>
<tr>
<td>GRASS</td>
<td>TICKET</td>
<td>BUTTER</td>
</tr>
<tr>
<td>ENGINE</td>
<td></td>
<td>QUEEN</td>
</tr>
</tbody>
</table>

**TOTAL CORRECT RESPONSES:**

<table>
<thead>
<tr>
<th>TRIAL 1</th>
<th>TRIAL 2</th>
<th>TRIAL 3</th>
</tr>
</thead>
</table>

### 2. Naming Objects and Fingers

The patient is asked to name 12 randomly presented real objects whose frequency values are high, medium, and low. The patient is also asked to name the fingers of his/her dominant hand. Standard clues may be used to assist those patients having difficulty.

Place a check in the box which corresponds to each object/finger named correctly. If no objects/fingers named correctly, check "NONE".

<table>
<thead>
<tr>
<th>OBJECT</th>
<th>STANDARD CLUE</th>
</tr>
</thead>
<tbody>
<tr>
<td>flower</td>
<td>grows in garden</td>
</tr>
<tr>
<td>bed</td>
<td>used for sleeping</td>
</tr>
<tr>
<td>whistle</td>
<td>makes sound when blown</td>
</tr>
<tr>
<td>pencil</td>
<td>used for writing</td>
</tr>
<tr>
<td>rattle</td>
<td>a baby's toy</td>
</tr>
<tr>
<td>mask</td>
<td>hides your face</td>
</tr>
<tr>
<td>scissors</td>
<td>cuts paper</td>
</tr>
<tr>
<td>comb</td>
<td>used on hair</td>
</tr>
<tr>
<td>wallet</td>
<td>holds your money</td>
</tr>
<tr>
<td>harmonica</td>
<td>a musical instrument</td>
</tr>
<tr>
<td>stethoscope</td>
<td>doctor uses it to listen to your heart</td>
</tr>
<tr>
<td>funnel</td>
<td>used to fill a bottle</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>FINGER</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>thumb</td>
<td></td>
</tr>
<tr>
<td>index (pointer, forefinger)</td>
<td></td>
</tr>
<tr>
<td>middle</td>
<td></td>
</tr>
<tr>
<td>ring</td>
<td></td>
</tr>
<tr>
<td>pinky (little finger)</td>
<td></td>
</tr>
</tbody>
</table>

CLINICAL RESEARCH & DEVELOPMENT

HOFFMANN-LA ROCHE INC. NUTLEY, NEW JERSEY
### 3. Commands

The patient is given 5 commands ranging from 1 to 5 steps. Each of the 5 commands may be repeated only in its entirety. Each command is scored as a whole, and if the patient fails a single step, the response is considered incorrect. For the 3rd and 4th commands, line up on the table in front of the patient, a pencil, a watch and a card in that order, from the right to the left of the patient.

<table>
<thead>
<tr>
<th>COMMAND</th>
<th>SCREENING</th>
<th>DATE</th>
</tr>
</thead>
<tbody>
<tr>
<td>Make a fist</td>
<td>□</td>
<td></td>
</tr>
<tr>
<td>Point to the ceiling, then to the floor</td>
<td>□</td>
<td></td>
</tr>
<tr>
<td>Put the pencil on top of the card, then put it back</td>
<td>□</td>
<td></td>
</tr>
<tr>
<td>Put the watch on the other side of the pencil and turn over the card</td>
<td>□</td>
<td></td>
</tr>
<tr>
<td>Tap each shoulder twice with two fingers keeping your eyes shut</td>
<td>□</td>
<td></td>
</tr>
</tbody>
</table>

### 4. Constructional Praxis

The patient's ability to copy four geometric forms is assessed. These forms, in order of presentation are:

<table>
<thead>
<tr>
<th>FORM</th>
<th>SCORING CRITERIA</th>
</tr>
</thead>
<tbody>
<tr>
<td>Circle</td>
<td>A closed curved figure.</td>
</tr>
<tr>
<td>Two overlapping rectangles</td>
<td>Forms must be four-sided and overlap must be similar to presented form. Changes in size are not scored.</td>
</tr>
<tr>
<td>Rhombus (diamond)</td>
<td>Figure must be four-sided, correctly (obliquely) oriented, the sides approximately equal length.</td>
</tr>
<tr>
<td>Cube</td>
<td>The form is three-dimensional, with front face in the correct orientation, internal lines drawn correctly between corners.</td>
</tr>
</tbody>
</table>

Each form is located in the upper middle of a sheet of white paper. Two attempts are permitted.

Place a check in the box which corresponds to each figure drawn correctly. If the patient makes an attempt but draws no forms correctly, place a check in the box marked “Some attempted but drew no forms correctly.” If the patient scribbles or writes words but draws no forms, place a check in the box corresponding to this action.

<table>
<thead>
<tr>
<th>FORM</th>
<th>SCORING CRITERIA</th>
</tr>
</thead>
<tbody>
<tr>
<td>Circle</td>
<td>□</td>
</tr>
<tr>
<td>Two overlapping rectangles</td>
<td>□</td>
</tr>
<tr>
<td>Rhombus</td>
<td>□</td>
</tr>
<tr>
<td>Cube</td>
<td>□</td>
</tr>
<tr>
<td>Some attempted but drew no forms correctly</td>
<td>□</td>
</tr>
<tr>
<td>Patient drew no forms; scribbled; wrote words</td>
<td>□</td>
</tr>
</tbody>
</table>
### 5. Ideational Praxis

The patient is given an 8 1/2" x 11" (A4) sheet of paper and a long envelope. The patient is instructed to pretend to send a letter to himself or herself. If the patient forgets part of the task, or is having difficulty on one or more components, the patient can be reinstructed once for each component. Impairment on this test should reflect dysfunction in executing an overlearned task only and not recall difficulty.

Check each step completed correctly or check "NONE" □.

- □ Fold letter
- □ Put letter in envelope
- □ Seal envelope
- □ Address envelope
- □ Indicate where stamp goes

### 6. Orientation

The components of orientation are full name, date, day of the week, name of the place, month, year, season and time of day.

Check each item answered correctly or check "NONE" □.

- □ What is your **surname** and your **first name**?
- □ What **date** is it today?
- □ What **day of the week** is it?
- □ Tell me the name of the **place** where we are.
- □ What **month** is it?
- □ What **year** is it?
- □ What **season** is it?
- □ Without looking at your watch, what **time** is it?
### 7. Word Recognition Task

The patient reads aloud 12 high imagery words presented in writing successively for 2 seconds each. Then words are then randomly mixed with 12 words the patient has not seen. For each of the 24 words presented, the patient must respond by saying "yes" if the word was presented previously and "no" if it was not. If the patient responds appropriately, i.e., "yes" or "no", then recall of the instructions is accurate. If the patient to respond, this signifies that the instructions have been forgotten. Then instruction is repeated. Each instance of failure to recall instructions is noted and summed up at the bottom of the page (for item 1).

Larger words are the original words and the patient should answer "yes" or "old"; smaller words are words and the patient should answer "no" or "new". Place a check in the box which corresponds to the patient's response for each word presented. The total correct for each trial is equal to the number of checks in unshaded boxes.

<table>
<thead>
<tr>
<th>TRIAL 1</th>
<th>YES (OLD)</th>
<th>NO (NEW)</th>
<th>TRIAL 2</th>
<th>YES (OLD)</th>
<th>NO</th>
</tr>
</thead>
<tbody>
<tr>
<td>EGG</td>
<td></td>
<td></td>
<td>FISHERMAN</td>
<td></td>
<td></td>
</tr>
<tr>
<td>WATER</td>
<td></td>
<td></td>
<td>COAT</td>
<td></td>
<td></td>
</tr>
<tr>
<td>MOUNTAIN</td>
<td></td>
<td></td>
<td>EGG</td>
<td></td>
<td></td>
</tr>
<tr>
<td>BALL</td>
<td></td>
<td></td>
<td>EFFECT</td>
<td></td>
<td></td>
</tr>
<tr>
<td>METHOD</td>
<td></td>
<td></td>
<td>CONDITION</td>
<td></td>
<td></td>
</tr>
<tr>
<td>CONDITION</td>
<td></td>
<td></td>
<td>TENDENCY</td>
<td></td>
<td></td>
</tr>
<tr>
<td>ADDITION</td>
<td></td>
<td></td>
<td>INFLUENCE</td>
<td></td>
<td></td>
</tr>
<tr>
<td>YACHT</td>
<td></td>
<td></td>
<td>FROG</td>
<td></td>
<td></td>
</tr>
<tr>
<td>WOODLAND</td>
<td></td>
<td></td>
<td>WITCH</td>
<td></td>
<td></td>
</tr>
<tr>
<td>STANDARD</td>
<td></td>
<td></td>
<td>FARMYARD</td>
<td></td>
<td></td>
</tr>
<tr>
<td>TRANSFER</td>
<td></td>
<td></td>
<td>LEMON</td>
<td></td>
<td></td>
</tr>
<tr>
<td>LIBRARY</td>
<td></td>
<td></td>
<td>WATER</td>
<td></td>
<td></td>
</tr>
<tr>
<td>MENU</td>
<td></td>
<td></td>
<td>MENU</td>
<td></td>
<td></td>
</tr>
<tr>
<td>TYPEWRITER</td>
<td></td>
<td></td>
<td>FOOTBALL</td>
<td></td>
<td></td>
</tr>
<tr>
<td>FROG</td>
<td></td>
<td></td>
<td>OUTSET</td>
<td></td>
<td></td>
</tr>
<tr>
<td>CANDLELIGHT</td>
<td></td>
<td></td>
<td>STANDARD</td>
<td></td>
<td></td>
</tr>
<tr>
<td>BLANKET</td>
<td></td>
<td></td>
<td>ENTERPRISE</td>
<td></td>
<td></td>
</tr>
<tr>
<td>TENDENCY</td>
<td></td>
<td></td>
<td>SELECTION</td>
<td></td>
<td></td>
</tr>
<tr>
<td>OUTSET</td>
<td></td>
<td></td>
<td>PRECURSOR</td>
<td></td>
<td></td>
</tr>
<tr>
<td>IMPURITY</td>
<td></td>
<td></td>
<td>ASATEMENT</td>
<td></td>
<td></td>
</tr>
<tr>
<td>CONJUGATION</td>
<td></td>
<td></td>
<td>CONJUGATION</td>
<td></td>
<td></td>
</tr>
<tr>
<td>RARITY</td>
<td></td>
<td></td>
<td>LIBRARY</td>
<td></td>
<td></td>
</tr>
<tr>
<td>EXCEPTION</td>
<td></td>
<td></td>
<td>INTENTION</td>
<td></td>
<td></td>
</tr>
<tr>
<td>SELECTION</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>TOTAL CORRECT</td>
<td></td>
<td></td>
<td>TOTAL CORRECT</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

HOW MANY TIMES WERE INSTRUCTIONS REPEATED? _____ (see Item 1)
### 8. Spoken Language Ability

Language abilities are evaluated throughout the interview and on specific tests. The following items should be scored based on the patient's abilities with the preceding seven items. This item is a global rating of quality of speech, i.e., clarity, difficulty in making oneself understood. Quantity and word finding difficulty is not rated on this item.

Place a check in the box which most closely corresponds to the patient's level of impairment in spoken language.

- **G 0 None**: patient speaks clearly and/or is understandable
- **G 1 Very mild**: one instance of lack of understandability
- **G 2 Mild**: patient has difficulty <25% of the time
- **G 3 Moderate**: patient has difficulty 25–50% of the time
- **G 4 Moderately severe**: patient has difficulty more than 50% of the time
- **G 5 Severe**: One or two word utterances; fluent, but empty speech; mute

### 9. Comprehension of Spoken Language

This item evaluates the patient's ability to understand speech. Do not include responses to commands (item 7).

Place a check in the box which most closely corresponds to the patient's level of impairment in comprehension of spoken language.

- **G 0 Normal**: patient understands
- **G 1 Very mild**: One instance of misunderstanding
- **G 2 Mild**: 3–5 instances of misunderstanding
- **G 3 Moderate**: requires several repetitions and rephrasing
- **G 4 Moderately severe**: patient only occasionally responds correctly; i.e., yes–no questions
- **G 5 Severe**: patient rarely responds to questions appropriately; not due to poverty of speech

### 10. Word-Finding Difficulty in Spontaneous Speech

Language abilities are evaluated throughout the interview and on specific tests. The patient has difficulty finding the desired word in spontaneous speech. The problem may be overcome by circumlocution, i.e., giving explanatory phrases or nearly satisfactory synonyms. Do not include finger and object naming in the rating (item 2).

Place a check in the box which corresponds to the patient's level of impairment in word-finding.

- **G 0 None
- G 1 Very mild**: One or 2 instances, not clinically significant
- **G 2 Mild**: noticeable circumlocution or synonym substitution
- **G 3 Moderate**: loss of words without compensation on occasion
- **G 4 Moderately severe**: frequent loss of words without compensation
- **G 5 Severe**: nearly total loss of content words; speech sounds empty; 1–2 word utterances

### 11. Remembering Test Instructions

(The patient's ability to remember the requirements of the recognition task is evaluated)

See 7. Word Recognition Task

HOW MANY TIMES WERE INSTRUCTIONS REPEATED?

Place a check in the box which corresponds to the patient's level of impairment with remembering test instructions.

- **G 0 None
- G 1 Very mild**: for got once
- **G 2 Mild**: must be reminded 2 times
- **G 3 Moderate**: must be reminded 3 or 4 times
- **G 4 Moderately severe**: must be reminded 5 or 6 times
- **G 5 Severe**: must be reminded 7 or more times
<table>
<thead>
<tr>
<th>INVESTIGATOR</th>
<th>PATIENT IDENTIFICATION</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>INITIALS</td>
</tr>
<tr>
<td></td>
<td>PROJECT NO.</td>
</tr>
<tr>
<td></td>
<td>A6327</td>
</tr>
<tr>
<td></td>
<td>CRTN</td>
</tr>
<tr>
<td></td>
<td>PT. ID. NO.</td>
</tr>
</tbody>
</table>

DO NOT WRITE IN SCREENED AREAS
<table>
<thead>
<tr>
<th>INVESTIGATOR</th>
<th>PATIENT IDENTIFICATION</th>
<th>PROJECT NO.</th>
<th>CRIN</th>
<th>PT. I.D. NO</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>A6327</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

DO NOT WRITE IN SCREENED AREAS
### Patient Identification Table

<table>
<thead>
<tr>
<th>INVESTIGATOR</th>
<th>PATIENT IDENTIFICATION</th>
<th>PROJECT NO.</th>
<th>CRTN</th>
<th>PT. I.D. N.</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td>A6327</td>
<td></td>
</tr>
</tbody>
</table>

This table is designed to record patient identification details, including project number and patient identification number.
1. WORD RECALL TASK

The patient reads 10 high imagery words on cards exposed successively for 2 seconds each. The patient then recalls the words aloud in any order. Three trials of reading and recall are given. Place a check in the box of each word recalled correctly.

<table>
<thead>
<tr>
<th>TRIAL 1</th>
<th>TRIAL 2</th>
<th>TRIAL 3</th>
</tr>
</thead>
<tbody>
<tr>
<td>BLOOD</td>
<td>FIRE</td>
<td>CAMP</td>
</tr>
<tr>
<td>CAMP</td>
<td>TOY</td>
<td>PLANT</td>
</tr>
<tr>
<td>COTTON</td>
<td>BLOOD</td>
<td>OCEAN</td>
</tr>
<tr>
<td>FIRE</td>
<td>STEAM</td>
<td>FIRE</td>
</tr>
<tr>
<td>HALL</td>
<td>COTTON</td>
<td>TOY</td>
</tr>
<tr>
<td>LAD</td>
<td>OCEAN</td>
<td>STEAM</td>
</tr>
<tr>
<td>PLANT</td>
<td>CAMP</td>
<td>BLOOD</td>
</tr>
<tr>
<td>OCEAN</td>
<td>LAD</td>
<td>HALL</td>
</tr>
<tr>
<td>STEAM</td>
<td>PLANT</td>
<td>COTTON</td>
</tr>
<tr>
<td>TOY</td>
<td>HALL</td>
<td>LAD</td>
</tr>
</tbody>
</table>

TOTAL CORRECT RESPONSES: TRIAL 1 _______ TRIAL 2 _______ TRIAL 3 _______

2. NAMING OBJECTS AND FINGERS

The patient is asked to name 12 randomly presented real objects whose frequency values are high, medium and low. The patient is also asked to name the fingers of his/her dominant hand. Standard clues may be used to assist those patients having difficulty.

Place a check in the box which corresponds to each object/finger named correctly. If no objects/fingers are named correctly, check "NONE" □.

<table>
<thead>
<tr>
<th>OBJECT</th>
<th>STANDARD CLUE</th>
</tr>
</thead>
<tbody>
<tr>
<td>□ flower</td>
<td>grows in garden</td>
</tr>
<tr>
<td>□ bed</td>
<td>used for sleeping</td>
</tr>
<tr>
<td>□ whistle</td>
<td>makes sound when blown</td>
</tr>
<tr>
<td>□ pencil</td>
<td>used for writing</td>
</tr>
<tr>
<td>□ rattle</td>
<td>a baby's toy</td>
</tr>
<tr>
<td>□ mask</td>
<td>hides your face</td>
</tr>
<tr>
<td>□ scissors</td>
<td>cuts paper</td>
</tr>
<tr>
<td>□ comb</td>
<td>used on hair</td>
</tr>
<tr>
<td>□ wallet</td>
<td>holds your money</td>
</tr>
<tr>
<td>□ harmonica</td>
<td>a musical instrument</td>
</tr>
<tr>
<td>□ stethoscope</td>
<td>doctor uses it to listen to your heart</td>
</tr>
<tr>
<td>□ funnel</td>
<td>used to fill a bottle</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>FINGER</th>
<th>STANDARD CLUE</th>
</tr>
</thead>
<tbody>
<tr>
<td>□ thumb</td>
<td></td>
</tr>
<tr>
<td>□ index (pointer, forefinger)</td>
<td></td>
</tr>
<tr>
<td>□ middle</td>
<td></td>
</tr>
<tr>
<td>□ ring</td>
<td></td>
</tr>
<tr>
<td>□ pinky (little finger)</td>
<td></td>
</tr>
</tbody>
</table>
The patient is given 5 commands ranging from 1 to 5 steps. Each of the 5 commands may be repeated only once in its entirety. Each command is scored as a whole, and if the patient fails a single step, the response is considered incorrect. For the 3rd and 4th commands, line up on the table in front of the patient, a pencil, a water and a card in that order, from the right to the left of the patient.

Place a check in the box which corresponds to each command performed correctly. If the patient does not perform any of the commands correctly, check "NONE".

- Make a fist
- Point to the ceiling, then to the floor
- Put the watch on the other side of the pencil and turn over the card
- Tap each shoulder twice with two fingers keeping your eyes shut

4. CONSTRUCTIONAL PRAXIS

The patient's ability to copy four geometric forms is assessed. These forms, in order of presentation are:

- Circle
- Two overlapping rectangles
- Rhombus (diamond)
- Cube

Each form is located in the upper middle of a sheet of white paper. Two attempts are permitted.

Place a check in the box which corresponds to each figure drawn correctly. If the patient makes an attempt but draws no forms correctly, place a check in the box marked "Some attempted but drew no forms correctly." If the patient scribbles or writes words but draws no forms, place a check in the box which corresponds to this action.

- Circle
- Two overlapping rectangles
- Rhombus
- Cube

Some attempted but drew no forms correctly
- Patient drew no forms; scribbled; wrote words
5. IDEATIONAL PRAXIS

The patient is given an 8 1/2" x 11" (A4) sheet of paper and a long envelope. The patient is instructed to pretend to send a letter to himself or herself. If the patient forgets part of the task, or is having difficulty on one or more components, the patient can be re-instructed once for each component. Impairment on this item should reflect dysfunction in executing an overlearned task only and not recall difficulty.

Check each step completed correctly or check “NONE” □.

☐ Fold letter
☐ Put letter in envelope
☐ Seal envelope
☐ Address envelope
☐ Indicate where stamp goes

6. ORIENTATION

The components of orientation are full name, date, day of the week, name of the place, month, year, season and time of day.

Check each item answered correctly or check “NONE” □.

☐ What is your surname and your first name?
☐ What date is it today?
☐ What day of the week is it?
☐ Tell me the name of the place where we are.
☐ What month is it?
☐ What year is it?
☐ What season is it?
☐ Without looking at your watch, what time is it?
<table>
<thead>
<tr>
<th>CDR 0</th>
<th>CDR 0.5</th>
<th>CDR 1</th>
<th>CDR 2</th>
<th>CDR 3</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>MEMORY</strong></td>
<td>No memory loss or slight inconsistent forgetfulness</td>
<td>Mild consistent forgetfulness; partial recollection of events;</td>
<td>Moderate memory loss; more marked for recent events; defect interferes with everyday activities;</td>
<td>Severe memory loss; only highly learned material retained, new memory rapidly lost</td>
</tr>
<tr>
<td><strong>ORIENTATION</strong></td>
<td>Fully orientated; aware of time, day, month and place</td>
<td>Fully orientated; aware of time, day, month and place</td>
<td>Some difficulty with time, date, etc.; oriented for familiar places and people, but not those which are unfamiliar</td>
<td>Usually disorientated in time, often for place</td>
</tr>
<tr>
<td><strong>JUDGEMENT</strong></td>
<td>Solves everyday problems well; judgement good in relation to past performance</td>
<td>Only doubtful impairment in solving problems</td>
<td>Moderate difficulty in handling complex problems</td>
<td>Severely impaired in handling problems</td>
</tr>
<tr>
<td><strong>PROBLEM SOLVING</strong></td>
<td>Independent function at usual level in job, shopping, business and financial affairs, volunteer and social groups</td>
<td>Only doubtful impairment or mild if any in these activities</td>
<td>Unable to function independently at these activities though may still be engaged in some.</td>
<td>Unable to function independently outside the home</td>
</tr>
<tr>
<td><strong>DECISION MAKING</strong></td>
<td>Normal</td>
<td>Only slightly impaired</td>
<td>Mild but definite impairment; difficult chores, and more complicated hobbies abandoned.</td>
<td>Simple chores preserved; very restricted interests.</td>
</tr>
<tr>
<td><strong>HOME (COOKING, HOUSEWORK)</strong></td>
<td>Normal</td>
<td>Only slightly impaired</td>
<td>Mild but definite impairment; difficult chores, and more complicated hobbies abandoned.</td>
<td>Simple chores preserved; very restricted interests.</td>
</tr>
<tr>
<td><strong>HOBBIES, INTERESTS</strong></td>
<td>Normal</td>
<td>Only slightly impaired</td>
<td>Mild but definite impairment; difficult chores, and more complicated hobbies abandoned.</td>
<td>Simple chores preserved; very restricted interests.</td>
</tr>
<tr>
<td><strong>PERSONAL CARE</strong></td>
<td>Fully capable of self care</td>
<td>Fully capable of self care</td>
<td>Needs occasional prompting; dressing, washing, keeping of personal effects</td>
<td>Requires assistance in dressing, washing, keeping of personal effects</td>
</tr>
<tr>
<td><strong>SCORE</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**SCORING**

Impairment must be due to cognitive loss. Memory is the primary category in determining the CDR, the others are secondary.

If at least 3 secondary categories are given the same numerical score as memory, then CDR = M

If at least 3 secondary categories are given a greater or lesser score than memory, then CDR = score of majority of secondary categories.
# Appendix B: Assessment Scales

## Cornell Scale for Depression in Dementia

<table>
<thead>
<tr>
<th>PATIENT STATUS AT TIME OF EVALUATION (Check one)</th>
</tr>
</thead>
<tbody>
<tr>
<td>☐ 0 INPATIENT</td>
</tr>
</tbody>
</table>

**SCORING SYSTEM**

- - UNABLE TO EVALUATE
- 0 = ABSENT
- 1 = MILD OR INTERMITTENT
- 2 = SEVERE

Ratings should be based on symptoms and signs occurring during the week prior to interview. No score should be given if symptoms result from physical disability or illness.

### A. Mood-Related Signs

1. Anxiety (Anxious expression, ruminations, worrying)
2. Sadness (Sad expression, sad voice, tearfulness)
3. Lack of Reactivity to Pleasant Events
4. Irritability (Easily annoyed, short tempered)

### B. Behavioral Disturbance

5. Agitation (Restlessness, handwringing, hairpulling)
6. Retardation (Slow movements, slow speech, slow reactions)
7. Multiple Physical Complaints (Score 0 if all symptoms only)
8. Loss of Interest (Less involved in usual activities) (Score only if change occurred acutely, i.e., in less than 1 month)

### C. Physical Signs

9. Appetite Loss (Eating less than usual)
10. Weight Loss (Score 2 if greater than 5 lb. in 1 month)
11. Lack of Energy (Fatigues easily, unable to sustain activities) (Score only if change occurred acutely, i.e., in less than 1 month)

### D. Cyclic Functions

12. Diurnal Variation of Mood (Symptoms worse in the morning)
13. Difficulty Falling Asleep (Later than usual for this individual)
14. Multiple Awakenings During Sleep
15. Early Morning Awakening (Earlier than usual for this individual)

### E. Ideational Disturbance

16. Suicide (Feels life is not worth living, has suicidal wishes, or makes suicide attempt)
17. Poor Self-Esteem (Self-blame, self-depreciation, feelings of failure)
18. Pessimism (Anticipation of the worst)
19. Mood-Congruent Delusions (Delusions of poverty, illness, or loss)

**Comments** (Please date and sign all comments)

---

**QUALITY OF LIFE IN DEMENTIA**

**Hospital no.**

---

**CLINICAL RESEARCH & DEVELOPMENT**

**HOFFMANN-LA ROCHE INC.**

**NUTLEY, NEW JERSEY 07110**
# RATING ANXIETY IN DEMENTIA-RAID

**PATIENTS NAME:**

**DOB:**

**HOSPITAL NO:**

**RATER'S NAME:**

**OCCUPATION:**

**DATE:**

Patients status at the time of evaluation:

1. In patient 2, out patient 3. Day hospital/daycentre patient 4. Other (specify) ...............

Scoring system:

U. Unable to evaluate 0. Absent 1. Mild or Intermittent 2. Moderate 3. Severe

Rating should be based on symptoms and signs occurring during two weeks prior to the interview. No score should be given if symptoms result from physical disability or illness.

<table>
<thead>
<tr>
<th></th>
<th>WORRY</th>
<th>SCORE</th>
</tr>
</thead>
<tbody>
<tr>
<td>A</td>
<td>1. Worry about physical health.</td>
<td></td>
</tr>
<tr>
<td></td>
<td>2. Worry about cognitive performance, falling memory, getting lost when going out, not able to follow conversation.</td>
<td></td>
</tr>
<tr>
<td></td>
<td>3. Worry over finances, family problems, physical health of relatives.</td>
<td></td>
</tr>
<tr>
<td></td>
<td>4. Worry associated with false belief and perception.</td>
<td></td>
</tr>
<tr>
<td></td>
<td>5. Worry over trifles, (repeatedly call for attention over trivial matters)</td>
<td></td>
</tr>
<tr>
<td>B</td>
<td>APPREHENSION &amp; VIGILANCE.</td>
<td></td>
</tr>
<tr>
<td></td>
<td>6. Frightened and anxious (keyed up and on the edge)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>7. Sensitivity to noise, (exaggerated startle response)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>8. Sleep disturbance, (Trouble falling or staying asleep)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>9. Irritability, (More easily annoyed than usual, short tempered and angry outbursts.)</td>
<td></td>
</tr>
<tr>
<td>C</td>
<td>MOTORTENSION</td>
<td></td>
</tr>
<tr>
<td></td>
<td>10. Trembling</td>
<td></td>
</tr>
<tr>
<td></td>
<td>11. Motor tension, (complain of headache, other bodyaches and pains)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>12. Restlessness, (Fidgeting, could not sit still, pacing, wringing hands, picking at clothes)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>13. Fatigueability, Tiredness</td>
<td></td>
</tr>
<tr>
<td>D</td>
<td>AUTONOMIC HYPERSENSITIVITY.</td>
<td></td>
</tr>
<tr>
<td></td>
<td>14. Palpitations, (complains of heart racing or thumping)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>15. Dry mouth, (not due to medication), sinking feeling in stomach.</td>
<td></td>
</tr>
<tr>
<td></td>
<td>16. Shortness of breath, (even when not exerting)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>17. Dizziness or light-headedness, (complains as if going to faint)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>18. Sweating, flushes or chills, tingling or numbness of fingers and toes.</td>
<td></td>
</tr>
<tr>
<td>E</td>
<td>PHOBIAS: (Fears which are excessive, that do not make sense and tend to avoid - like afraid of crowds, going out alone, being in a small room; or being frightened by some kind of animals, heights etc.)</td>
<td></td>
</tr>
<tr>
<td>F</td>
<td>PANIC ATTACKS: (Feelings of anxiety or dread that are so strong that they simply have to do something to stop them, like immediately leaving the place, phoning the relatives, going to see a neighbour etc.)</td>
<td></td>
</tr>
</tbody>
</table>
**CLIFTON ASSESSMENT PROCEDURES FOR THE ELDERLY (CAPE)**

**Behaviour Rating Scale.**

Name: ........................................ Date of birth: ........................................

Current address/placement: .........................................................................................

Please ring the appropriate number for each item:

1. When bathing or dressing, he/she requires: — no assistance 0
   — some assistance 1
   — maximum assistance 2

2. With regard to walking, he/she:
   — shows no signs of weakness 0
   — walks slowly without aid, or uses a stick 1
   — is unable to walk, or if able to walk, needs frame, crutches or someone by his/her side 2

3. He/she is incontinent of urine and/or faeces (day or night):
   — never 0
   — sometimes (once or twice per week) 1
   — frequently (3 times per week or more) 2

4. He/she is in bed during the day (bed does not include couch, settee, etc):
   — never 0
   — sometimes 1
   — almost always 2

5. He/she is confused (unable to find way around, loses possessions, etc):
   — almost never confused 0
   — sometimes confused 1
   — almost always confused 2

6. When left to his/her own devices, his/her appearance (clothes and/or hair) is:
   — almost never disorderly 0
   — sometimes disorderly 1
   — almost always disorderly 2

7. If allowed outside, he/she would:
   — never need supervision 0
   — sometimes need supervision 1
   — always need supervision 2

8. He/she helps out in the home/ward:
   — often helps out 0
   — sometimes helps out 1
   — never helps out 2

9. He/she keeps him/herself occupied in a constructive or useful activity (works, reads, plays games, has hobbies, etc):
   — almost always occupied 0
   — sometimes occupied 1
   — almost never occupied 2

10. He/she socialises with others:
    — does establish a good relationship with others 0
    — has some difficulty establishing good relationships 1
    — has a great deal of difficulty establishing good relationships 2

11. He/she is willing to do things suggested or asked of him/her:
    — often goes along 0
    — sometimes goes along 1
    — almost never goes along 2
12. He/she understands what you communicate to him/her (you may use speaking, writing, or gesturing):
- understands almost everything you communicate 0
- understands some of what you communicate 1
- understands almost nothing of what you communicate 2

13. He/she communicates in any manner (by speaking, writing or gesturing):
- well enough to make him/herself easily understood at all times 0
- can be understood sometimes or with some difficulty 1
- can rarely or never be understood for whatever reason 2

14. He/she is objectionable to others during the day (loud or constant talking, pilfering, soiling furniture, interfering with affairs of others):
- rarely or never 0
- sometimes 1
- frequently 2

15. He/she is objectionable to others during the night (loud or constant talking, pilfering, soiling furniture, interfering in affairs of others, wandering about, etc.):
- rarely or never 0
- sometimes 1
- frequently 2

16. He/she accuses others of doing him/her bodily harm or stealing his/her personal possessions — if you are sure the accusations are true, rate zero, otherwise rate one or two:
- never 0
- sometimes 1
- frequently 2

17. He/she hoards apparently meaningless items (wads of paper, string, scraps of food, etc.):
- never 0
- sometimes 1
- frequently 2

18. His/her sleep pattern at night:
- almost never awake 0
- sometimes awake 1
- often awake 2

Eyesight:
- can see (or can see with glasses)
- partially blind
- totally blind

Hearing:
- no hearing difficulties, without hearing aid
- no hearing difficulties, though requires hearing aid
- has hearing difficulties which interfere with communication
- is very deaf

Rated by: ____________________________ Date: ____________________________

Copyright © 1978 A.H. Pattle and C.J. Gilleard
Fifteenth Impression 1992
All rights reserved. No part of this publication may be reproduced or transmitted in any form or by any means, without permission in writing from the publisher.
This publication is excluded from the reprographic licensing scheme administered by the
# Holden Communication Scale

**Score:**

1. **Response:**
   - Initiates conversation, deeply involved with anyone: Good for those familiar to him/her
   - Fair response to those close by. No initiation of conversation: Rather confused
   - No comprehension: Rarely or never converses

2. **Interest in past events:**
   - Long full account of past events: Fairly good description
   - Short. Description a little confused: Confused or disinterested
   - No response: No response

3. **Pleasure:**
   - Shows real pleasure in situation/achievement: Smiles and shows interest
   - Variable response, slight smile, vague: Rarely shows even a smile
   - No response or just weeps: No response or just weeps

4. **Humour:**
   - Creates situation or tells funny story on own initiative: Enjoys comic situations or stories
   - Needs an explanation and encouragement to respond: Vague smile, simply copies or negativistic
   - No response: No response or negativistic

5. **Names:**
   - Knows most people’s names on ward: Knows most names
   - Needs a constant reminder: Knows own name only
   - Forgets own name: Forgotten even own name

6. **General orientation:**
   - Knows day, month, weather, time and whereabouts: Good on current events, generally able
   - Usually gets two right but tries: Confused about many things
   - Rarely shows even a smile: Confused about everything

7. **General knowledge:**
   - Knows own name only: Very confused
   - Slight hesitation or odd wording: Inappropriate words, odd sounds.
   - Communicates with ease: Nodding, Euphoric laughter, weeping, aggressive
   - No attempt: No attempt

8. **Ability to join in games and activities with ease:**
   - Becomes anxious and upset: Cannot or will not join in
   - Requires careful instructions but joins in: Inappropriate words, odd sounds.
   - Communicates with ease: Nodding, Euphoric laughter, weeping, aggressive
   - No attempt: No attempt

9. **Speech:**
   - No known difficulty: Outstanding events only
   - Poor general knowledge: Confused about many things
   - Requires careful instructions but joins in: Inappropriate words, odd sounds.
   - Communicates with ease: Nodding, Euphoric laughter, weeping, aggressive
   - No attempt: No attempt

10. **Attempts at communication:**
    - Tries hard to speak clearly: Euphoric laughter, weeping, aggressive
    - No attempt: No attempt

11. **Interest and response to objects:**
    - Despite difficulties, shows interest: Weeps, rejects objects, shows aggression
    - No response: No response

12. **Success in communication:**
    - Uses gestures and sounds effectively: Becomes frustrated and angry
    - Makes no attempt: Makes no attempt
Appendix C:

Group Programme
Group programme

At the beginning of each session:

1. Warm-up exercises, e.g. physical game with cognitive component (throw ball & say people’s names).
2. Orientate members to time & place.
   - have RO board; containing name of group (decided in session one), session number & content, day, date, name of home, one news headline, weather, time & content of next session. Use as introductory tool/focus.

1) Introduction
Rapport building, movement, touch and cognition.
   - do introductions of group and members, choose a group name, and create RO board.
   - physical game, e.g. ‘Rollaball’ or indoor bowls. Get people to calculate their scores.

2) Sound
Use of auditory sense & long-term memory
   - sound effects tapes, accompanied by pictures
   - percussion instruments (or alternatively spoons, comb with paper etc.) played with appropriate music.
   - tapes can be played (‘voices from the 40’s and 50’s’, ‘nostalgia’, ‘great singers of yesteryear’, classical, hymns). Ask people to guess name of song/singer.
3) Early memories

Reminiscence/use of long-term memory & taste.

- 1st page of memory diary/reconstruct pictures of person’s house / bedroom on board
- get people to demonstrate how to use childhood toys (spinning top, Jacobs ladder etc.)
- use sweets: liquorice, pear drops, aniseed balls, gob stoppers, bulls eyes, barley sugar, treacle toffee, sherbet fountains to stimulate memories.

4) Food

Reminiscence/cognitive stimulation & taste.

- use Sainsbury’s ‘playfood groceries’ kit to categorise objects. (e.g. different mealtimes, special occasions, savoury, sweet).
- use food with reminiscent value, e.g., Typhoo tealeaves, Bovril, Lyons syrup, cream soda, Battenburg cake, alcoholic drinks, etc. to categorise and discuss.
- give each person a different flavoured sweet – guess.
- use food page in ‘Activities & Ideas’ to complete names of food item, e.g. ‘Yorkshire X’/brainstorm food categories on board, e.g. bread, cereal, Christmas foods (verbal fluency).

5) Current affairs

Orientation to place, time and current issues of debate.

- use cut-outs of interesting articles to discuss and express opinions/use cue cards
to stimulate discussion (e.g. news, views, attitudes, dreams, aspirations).

6) Faces / scenes

Cognitive stimulation/use of long-term memory.

- use laminated pictures from famous faces, CD-ROM & postcards and give people 2-4 cards. Ask them to hold up named person/scene. Ask opinions, e.g. ‘most beautiful’, ‘oldest’. Attempt to use opinions to generate memories for names.

7) Associated words/discussion

Cognitive stimulation/use of long-term memory.

- use photocopies of ‘Activities & Ideas’ - ask group to complete. Includes: amounts, famous couples/names/places, film titles, pairs.

8) Categorising objects

Cognitive stimulation.

- topix game. Includes cards with letters, card with categories (e.g. womens' name, hairy things), scoring cards, egg timer. People in group have to pick letters & categories, and think of as many things beginning with that letter in allocated time. Can be adapted accordingly.

- more informal adaptation of the above/breakstorm categories on board.

- use pictures, cards or objects to play “Odd man out”.

9) Orientation

Cognitive stimulation & orientation of group members to place & time (where they are now in relation to then).
construct map of England / local area / home / bedroom.
- use ‘country walks’ calendar, large London tube map (in ‘London game’
  which also contains individual cards with different info about London), large
  map of England (in Stately Homes game).

10) Using money
Cognitive stimulation.
- cut out pictures of common/household objects from a catalogue. Stick on
  card (laminate) with prices on back. Alternatively, use objects.
- tasks involving adding prices (how much will the bill be).
- match the pricetag with the object, or give people 3 amounts of money and 3
  objects match objects with price.

11) Number-related activity
Cognitive stimulation.
- bingo / card adaptation. If people are adverse to bingo, play equivalent style
  game with cards.

12) Word-related activity
Cognitive stimulation.
- On A3 paper, make “find the word”.
- On A3 paper, make simple crossword.

13) Using objects
Cognitive stimulation/problem solving & practising motor function.
- creative session, e.g. cookery, make apple crumble. Task includes: greasing bowl, mixing ingredients, making crumble mixture, peeling & slicing apples etc.

14) End of programme activity

Cognitive stimulation, closure.

- Get into 2 teams - quiz, with prizes.
- Have tea & eat what the group baked in previous session.
- Discuss how people have felt about the group.
Appendix D:
Letters/forms
Our Ref: KS/ab
10 May 1999

Dr Martin Orell
Reader in Psychiatry of Ageing
Royal Free and University College Medical School
University College of London
(Gower Street Campus and Whittington Campus)
Wolfson Building
48 Riding House Street
LONDON W1N 8AA

Dear Martin

RESEARCH PROJECT - PSYCHOLOGICAL THERAPIES IN THE ELDERLY WITH DEMENTIA

Thank you for your letter dated 7.5.99, enquiring whether Mid Essex would be interested in this Research Project. Further to our discussion on Thursday 6 May 1999, I wish to confirm that Mid Essex would be pleased to join you in this Research Project. Although I do not have the detailed figures to hand I wish to confirm that there is a total of 58 elderly people with a diagnosis of dementia attending our Day Hospitals.

I am unable to confirm the exact numbers of people with dementia being offered a service by Social Services Day Centres and Residential facilities. However, I have a figure of 140 such people on my records.

I would be pleased to provide you with further information and hope that your application for the Responsive Funding from the London NHS Regional Executive would be made available.

I would be most pleased to join you in this Research Project.

With kind regards,

Yours sincerely

Dr Knightly Seneviratna
Consultant Psychiatrist for the Elderly

Trust Headquarters Atlantic Square Station Road Witham Essex CM8 2TL
Telephone: 01376 393000 Facsimile: 01376 393001
Chairman: David Bullock Chief Executive: Richard Coleman
OUR REF: DELAPPV.DOC

Dr S Evans Chairman
Dr C Barton Vice Chairman

Anglia & Oxford MREC
Cambridgeshire Health Authority, St John's, Thorpe Road, Peterborough PE3 6JG

Anne Burnley, Manager
Direct Line: 01733 882114
Answerphone: 01733 882115
Fax: 01733 882299 (general)

Our ref: Letters00/delappv/00503caMAR00.doc
Please use our reference on all correspondence

29 March 2000

Dr M Orrell
UCL, Dept of Psychiatry & Behavioural Sciences
Wolfson Building, 48 Riding House Street
London, W1N 8AA

Dear Dr Orrell

Research Protocol: MREC 00/5/03
Proposal Title: Evidence based psychological therapy package for dementia.
Meeting date: 8 March 2000

The Chairman of the Anglia and Oxford MREC has considered the amendments submitted in response to the Committee's earlier review of your application on 9/2/00 as set out in our letter dated 17/2/00 and your response dated 1/3/00.

The Chairman, acting under delegated authority is satisfied that these accord with the decision of the Committee and has agreed that there is no objection on ethical grounds to the proposed study, whose title is given at the head of this letter. I am, therefore, happy to give you our approval. This is on the understanding that you will follow the protocol as agreed. The project must be started within three years of the date on which MREC approval is given. I would ask you to submit to LRECs only the revised paperwork reflecting the requirements of the MREC as referenced in the response form.

Please read the notes regarding notification of changes and completion of progress reports at the end of the Response Form carefully, as the MREC requires that they be followed. In addition, approval is given subject to the conditions set out below:-

Conditions of Approval

- You follow the protocol agreed and advise the MREC of any changes made. Any changes to the protocol will require prior MREC approval.
- You complete the final report form at the end of your project and the annual report form (progress of study) and return both to the MREC Administrator. (these may be sent at a later date)
- You notify any serious unexpected adverse drug reactions to the MREC Administrator, appropriate LRECs and your sponsor using the procedure set out in the General Guidance for Researchers.
You will no doubt realise that whilst the MREC has given approval for the study on ethical grounds, it is still necessary for you to obtain management approval from the relevant Clinical Directors and/or Chief Executive of the Trusts (or Health Boards/DHAs) in which the work will be done.

Local Submissions

It is also your responsibility to ensure that any local researcher seeks the approval of the relevant LREC before starting their research. To do this you should submit the appropriate number of copies of the following to the relevant LRECs:-

- this letter
- the MREC Application Form (including copies of any questionnaires)
- the attached MREC response form (if not attached will be sent at a later date)
- Annexe D of the Application Form
- one copy of the protocol

It is important to check with the respective LRECs the precise numbers of copies required as this will vary and failure to supply sufficient copies could lead to a delay.

Local Sites

Whilst the MREC would like as much information as possible about local sites at the time you apply for ethical approval, it is understood that this is not always possible. You are asked, however, to send a completed copy of Annexe C for each local site as soon as a researcher has been recruited. This is essential to enable the MREC to monitor the research it approves and to the smooth running of the evaluation.

ICH GCP Compliance

The MRECs are fully compliant with the International Committee on Harmonisation/Good Clinical Practice (ICH) Guidelines for the Conduct of Trials Involving the Participation of Human Subjects as they relate to the responsibilities, composition, function, operations and records of an Independent Ethics Committee/Independent Review Board. To this end, it undertakes to adhere as far as is consistent with its Constitution, to the relevant clauses of the ICH Harmonised Tripartite Guideline for Good Clinical Practice, adopted by the Commission of the European Union on 17 January 1997. The Standing Orders and a Statement of Compliance were included on the computer disk containing the guidelines and application form and are available on request or on the Internet at http://dspace.dial.pipex.com/mrec.

Yours sincerely

[Signature]

ANNE M BURNLEY
MANAGER
MREC

cc
20th June 2000

Dr M Orrell  
UCL Department of Psychiatry and Behavioural Sciences  
Wolfson Building  
48 Riding House Street  
London  
W1N 8AA

Dear Dr Orrell

Application No: MREC(1) 00/5/03  
LREC 00/34 (please use in all further correspondence)  
Title: Evidence-Based Psychological therapy package for dementia

Thank you for your submitting the above MREC approved project to this Ethics Committee for review. I am pleased to tell you that this project has been granted approval to proceed in Camden and Islington Community Trust. However, the Committee noted that the information to be given to patients did not include an indication of how long the reassessment after 7 weeks would take. We recommend that you include this detail on the patient information sheet.

The following documents were reviewed:

- MREC application form
- Supplementary Form for LRECs - Annex D
- Correspondence between MREC and investigator
- MREC letter of approval (dated 29/03/00)
- North Thames RHA application for regional R&D funding
- Patient information sheet and consent form
- Carer’s information sheet and consent form
- Local Investigator’s CV – Lene Marie Thorgrimsen
- Questionnaire: Details of Specialist Accommodation Facilities
- Memory Tests
Please note that the following general conditions of approval apply:

- Investigators must ensure that all associated staff, including nursing staff, are informed of research projects and are told that they have the approval of the Local Research Ethics Committee.

- If data are to be stored on a computer in such a way as to make it possible to identify individuals then the project must be registered under the Data Protection Act 1984. Please consult your department data protection officer for advice.

- The Committee must receive immediate notification of any adverse event or unforeseen circumstances arising out of the trial.

- The Committee must receive notification: (a) when the study is complete; (b) if it fails to start or is abandoned; (c) if the investigator/s change; and (d) if any amendments to the study are proposed or made.

- The Committee will request details of the progress of the research project periodically (i.e. annually) and require a copy of the report on completion of the project.

Please forward any additional information/amendments regarding your study to the Ethics Committee Administrator or myself, at the above address. If you have any queries, please do not hesitate to contact Michael Peat at the research office.

Yours sincerely

Stephanie Ellis
CHAIR

cc. Dr S Evans, Chairman of Anglia and Oxford MREC, Cambridgeshire Health Authority
EVIDENCE BASED PSYCHOLOGICAL THERAPY PACKAGE FOR
PEOPLE WITH MEMORY PROBLEMS.

Information Sheet

This project looks at the effects of activity groups for people with memory problems. It takes place in a number of day centres and residential homes in London and the South-East area, hoping to find out which things help older people cope with memory problems. We would like to invite you to participate in our project.

Taking part would involve being interviewed for about 45 minutes, using standard forms. Some people would then be allocated to the groups, which will involve attending two 45-minute sessions per week for 7 weeks. Other people will not be involved in the groups, and will continue with normal activities during these times. Allocation to the groups will be entirely random. The groups will be interesting and varied, involving discussion, games, quizzes, cookery etc. They should be enjoyable and will usually involve people you know. The aim of the groups is to help memory and for us to learn what works best. No medication is involved, therefore it is very unlikely that there will be any side effects. However, very occasionally people may feel slightly frustrated or distressed by some of the activities if they have difficulty with them, and this may last for a few minutes. After 7 weeks, we will talk to you again. Eventually, we hope to train staff working with people with memory problems, so that they can also run groups like these, to help people to have more stimulating and varied lives. By taking part in this important study, you will be helping numerous other people in the future, as we hope that this project will influence health and social services to provide the care, support and stimulation needed by people like yourselves.

Taking part is your choice, and if you do not it will not affect your treatment in any way. You can leave the project at any time, without having to explain why. Information obtained from your interviews is confidential, your name will remain anonymous to all involved, and the outcome of the interviews will not affect you in any way. If you have any concerns or questions about this research, please contact Aimee Spector or Lene Thorgrimsen.

Contacts: Lene Thorgrimsen – Tel. 0797-4728538
Aimee Spector - Tel. 0958-993973
EVIDENCE BASED PSYCHOLOGICAL THERAPY PACKAGE FOR PEOPLE WITH MEMORY PROBLEMS.

Patient Consent Form

(1) I know that the trial is designed to help the care of older people. I am aware that I may withdraw my consent at any stage, without having to explain why, and that any information obtained from me will remain entirely confidential. I know that my participation in/withdrawal from this project will not affect my usual treatment in any way.

I had a written explanation about this research (attached to this form). Any questions have been answered for me by Aimee Spector or Lene Thorgrimsen.

I agree/do not agree to participate in the project.

Signed: ............................................................... Date: ..............................................

(2) WITNESS (a member of staff from the Centre) to signature of participant, and to the fact that (s)he has read the supporting document and freely given her/his consent.

Signed: ............................................................... Date: ..............................................

(3) I (member of project team) confirm that I have explained to the participant the nature and effects of the trial.

Signed: ............................................................... Date: ..............................................
A Validation Study of the Quality Of Life –Alzheimer’s Disease scale.

- Does it measure what it is supposed to?

INFORMATION SHEET

You are being invited to take part in a research study. Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to read this information carefully and discuss it with friends, relatives, and your GP if you wish. Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

Having dementia has a great effect on people’s lives, and our capacity to help improve the wellbeing of the person is important. One way to find out whether or not we are successful in doing so, is using a scale in an interview. This means asking people questions about them and their lives. However, wellbeing, or quality of life as it is also called, is something which is difficult to measure like this, and that is why we are now trying to test such a scale, to make sure that it measures what it is supposed to.

You have been suggested to us as someone who has dementia, and who might be willing to spare some time to help us conduct this research. It is up to you to decide...
whether or not to take part. If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form. You will still be free to withdraw at any time and without giving a reason. This will not affect the care you receive.

If you choose to take part, you will be interviewed for about 45 minutes by one researcher. This will involve answering some questions about yourself, your life, and how you are feeling. You will not have to answer anything you do not want to. The questions that we are going to ask you and everything we do in this study has been found to be acceptable by the Ethics Committee in Barking & Havering.

All information which is collected about you during the course of the research will be kept strictly confidential, and it will have your name and address removed so that you cannot be recognised from it.

If you have any questions or need some more information, please contact:

Lene Thorgrimsen
UCL (University College London)
Department of Psychiatry & Behavioural Sciences
Wolfson Building, 48 Riding House Street, London, W1N 8AA
Tel: 020 7679 9587 - Fax: 020 7679 9426 - Mob: 07974 728 538

Thank you very much for taking the time to read this, and for considering taking part in this research.
CONSENT FORM
14.12.00 - Version 1

Title of Project: A Validation Study of the Quality Of Life – Alzheimer’s Disease scale.

Name of Researcher:

1. I confirm that I have read and understand the information sheet dated 14.12.00 for the above study and have had the opportunity to ask questions.

2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my medical care or legal rights being affected.

3. I agree to take part in the above study.

Name of Patient Date Signature

Name of Person taking consent (if different from researcher)

Name of Person Date Signature

Researcher Date Signature
Dear Colleague,

RE: A Validation Study of the Quality Of Life – Alzheimer’s Disease scale.

INFORMATION SHEET

The process of dementia affects a wide range of cognitive and functional abilities, and the capacity to improve the well being of the sufferer is far greater than the capacity to affect the course of the disease. There is also increasing recognition that assessment scales such as those of cognition or behaviour might not be only significant measures of change, and that QoL might be a more useful guide to potential benefits. Thus, there is increasing emphasis on including a measure of quality of life (QoL) when evaluating interventions with people with dementia.

QoL assessments comprise a highly complex procedure of introspection and evaluation, involving several components of cognition, and so it is difficult to measure and validate QoL with people with dementia. Research has shown that the effects of therapeutic interventions to improve QoL in any condition is best measured with sensitivity by disease-specific instruments that focus on the domains most relevant to the disease under investigation and have an increased likelihood of capturing change over time. However, dementia-specific QoL scales have only recently begun to be developed, and to date few of them have been sufficiently validated. One such scale, the Quality of Life – Alzheimer’s Disease by Logsdon et al. (1998; enclosed) has the advantage of being brief and incorporating both client and proxy ratings. Early studies by Logsdon et al. (1999) suggest it to have good internal consistency and reliability, but further validation is needed. This is the aim of the present study.

The QOL-AD and the enclosed questionnaire have been sent out to 100 health professionals in Camden & Islington and Barking & Havering. It would be a great help if you could spare the time to look at the QOL-AD Scale, and complete the questionnaire.

This study has been approved by Barking & Havering Local Research Ethics Committee. All information provided by you is anonymous and confidential.

If you have any questions or want some more information, please contact me on the above address.

Thank you very much.

Yours sincerely,

Len Thorgrimsen
Research Psychologist

Dr Martin Orrell
Reader/ Hon. Consultant in Old Age Psychiatry

UCL Institute of Child Health
30 Guilford Street, London WC1N 1EH
Tel: +44 (0) 20 7679 9587 / 07974 728 538

Head: Professor Stanton Newman

14.12.00 - Version 4
Please read through the scale below, and make your comments on the next two pages.

<table>
<thead>
<tr>
<th>Subject Number</th>
<th>Assessment Number</th>
<th>Interview Date</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Interviewer administer according to standard instructions. Circle responses.

1. Physical health. | Poor | Fair | Good | Excellent
2. Energy. | Poor | Fair | Good | Excellent
3. Mood. | Poor | Fair | Good | Excellent
4. Living situation. | Poor | Fair | Good | Excellent
5. Memory. | Poor | Fair | Good | Excellent
6. Family. | Poor | Fair | Good | Excellent
7. Marriage. | Poor | Fair | Good | Excellent
8. Friends. | Poor | Fair | Good | Excellent
9. Self as a whole. | Poor | Fair | Good | Excellent
10. Ability to do chores around the house. | Poor | Fair | Good | Excellent
11. Ability to do things for fun. | Poor | Fair | Good | Excellent
12. Money. | Poor | Fair | Good | Excellent
13. Life as a whole. | Poor | Fair | Good | Excellent

Now please turn to page two to make your comments.
# QOL-AD Questionnaire

Please circle the responses most representative of your thoughts about this scale.

<table>
<thead>
<tr>
<th>1. Physical health.</th>
<th>Not important</th>
<th>Not very important</th>
<th>Important</th>
<th>Very important</th>
<th>Essential</th>
</tr>
</thead>
<tbody>
<tr>
<td>2. Energy.</td>
<td>Not important</td>
<td>Not very important</td>
<td>Important</td>
<td>Very important</td>
<td>Essential</td>
</tr>
<tr>
<td>3. Mood.</td>
<td>Not important</td>
<td>Not very important</td>
<td>Important</td>
<td>Very important</td>
<td>Essential</td>
</tr>
<tr>
<td>4. Living situation.</td>
<td>Not important</td>
<td>Not very important</td>
<td>Important</td>
<td>Very important</td>
<td>Essential</td>
</tr>
<tr>
<td>5. Memory.</td>
<td>Not important</td>
<td>Not very important</td>
<td>Important</td>
<td>Very important</td>
<td>Essential</td>
</tr>
<tr>
<td>6. Family.</td>
<td>Not important</td>
<td>Not very important</td>
<td>Important</td>
<td>Very important</td>
<td>Essential</td>
</tr>
<tr>
<td>7. Marriage.</td>
<td>Not important</td>
<td>Not very important</td>
<td>Important</td>
<td>Very important</td>
<td>Essential</td>
</tr>
<tr>
<td>8. Friends.</td>
<td>Not important</td>
<td>Not very important</td>
<td>Important</td>
<td>Very important</td>
<td>Essential</td>
</tr>
<tr>
<td>9. Self as a whole.</td>
<td>Not important</td>
<td>Not very important</td>
<td>Important</td>
<td>Very important</td>
<td>Essential</td>
</tr>
<tr>
<td>10. Ability to do chores around the house.</td>
<td>Not important</td>
<td>Not very important</td>
<td>Important</td>
<td>Very important</td>
<td>Essential</td>
</tr>
<tr>
<td>1. Ability to do things for fun.</td>
<td>Not important</td>
<td>Not very important</td>
<td>Important</td>
<td>Very important</td>
<td>Essential</td>
</tr>
<tr>
<td>2. Money.</td>
<td>Not important</td>
<td>Not very important</td>
<td>Important</td>
<td>Very important</td>
<td>Essential</td>
</tr>
<tr>
<td>3. Life as a whole.</td>
<td>Not important</td>
<td>Not very important</td>
<td>Important</td>
<td>Very important</td>
<td>Essential</td>
</tr>
</tbody>
</table>
(1) Do you think this scale covers all the important domains in a dementia sufferer's life?  
YES  NO
If no, please expand. (please tick)

(2) Do you think any of the items not relevant for the quality of life for a person with dementia?
YES  NO
If yes, please expand. (please tick)

(3) Do you have any additional comments about the scale?

THANK YOU.
Exclusion criteria

Does this person show any signs of confusion/dementia?

YES

This person is appropriate for screening.

NO

Can this person have a meaningful conversation?

YES

Can this person hear well enough to participate in a small group discussion?

YES

Is this person likely to come into a room and answer questions for 45 minutes?

YES

This person is likely to remain in a small group for 45 minutes without wandering?

YES

This person is appropriate for screening.

NO

This person is not appropriate for this project.

NO

Does this person have any other mental illness/handicap, e.g. a Learning Disability or major depression?

NO

This person is appropriate for screening.

YES

Can this person have a meaningful conversation?

NO

This person is not appropriate for this project.
Appendix E:

Economic Evaluation
ECONOMIC EVALUATION OF AN EVIDENCE-BASED
PSYCHOLOGICAL GROUP THERAPY PROGRAMME FOR PEOPLE
WITH DEMENTIA

INTRODUCTION

Health Economics

Resources for health care are almost always scarce relative to needs or wants. It is this recognition that signals a need for a thorough examination of how these resources are being used. While QoL is one element informing health economic decisions about the allocation of scarce recourses, cost and effectiveness are others. QoL is linked to the field of health economics through the direct involvement of QoL in cost-utility studies, where the utility weights commonly are represented in QALYs, as discussed above. QoL is also linked to health economic evaluations through being increasingly perceived as a meaningful measure of effectiveness when evaluating therapeutic interventions. Some arguments have been put forward in relation to allocation of resources, which emphasises utilising these to the greatest good of society, focusing on quantity of life rather than quality. In Denmark for example, out of 50,000 deaths a year, only 20,000 are of people between the ages of 1 and 70, and Gold et al. (1996) has argued that these are the deaths that count, thus society should aim the allocation of resources at preventing these deaths. It follows from his argument that older people with health problems, such as dementia, should not receive resources for prevention and treatment. Luckily, these kind of arguments are not currently in favour, although they might still be reflecting an attitude among
certain clinicians, who for example might prefer recommending cataract operations to people without dementia.

**Economic evaluations in health care**

The inclusion of cost-information in needs-based planning, devolving budgets to case managers, preparing community care plans, examining the consequences of care programmes, and bidding for grants, are all recent phenomenon. Demands for high quality cost data are a result of a perceived need for evaluations of both outcomes and the resource implications of new and different policies and practices, calculations of the social costs of health problems, pricing of available services for clients and relatives or public decision makers, and performance reviews of the spending of public money (Beecham & Knapp, 1992). Economic analyses can be at a macro level, which are investigations into how health care systems operate, effects of different funding arrangements, or at a micro level, which include resource implications of new drug treatments and cost-effectiveness of new ways of delivering care.

There are a number of different tools available when conducting these latter analyses. One such tool is cost-benefit analysis, which assign a monetary value to the benefit of an intervention and compare this with the costs of the intervention. Thus, the extent to which a treatment or policy is socially worthwhile is addressed with all costs and benefits involved valued in the same monetary units, allowing a total cost to be calculated. In contrast, cost-effectiveness analysis is an approach that is concerned with the measurement of ‘natural units’, such as improvement of
cognition or QoL, which are compared to the monetary costs of an intervention. Costs are here more narrowly defined than those of a cost-benefit analysis, and thus dealing with more than one output can be difficult, for which a cost-consequence analysis can be used. However, cost-effectiveness analysis has the advantage of being deterministic. Cost-utility analysis is an approach that relates the costs of an intervention to a measure of its usefulness, which is based on an index of health status in relation to output, such as QALYs (discussed in paragraph 1.2.1.4 - Generic quality of life scales of this chapter). Hence, this method can be used to compare the efficiency of interventions across different disorders, but this does entail difficulties, particularly in relation to equity issues. Lastly, there are cost-of-illness studies, which are descriptive rather than evaluative, and cannot be used for setting priorities.

The most frequently measured economic consequences of illness are the costs of the health services used. Others include effects on a range of non-health professionals' time and organisations, such as social care, education, and criminal justice (Karlsson et al., 1998). The effects of illness also impose other costs on society, including lost employment and reduced productivity. These long-term costs might, however, be difficult to calculate. This also applies to a range of costs usually borne by the sufferer and her/his family. These include caregiver time and effort, and also out-of-pocket expenses like travel, prescription charges, and loss of earnings (Koopmanschap & Brouwer, 1998).
Evaluation issues

When conducting an economic evaluation of a healthcare intervention, there are several design issues that have to be considered. One is the selection of alternative intervention(s) to use as comparator(s). The intervention in question could be compared to no intervention, a placebo, treatment as usual, or to best current treatment and care. Another decision to be made relates to the perspective of the study. It can consider costs to the individual, costs to one provider of care, costs to the health service, or costs to society in general. Economists typically argue that evaluations should be conducted from a broad, societal viewpoint rather than just a health service or public purse perspective, and thus the findings might help to encourage decision makers to take a broad view of costs and consequences beyond their own budget (Drummond, 1998), but this might not always be plausible or attractive to individual budget holders. For example, reductions in admissions to long term care as a result of use of anti-dementia drugs would reduce social services costs, but increase costs of health care through prescribing and monitoring costs.

Economic evaluations can either be conducted retrospectively, using the published results from clinical trials, or prospectively alongside a clinical trial, which has the advantage of collecting data on cost and efficacy on the same patients. Additionally, when performing economic analyses of long-term costs, the level of 'discounting' used must be decided upon. This is based on the principle that as individuals and as a society we have a positive rate of time preference, that is we prefer benefits sooner rather than later and prefer also to postpone costs (Drummond, 1998). Other issues faced when conducting economic evaluations relate to issues of differential
preferences for outcomes between groups of service users and the different equity criteria embodied in the various economic analyses (Drummond et al., 2000).

**Methodological issues faced when conducting economic evaluations in dementia**

With age-specific prevalence rates for AD and cognitive impairment and other disabilities that are seemingly consistent over time (O'Brien et al., 2000), the numbers of people with dementia will "outpace the increase in the elderly population as a whole" (Melzer et al., 1991). As the challenge of providing care for people with dementia continues to grow, due also to other trends in demography, labour force participation, geographical mobility, and family patterns, the demands for long-term care services are likely to increase. However, the consequences of these demands on the financial and labour forces could be difficult to meet, as the proportion of working adults relative to the retired population is falling (Knapp et al., 1998). How this challenge is going to be met, warrants investigation.

As described above, there are important methodological challenges to consider when conducting an economic evaluation of any intervention, including the choice regarding the type and perspective of the study. When conducting an economic evaluation of an intervention for people with dementia, there are additional issues in need of consideration. For example, informal care is one of the most important resources in dementia care (Karlsson et al., 1998), and difficulties arise when considering: how to include this in the equation; how to put a monetary value on caregivers' time and use of emotional resources; and how to include the negative and positive consequences for the carer into the evaluations (McDaid, 2001). This is
further accentuated by the fact that the majority of informal care is provided by female relatives, and this demanding task is associated with high degrees of morbidity (Donaldson et al., 1997). However, female carers are likely to have a relatively lower income than men (if any), and society's expectations may be signalling to them that caring is their responsibility, and hence they should be able to cope with it. The personal cost to these women is largely unknown. Even so, this traditional care pattern is changing. The shrinking ratio of women in middle age to elderly people represents a significant decline in the ‘daughter care potential’, which is amplified by the fact that the proportion of women in paid employment is increasing (Pickard, 2000). Another rarely quantified cost is the input from the voluntary sector, upon which some proportion of dementia care relies. This might also be a changing pattern. As we increasingly become a society of individualists, the notion of providing our services for free might become increasingly alien to us. These issues imply greater societal costs for the future treatment of dementia.

With conducting economic evaluations of dementia, problems emerge when comparing a new intervention with current services that are often inadequate. One example is the cost of diagnostic procedures. Historically, giving a diagnosis of dementia without any significant options available for treatment, has not always been prioritised. Recent years have seen the introduction of new medications for AD. However, the medication currently available is effective only for some people in the mild or moderate stages of AD. Thus, additional resources are needed to ensure early detection and appropriate referrals for assessment. Additionally, most referrals are made for people living at home, and many cognitively impaired people living in
institutional care may not have been given a formal diagnosis of dementia. Thus new treatment programmes for dementia have imposed higher diagnostic and monitoring costs, and have led to an influx of referrals, often with mild symptoms and little functional impairment, who would not otherwise have entered the health care system.

The costs of dementia

Many cost of illness studies have been carried out within the field of dementia. Lowin et al. (2001) found in their literature search of cost of illness studies conducted the direct gross annual cost of AD in the UK today to lie somewhere between £7 billion and £15 billion. This was significantly greater than the costs arising from stroke (£3.2 billion), heart disease (£4.05 billion), and cancer (£1.6 billion excluding informal care costs). In one American study the full cost of AD was estimated at around $67 billion, 31% of which were direct care costs, 49% unpaid caregiver costs, and 20% the value of lost productivity due to illness and premature mortality (Ernst & Hay, 1997). Equivalent exercises for other countries have reached similar conclusions in relation to the significant proportional size of caregiver and family contributions, generally between 1.4 and 3 times the costs of formal care services (Knapp et al., 1998). Kavanagh et al. (1995) looked at the component and total costs for England in 1992/93, totalling £5 billion, and projected the cost consequences of a number of alternative policy scenarios such as: greater emphasis on home-based care; greater availability of respite services; and quality improvements in residential care settings. Kavanagh and Knapp (2002) also found in their analyses of data from the UK Office of Population Censuses and Surveys’ disability surveys significant associations between costs and gender, living alone,
continence, severity of some aspects of physical disability, and mental disability. Ernst et al. (1997) reported that preventing a two-point decline on the Mini Mental State Examination (MMSE; Folstein et al., 1975) scale among older people with moderate to severe dementia living at home could annually save US$3700 per patient each year. Thus, Kavanagh and Knapp (2002) have concluded that treatment interventions or preventative measures delaying the rate of cognitive decline have the potential to significantly reduce the costs of supporting people with dementia, particularly if admission to nursing home or inpatient care can be postponed. Other studies looking into patterns of care have found that people with dementia living with others use more respite care, sitting services, nursing care, and general health care (Knapp & Wigglesworth, 1998). Possible explanations for this might be that people living with others generally may have higher levels of confusion (Schneider et al., 1993), or that caregivers act as advocates or are better informed about which services are available (Knapp & Wigglesworth, 1998). The latter explanation may indicate unmet needs among people with dementia living on their own, which ought to be identified and met. Some evidence for this has been found in the literature (Martin et al., 2002).

When conducting cost-of-illness studies, such as those described above, cost in these economical terms means opportunity cost, which is 'the highest value forsaken' when a given event or productive activity takes place (Alchian, 1968). The opportunity cost of dementia is thus the value of all alternative goods and services that could have been produced by these resources if the illness did not exist. This is the 'economic burden' of dementia. However, this issue is not straightforward.
Weinstein (1997) has argued that if dementia did not exist, people would be unlikely to remain healthy until the end of their life. These people, who otherwise would have dementia, might contract other illnesses and disorders, such as heart disease, cancer, emphysema or stroke. Thus the cost of caring for these disorders should be subtracted from the cost of dementia, and if these costs are greater, the cost of dementia to society might even be negative, a saving of resources. This concept might be difficult for some of us to grasp. However, in their analyses, Kavanagh and Knapp (2002) found the link between costs and cognitive disability to be sensitive to the inclusion or exclusion of behavioural disability, and as such highlight the danger of relying exclusively on cognitive outcome measures when evaluating costs of interventions for dementia. As such, using more holistic measures, such as those of QoL, might be more meaningful.

**Economic evaluations in dementia**

When conducting an economic evaluation of one or more interventions for dementia, the question of what outcome measure or measures to use must be addressed. Traditionally the focus has been on cognitive measures (as described above), but there is now growing recognition of the need for more holistic measures. Dementia is a multidimensional disorder, and as such measures of aspects such as the person's level of dependency and need for care, prevention of disease progression, extension of disability-free life expectancy, delay of institutionalisation, decrease of caregiver burden, and increase in QoL need to be incorporated (Witthaus, 1998). Additionally, economic analyses need to be conducted in such a way to allow international
Relatively few economic studies on dementia have included outcome indicators, and few clinical studies have built an economics dimension into their design. Most economic evaluations conducted have been of medication for AD. One example is a cost-effectiveness analysis conducted by Neumann et al. (1997), which aimed to estimate the incremental cost per QALY gained for people with mild to moderate AD using donepezil. Their results, although inconclusive about the effects of the medication in question, suggested that patient values were sensitive to AD stages and settings of care, whilst caregiver values were not. One of the few published economic evaluations of dementia care compared home care, group or sheltered living, and institutionalisation (Wimo et al., 1995). The researchers used patients’ scores on the Geriatric Depression Scale (GDS; Yesavage et al., 1983), which were converted into an ‘Index of Well-Being’ rating and used to estimate QALYs in a one-year and multiyear cost-effectiveness analysis. In the one-year analysis the home care was found to have the lowest cost and the largest number of QALYs per case, and in the multiyear analysis the group living was found to be the more cost-effective living arrangement. However, the method used to estimate well-being, or QoL, was not a standardised method, and QoL encompasses much more than what is covered by the GDS, which in any case is only suitable for those with mild to moderate cognitive impairment. Wimo et al. (1994) also compared the costs of dementia care in different care alternatives with decline in cognitive function and activities of daily living (ADL) skills and behavioural difficulties. They found that
the costs remained the same in group living arrangements as cognition declined, but increased considerably in home care and day care groups, parallel to declining cognitive abilities. In the UK, Beecham et al. (1993) found that costs of a Domus care unit with residents with dementia were higher than the costs of private and voluntary nursing homes. Volicer et al. (1994) found in their study that the annual costs for medication, radiology, laboratory service and treatment for residents with dementia in special care units was US$1477 lower than in traditional nursing homes. These authors did not, however, measure the basic costs of care. In Australia, Brodaty et al. (1991) evaluated a training programme for carers for people with dementia, and concluded that the programme resulted in an annual saving of US$2160 per case. In contrast, Weinberger et al. (1993) found in a longitudinal randomised controlled trial that a social intervention programme (consisting of extensive contact between social workers and families of people with dementia to develop an individualised service plan) was no cheaper than usual care. Drummond et al. (1992) found in a randomised cost utility analysis of a support programme for caregivers for people with dementia, consisting of caregiver support nurses helping caregivers enhance their competence and coping capacity, that the incremental cost per QALY gained was about US$17,000. With a few exceptions, as those noted above, randomised controlled trials with economic evaluations within the field of dementia are rare. Often different care alternatives are compared, but allocations to the different alternatives are not often made randomly. Similarly, longitudinal studies of different aspects of dementia care are difficult to conduct, but sorely needed. Particularly important are prospective studies with a well-designed economical evaluation and key outcome variables.
Services for people with dementia have not traditionally been prioritised to the extent of younger adults' and children's acute hospital services (Keen, 1993). Thus, the comparable value of the services currently provided for people with dementia is not clear. Currently there is far less evidence on cost and effectiveness of services for people with dementia than for elderly people in general (Keen, 1993). However, if these services are to be developed, evidence-based arguments have to be put forward for diverting scarce resources from elsewhere.

**METHOD**

**Design**

**Recruitment of centres**

Various health authorities and organisations were contacted by mail, and letters of support received. Approval was then sought and obtained from the Multi-Research Ethics Committee and Local Research Ethics Committees for the relevant areas (Appendix D). Addresses for possible centres were obtained from social services, or the central body of the organisation. These were sent: (a) an introductionary letter providing D); (b) a copy of the information sheet and consent form (Appendix D); and (c) for the second half of the study, a copy of the inclusion flow chart (Appendix D). This was then followed up with a phone call to the manager of the day centre (DC) or residential home (RH) within a week, inquiring about interest in participating in the project and suitability of the centre, and providing any additional information required. If appropriate, a meeting was arranged with the manager.
Selection of participants

Inclusion criteria: (1) Meeting the DSM-IV (APA, 1994) criteria for dementia; (2) Scoring between 10 and 24 on the Mini Mental State Examination (MMSE; Folstein et al., 1975); (3) Some ability to communicate and understand communication, which was determined by a score of 1 or 0 in questions 12 and 13 of the CAPE Behaviour Rating Scale (Pattie and Gillette, 1979); (4) Being able to see and hear well enough to participate in a meaningful assessment; (5) Not displaying behaviour that would make interview impossible, such as constant wandering, shouting, or aggression; and (6) Not having a diagnosis of learning disability or current clinical depression, which would also make reliable assessment difficult. In the meeting with the manager of the centre, the inclusion flow chart was used to select possible participants, who were then approached by their key worker with information about the project (Appendix D), and their relatives were contacted to ensure their approval of their relative being included in the project. In DCs, the informed consent of the relative was also sought. Subsequently, possible participants were screened, using the MMSE. Before screening, informed consent was obtained in conjunction with the person's key worker. A day was then agreed upon to conduct the full assessments.

Assessment procedure

Informed consent was obtained on the day of the full assessment, and an interview was subsequently conducted, lasting approximately 45 minutes. This included the QOL-AD (Logsdon et al., 1999), the MMSE (Folstein et al., 1975) and the Alzheimer's Disease Assessment Scale - Cognition (ADAS-Cog; Rosen et al., 1984). The person’s key worker completed the Clifton Assessment Procedures for
the Elderly - Behaviour Rating Scale (CAPE-BRS; Pattie & Gilloard, 1979) and the Holden Communication Scale (Holden & Woods, 1995) individually, and the Cornell Scale for Depression in Dementia (CSDD; Alexopoulos et al., 1988) and the Rating Anxiety in Dementia (RAID; Shankar et al., 1999) in conjunction with the researcher. The Clinical Dementia Rating (CDR; Hughes et al., 1982) was completed by the researcher on the basis of the information obtained from the above scales. For DCs, an interview was additionally arranged with the participant’s informal carer or closest relative, where the QOL-AD was completed. Assessments were repeated 8 weeks after the initial assessment.

As part of this assessment procedure, the Client Service Receipt Inventory (CSRI; Beecham and Knapp, 1992) was completed by the manager of the centres (or the person’s closest relative if living in the community), pre and post intervention. This meant that it was 8 weeks separating baseline and follow-up data collection.

**Randomisation**

This was done by the researcher blind to the outcomes of the assessment, by drawing sealed envelopes containing participants’ names from a container, allocating 5 to the experimental group and a minimum of 3 to the control group. Group allocation was not disclosed to the researcher doing the follow-up assessments, or the manager completing the CSRI.
**Intervention**

**Procedure**

The groups commenced on the week subsequent to the baseline assessment being completed. They ran for 7 weeks, twice weekly for 45 minutes, in the same room at the same times. The group each consisted of the five participants randomly allocated to the experimental group, the researcher blind to assessment outcomes, and the same member of the care staff team in the DC or RH where the group was conducted.

**Development of programme**

Two Cochrane systematic reviews were conducted (Spector et al, 1998a, Spector et al., 1998b) on reality orientation and reminiscence therapy for dementia. The elements found to be effective in the trials included in these review were identified, and were used to develop a programme of evidence-based psychological group therapy (Spector et al, 2001). This was piloted in three residential care homes and one day centre and there were appreciable improvements in cognition and depression for people participating in the programme compared to a no-treatment control group (Spector et al., 2001).

**Group programme**

Group sessions included a reality orientation board to provide a focus, reminding people of the name and nature of the group, and creating continuity. All sessions began with a gentle, non-cognitive exercise, aiming to provide continuity and orientation by beginning all sessions in the same way. The sessions focused on themes (such as childhood and food), allowing the natural process of reminiscence
but with an additional focus on the current day. Multi-sensory stimulation was introduced when possible. Sessions encouraged the use of information processing and the use of implicit memory rather than factual knowledge and explicit memory. A choice of activities was given for each session, enabling the facilitator to adapt the session according to the group’s abilities, interests and gender mix.

**Sessions:**

1) Introduction
2) Sound
3) Early memories
4) Food
5) Current affairs
6) Faces / scenes
7) Associated words/discussion
8) Categorising objects
9) Orientation
10) Using money
11) Number-related activity
12) Word-related activity
13) Using objects
14) End of programme activity

**Diagnostic criteria**

*DSM-IV.* As described in Chapter 2 - 2.2.1 Diagnostic criteria.
Outcome measures

A) **Client Service Receipt Inventory:** The instruments used to measure cost were two versions of the Client Service Receipt Inventory (CSRI; Beecham and Knapp, 1992), adapted for this study by Martin Knapp and Angela Hallam from London School of Economics and Political Science. One of the measures is aimed at people living in residential homes, and requests information about the service user's background, and details about their accommodation, medication profile, what informal care support they receive, and the formal services they use. The other measure is appropriate for people attending day centres/hospitals, and include in addition to the above the carer's background, accommodation details, and income. The CSRI was developed as an easily adaptable instrument for the Personal Social Services Research Unit's evaluation of the Department of Health's Care in the Community demonstration programme running from 1984 to 1988 (Renshaw et al., 1988) for a mainly adult client group. This instrument has also been used in many other evaluation studies, such as of community living for people with schizophrenia (Melzer et al., 1991), of community psychiatric nursing (McCrone et al., 1992), and has recently formed the basis for the development of the Client Socio-Demographic and Service Receipt Inventory – European Version (Chisholm et al., 2000).

*Quality of Life – Alzheimer's Disease (QOL-AD; Logsdon et al., 1999).*

As described in Chapter 2 – 2.2.1 Measures.
Unit costs

All unit costs were estimated so as to be nationally generalisable, and were collected and calculated with help from Angela Hallam, Researcher at the Centre for the Economics, Institute of Psychiatry.

Accommodation and living expenses costs information

The costs in sections on domestic accommodation and running costs for domestic households are taken from previous calculations made in 1998-99. These have been uprated using relevant inflation indices (Netten, Rees and Harrison, 2001) as in Table 22.

Domestic accommodation (capital costs)

<table>
<thead>
<tr>
<th></th>
<th>Owner-occupied or privately rented</th>
<th>Weekly cost</th>
<th>Local authority</th>
<th>Weekly cost</th>
</tr>
</thead>
<tbody>
<tr>
<td>Flat/maisonette</td>
<td>£104,549</td>
<td>£162.00</td>
<td>£56,457</td>
<td>£87.48</td>
</tr>
</tbody>
</table>

Owner-occupied property valuations were taken from Halifax House Price Index for the fourth quarter of 1998 and uprated to 2000-01 price levels.

For local authority rented property, a discount rate of 49 per cent was assumed (Housing and Construction Statistics, 1998). The percentage difference between the average prices of property mortgaged to local authority sitting tenants (plus 51 per cent) and other first time purchasers during one year was calculated (Housing and Construction Statistics, 1987-97) and this percentage removed to arrive at local
authority property prices. Prices were annuitised over a 60 year period at an 8 per cent discount rate. The weekly cost for local authority property includes management and maintenance costs at £33 per household per week (Housing Revenue Account Statistics 1998). The inflation index used was the Building Cost Information Service (multiplier = 1.11).

Running costs for domestic households (capital elements excluded).

Household expenditure information was taken from the Family Expenditure Survey (FES). The average amount for one adult, retired, dependent on state pension, was used: £75.50 per week. It is possible that expenditure per person might be lower in households where the service user was not the only occupant, but this amount ensures that costs are not under-estimated. The inflation index used was the Retail Price Index (multiplier = 1.04).

Specialised accommodation arrangements.

<table>
<thead>
<tr>
<th>Accommodation category</th>
<th>Schema reference</th>
<th>Capital, staffing and revenue costs</th>
<th>Personal living expenses</th>
<th>Total cost per week</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sheltered housing (housing association)</td>
<td>1.8</td>
<td>£184</td>
<td>£82</td>
<td>£266</td>
</tr>
<tr>
<td>Residential home (private organisation)</td>
<td>1.2</td>
<td>£367</td>
<td>£8</td>
<td>£375</td>
</tr>
</tbody>
</table>

Costs are taken from Netten et al. (2001), as shown in Table 23.
Service unit costs information

All costs are quoted at 2000-01 price levels. Schema references relate to Netten et al. (2001).

Hospital services

Assessment/rehabilitation ward

£172 per inpatient day (London multiplier = 1.121)

(Acute NHS hospital services for people with mental health problems – Schema 2.6)

Continuing care/respite ward

£163 per inpatient day (London multiplier = 1.121)

(Elderly people with mental health problems – Schema 6.1)

Medical ward

£271 per inpatient day (London multiplier = 1.121)

(Generic – Schema 6.1)

Other hospital ward

£271 per inpatient day (London multiplier = 1.121)

(Generic – Schema 6.1)

Outpatient services

£154 per attendance (London multiplier = 1.121)

(Elderly people with mental health problems – Schema 6.1)

Day treatment

£92 per day attendance (London multiplier = 1.121)

(Elderly people with mental health problems – Schema 6.1)
**Accident and emergency**

£68 per attendance (London multiplier = 1.121)

(Accident and emergency – Schema 6.1)

**Day care services**

**Local authority day services**

£62 per day (London multiplier = 1.47)

(Local authority day care for elderly people – Schema 1.5)

**Voluntary organisation day services**

£40 per day (London multiplier = 1.47)

(Voluntary day care for elderly people – Schema 1.6)

**NHS day care**

£92 per day (London multiplier = 1.121)

(Day hospital attendance for elderly people with mental health problems – Schema 6.1)

**Lunch club**

£15 per attendance (London multiplier = 1.47)

(Voluntary day care for elderly people – Schema 1.6. 33% of day cost plus cost of meal)

**Social club**

£13 per attendance (London multiplier = 1.47)

(Voluntary day care for elderly people – Schema 1.6. 33% of day cost)
Travel to day services

£2 each way travel costs were assumed, with one hour of the cost of a care attendant where the service user was accompanied on the journey. If transport was arranged by the day service, provision of a minibus was assumed and eight people sharing the same vehicle.

Community-based services

Unless otherwise stated, the cost of domiciliary visits has been estimated assuming 20 minutes at client contact rates, 20 minutes travel time and £1.10 travel costs.

Community psychiatrist

£4.46 per minute, face to face contact, office visit (London multiplier = 1.11)

£111.55 per domiciliary visit.

(Hospital-based psychiatric consultant – Schema 13.6, salary and payroll on costs.
NHS clinical psychiatry team member – Schema 10.3, overheads and capital costs)

Community psychologist

£1.20 per minute, face to face contact, office visit (London multiplier = 1.12)

£32.18 per domiciliary visit.

(Clinical psychologist – Schema 7.5)

General practitioner

£16.80 per surgery consultation (London multiplier = 1.12)

£66.08 per domiciliary visit. Includes 12 minutes’ travel time and a 13.2 minute consultation.

(General practitioner unit costs – Schema 8.7b)
District nurse
£0.80 per minute in clinic (London multiplier = 1.12)
£24.93 per domiciliary visit
(District nurse – Schema 8.1)

Community psychiatric nurse
£1.12 per minute, face to face contact, clinic consultation (London multiplier = 1.14)
£31.50 per domiciliary visit
(Community psychiatric nurse – Schema 8.2)

Social worker/care manager
£1.65 per minute, face to face contact, office consultation (London multiplier = 1.14)
£40.96 per domiciliary visit
(Social worker, adult – Schema 9.2.)

Occupational therapist
£0.73 per minute, face to face contact, office consultation (London multiplier = 1.1)
£23.37 per domiciliary visit
(Community occupational therapist – local authority – Schema 9.7)

Home care worker/bathing service
£12 per hour (London multiplier = 1.1). This does not reflect unsocial hours.
(Local authority home care worker – Schema 9.5)

Care attendant/sitting service/laundry service
£9 per hour (London multiplier = 1.1). This does not reflect unsocial hours.
(Prices of independently provided personal home care – Schema 9.6)

Physiotherapist
£0.68 per minute of client contact, clinic consultation (London multiplier = 1.12)
£24.11 per domiciliary visit (travel costs estimated at £2.11 per visit, based on expenditure details provided by a community trust)

(Community physiotherapist – Schema 7.1)

**Chiropodist**

£0.17 per minute of client contact, clinic consultation (London multiplier = 1.12)

£20.31 per domiciliary visit

(Community chiropodist – Schema 7.4)

**Meals on Wheels**

£4.95 per meal

(Unit Cost of Health and Social Care 1996, Schema 1.13, inflated to 2000-01 price levels)

**Geriatric specialist**

£5.70 per minute of patient contact, clinic consultation (London multiplier = 1.24)

(Consultant: psychiatric – Schema 13.6)

**Optician**

£18 per clinic contact

£31 per home visit

(Beecham, O’Neil and Goodman, 1998; uprated using PSS pay and prices index (multiplier = 1.17).

**Health Visitor**

£1.12 per minute of clinic consultation (London multiplier = 1.11)

£28.09 per domiciliary visit

(Health Visitor – Schema 8.3)
Police Officer

£32 per contact

(Hallam, Knapp and Astin, 2000; uprated using PSS pay and prices index (multiplier = 1.04).

MIND worker

£0.64 per minute, office consultation (London multiplier = 1.14)
£40.96 per domiciliary visit

(Social worker (adult) - Schema 9.2)

Welfare Officer

£0.64 per minute, office consultation (London multiplier = 1.14)
£40.96 per domiciliary visit

(Social worker (adult) - Schema 9.2)

Dentist

£1.10 per minute

(Beecham et al., 1998; uprated using PSS pay and prices index (multiplier = 1.17).

Dietician

£0.50 per minute (office contact – London)
£18.81 per domiciliary visit

(Dietician – Schema 11.4)

Patient transport service

£39 per journey

(Ambulance service – Schema 6.2)

Aromatherapy massage

£0.68 per minute of client contact (London multiplier = 1.12)
£24.11 per domiciliary visit (travel costs estimated at £2.11 per visit, based on expenditure details provided by a community trust)

(Community physiotherapist – Schema 7.1.)

**Telephone care service**

£9.60 for a 15 minute phonecall (London multiplier = 1.14)

(Social worker (adult) - Schema 9.2)

**Individual alarm system**

£0.83 per week

(Local authority aids and adaptations – Schema 6.4)

**Drug costs**

Information and prices were taken from the British National Formulary, Number 35, March 1998, British Medical Association and the Royal Pharmaceutical Society of Great Britain (multiplier = 1.11). A full list of these costs are given in Appendix D.

**Costing of intervention**

Unless otherwise stated, cost estimations are based on data from the *Unit Costs of Health and Social Care, 2001*. Staff costs per hour are for working time, and not adjusted for non-contact time or non-clinical work.

The cost of preparing the intervention was borne by the research project and involved many people over a lengthy period of time. The two researchers were already skilled in group work techniques and received no particular training in providing the intervention.
The unit cost estimate includes the researchers’ time, mileage costs, care assistant time, and equipment costs.

2 x Researchers; Salary estimated at £20,000 each. A multipliers of 1.34 on the salary was used to account for salary on-costs, and revenue and capital overheads; cost per annum = £26,800. Working time was estimated as 41 weeks p.a. at 36 hours per week; cost per hour = £18.16 per hour.

A broad estimate was made for miles travelled to give the intervention as two or three centres/homes were visited on each trip to locations as diverse as north London, Hertfordshire and Essex from central London. The estimate was for 15 miles return journey per session. Data are taken from the AA standing and running costs for a 1550-2000cc car based on an annual mileage of 20,000.

Mileage costs per session = (15 * 35.54 pence) = £5.33

4 person-hours per session (includes travel time) = £73

A care assistant from the centre or home prepared and attended the sessions. This was within normal work patterns and no replacement staff were employed. Cost estimate for a hospital auxiliary nurse was used which includes an element for revenue and capital overheads.

1 person hour (of patient contact) per session = £11

£300 was spent on equipment, including two white boards and activity equipment.

Total number of sessions: 23 groups of 14 sessions each (322).

300/322 = £0.93.
Cost per session: £73 + £5 + £11 + £1 = £90

Five people were treated each session and 14 sessions made up the intervention.

Total cost of intervention per person: (£90 / 5) * 14 = £252

Cost of intervention per week of study (7 weeks): £252 / 7 = £36.00

Economic Analysis

The economic evaluation was a cost-effectiveness analysis as it measures comprehensive costs and relates costs to change in the primary outcome measure (QOL-AD). This was chosen because only one outcome variable was investigated in this study (QoL), and as such a cost-consequence analysis was not appropriate. A cost-utility analysis was decided against, due to the difficulties of measuring utility in studies of people with disorders such as dementia, as outlined in the introduction of this thesis. Lastly, a cost-benefit analysis would have involved attaching a monetary value to QoL, which was not what the researchers wanted to do. The cost measures ranged over all health and social services, plus other services used, and an estimate of caregiver cost. Costs were established from the CSRI completed by care managers.

RESULTS

Characteristics of participants

The characteristics of the participants included in the study at baseline are shown in Table 24. As can be seen here, the total number was 161, of which 91 were in the
The mean age was slightly higher for participants in the experimental group (86.1) relative to controls (85.3) and the participants in residential care in the experimental group had been there longer on average (19.9 vs. 17.0 months). The control group had a somewhat higher female – male ratio 81.4 % vs. 75.8% females). None of these differences reached statistical significance.

**Descriptive characteristics of participants at baseline.**

<table>
<thead>
<tr>
<th>CHARACTERISTICS</th>
<th>TREATMENT</th>
<th>CONTROL</th>
<th>ALL</th>
</tr>
</thead>
<tbody>
<tr>
<td>Number:</td>
<td>91</td>
<td>70</td>
<td>161</td>
</tr>
<tr>
<td>Age: mean (sd), [range]</td>
<td>86.1 (5.8)</td>
<td>85.3 (6.8)</td>
<td>85.8 (6.3)</td>
</tr>
<tr>
<td></td>
<td>[66-97]</td>
<td>[68-98]</td>
<td>[66-98]</td>
</tr>
<tr>
<td>Gender:</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>69 (75.8%)</td>
<td>57 (81.4%)</td>
<td>126 (78.2%)</td>
</tr>
<tr>
<td>Male</td>
<td>22 (24.2%)</td>
<td>13 (18.6%)</td>
<td>35 (21.7%)</td>
</tr>
<tr>
<td>Marital status:</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Single/unmarried</td>
<td>8 (8.8%)</td>
<td>1 (1.4%)</td>
<td>9 (5.6%)</td>
</tr>
<tr>
<td>Married/cohabiting</td>
<td>5 (5.5%)</td>
<td>5 (7.1%)</td>
<td>10 (6.2%)</td>
</tr>
<tr>
<td>Separated</td>
<td>1 (1.1%)</td>
<td>2 (2.9%)</td>
<td>3 (1.9%)</td>
</tr>
<tr>
<td>Divorced</td>
<td>2 (2.2%)</td>
<td>1 (1.4%)</td>
<td>3 (1.9%)</td>
</tr>
<tr>
<td>Widow(er)</td>
<td>66 (72.5%)</td>
<td>56 (80.0%)</td>
<td>122 (75.8%)</td>
</tr>
<tr>
<td>Unknown</td>
<td>9 (9.9%)</td>
<td>5 (7.1%)</td>
<td>14 (8.7%)</td>
</tr>
<tr>
<td>Type of accommodation:</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Owner occupied home</td>
<td>3 (3.3%)</td>
<td>3 (4.3%)</td>
<td>6 (3.7%)</td>
</tr>
<tr>
<td>Privately rented home</td>
<td>2 (2.2%)</td>
<td>2 (2.9%)</td>
<td>4 (2.5%)</td>
</tr>
<tr>
<td>Home rented from</td>
<td>7 (7.7%)</td>
<td>3 (4.3%)</td>
<td>10 (6.2%)</td>
</tr>
<tr>
<td>housing association/local authority</td>
<td>74 (81.3%)</td>
<td>57 (81.4%)</td>
<td>131 (81.4%)</td>
</tr>
<tr>
<td>Residential home</td>
<td>4 (4.4%)</td>
<td>4 (5.7%)</td>
<td>8 (5.0%)</td>
</tr>
<tr>
<td>Sheltered housing</td>
<td>1 (1.1%)</td>
<td>1 (1.4%)</td>
<td>2 (1.2%)</td>
</tr>
<tr>
<td>Unknown</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>If in residential home:</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Duration (months) mean (sd), [range]</td>
<td>[1-120]</td>
<td>[2-65]</td>
<td>[1-120]</td>
</tr>
</tbody>
</table>
Service utilisation and costs

The services used by participants during the 8 weeks prior to the intervention being conducted (baseline) and during the 8 weeks the intervention and assessments were carried out (follow-up) are shown in Table 25. As service use in addition to residential care was relatively low, individual services are not reported, but summarised under relevant categories. Table 26 reports the number of people with dementia in the two groups using the services, and the mean weekly cost of these. For the use of medication, mean number of drugs per participant is reported. As shown in the table, 78 (85.7%; mean weekly cost £329.00) of participants in the experimental group and 61 (87.1%; mean weekly cost £339.00) of controls lived in residential care, both at baseline and follow-up. The number of participants using hospital services (assessment/rehabilitation ward, continuing care/respite ward, medical ward, other hospital ward, outpatient services, day treatment, or accident and emergency) increased from 17 (18.7%) to 18 (19.8%) in the experimental group, while the mean weekly cost of these services decreased by £6.42. For the controls, the number of people using hospital services was slightly lower (11, 15.7%). This remained relatively unchanged, but the mean weekly cost of these services went down £14.31. The number of people using day services (i.e. local authority day services, voluntary organisation day services, NHS day care, lunch club, or social club) remained unchanged in both groups (8, 8.8% and 11, 15.7%), while the mean weekly cost of these services decreased by £16.31 and £5.92 respectively. The number of people using community services (i.e. community psychiatrist, community psychologist, general practitioner, district nurse, community psychiatric nurse, social worker/care manager, occupational therapist, home care worker/bathing
service, care attendant/sitting service/laundry service, physiotherapist, chiropodist, 
meals on wheels, geriatric specialist, optician, health visitor, police officer, MIND 
worker, welfare officer, dentist, dietician, patient transport service, aromatherapy 
massage, telephone care service, or individual alarm system) remained stable in both 
the experimental group (from 57, 62.6% to 56, 61.5%) and the control group (43, 
61.4%). The mean weekly cost of these services decreased by £4.71 in the 
experimental group and £3.57 in the control group. The use of medication (see 
Appendix D) for participants in the experimental group remained relatively 
unchanged from baseline to follow-up (mean difference −0.14, sd 0.8), as did it for 
the controls (mean difference −0.16, sd 0.7). The participants in the control group, 
however, used on average more medication than participants in the experimental 
group, both at baseline (2.95, sd 3.0) and follow-up (2.79, sd 3.1). The mean weekly 
cost of medication decreased more for participants in the experimental group than for 
controls (−£5.04 and −£2.17 respectively). The mean weekly total cost of service 
used decreased by £32.48 for participants in the experimental group and £15.97 for 
controls. When adding to this the weekly cost of the intervention for participants in 
the experimental group (£36.00), the mean weekly cost difference for this group was 
£3.49. None of these differences between the groups reached statistical significance.

Costs and quality of life in dementia

In order to investigate the relationship between costs and QoL in dementia, Pearson’s 
Correlations were conducted for the weekly costs and QOL-AD score at baseline for 
both groups (Table 26). The results showed a small but significant negative
correlation between higher QoL and lower costs of medication (-.190, p < .05).

There was also a trend between accommodation cost and QoL (.158, p < .075).

_Correlations between QOL-AD score and costs at baseline._

<table>
<thead>
<tr>
<th>COSTS</th>
<th>QOL-AD</th>
</tr>
</thead>
<tbody>
<tr>
<td>Accommodation</td>
<td>.158, p = .075</td>
</tr>
<tr>
<td>Hospital services</td>
<td>-.027, p = .763</td>
</tr>
<tr>
<td>Day services</td>
<td>-.103, p = .246</td>
</tr>
<tr>
<td>Community services</td>
<td>-.144, p = .105</td>
</tr>
<tr>
<td>Medication</td>
<td>-.190, p &lt; .05</td>
</tr>
<tr>
<td><strong>TOTAL</strong></td>
<td>-.031, p = .728</td>
</tr>
</tbody>
</table>

Costs and change in quality of life in dementia

_Correlations between difference in QOL-AD score and costs._

<table>
<thead>
<tr>
<th>COSTS</th>
<th>QOL-AD</th>
</tr>
</thead>
<tbody>
<tr>
<td>Accommodation</td>
<td>(no change)</td>
</tr>
<tr>
<td>Hospital services</td>
<td>.084, p = .388</td>
</tr>
<tr>
<td>Day services</td>
<td>-.012, p = .902</td>
</tr>
<tr>
<td>Community services</td>
<td>-.046, p = .641</td>
</tr>
<tr>
<td>Medication</td>
<td>-.226, p &lt; .05</td>
</tr>
<tr>
<td><strong>TOTAL</strong></td>
<td>.035, p = .718</td>
</tr>
</tbody>
</table>
In order to investigate the relationship between costs and change in QoL in dementia, Pearson’s Correlations were conducted for the change in weekly costs and difference in QOL-AD score between baseline and follow-up for both groups. The results are shown in Table 27. As can be seen here, a significant correlation was found between a positive change in QoL and reduction in cost of medication (-.226, p < .05). No other correlations were detected.

DISCUSSION

Service utilisation

The number of services used by participants in this study was relatively low, compared to service use reported by people with dementia living in the community (Livingston et al., 1997; Kavanagh and Knapp, 1999). This could be due to the fact that the majority of participants were in residential care (86.4%), and that most of their needs could be accommodated within these settings. A more pessimistic explanation would be that not all the service needs of this group were met. A total of 29 (18.0%) people in this study used some kind of hospital service (e.g. assessment/rehabilitation ward or medical ward) during the study (8 weeks). 11.8% (19) of participants attended day care, but none of the people living in residential care used any day service outside their residential home. 61.5% (99) of people with dementia used some kind of community service whilst participating in the study, the most common of which were chiropodist (42, 42.58%) and GP (28, 27.72%), and a mean of 2.13 different drugs were prescribed.
Costs of services

The mean weekly cost of accommodation for participants remained stable throughout the duration of this study. The mean weekly costs of other services went down somewhat, with £10.00 for hospital services, £11.75 for day services, £4.21 for community-based services, and £3.78 for medication. Mean total weekly cost for this sample decreased by £29.74. None of the differences in costs between the participants in the experimental group and control group were significant, either before or after adding the cost of the intervention, which was estimated to be £31.50 per person per week. Thus, taking part in the evidence-based psychological group therapy programme did not make any significant difference to the costs for the participants relative to controls receiving care as usual.

Costs and quality of life in dementia

The relationship between costs and QoL for participants was investigated. The results showed a significant correlation between QoL and cost of medication. Thus, receiving fewer drugs was correlated with having higher QoL. It could be that people with dementia in this study with higher QoL, for example physical health, needed less drugs. However, it could also be that a consequence of taking less medication was experiencing higher QoL. As none of the participants in this study received acetylcholine-esterase inhibitors medication for their dementia, the drugs they were taking were for co-existing difficulties, such as psychotropic medication for behavioural symptoms and sleep disturbances, and for mood disturbances, all common problems in dementia (Fastbom and Giron, 1998).
Costs differences and change in quality of life in dementia

Receiving the intervention had a significant positive effect on participants' QoL, as described in Chapter 4 of this thesis. Investigations into the relationship between the (small) differences in costs and this improvement in QoL revealed a significant correlation between improvement in QoL and difference in cost of medication. Hence, QoL for the people with dementia in this study improved as cost of medication decreased. The relationship here is unclear. However, it is clear that taking less drugs was associated with having higher QoL in dementia.

Limitations

The majority of participants in this study lived in residential care, and were people with mild to moderate dementia. Their inclusion into the study also depended on some ability to hear and see. As such, the results of this study must be considered accordingly. Additionally, the power analysis for this study was conducted using cognition as the outcome measure, and hence there was a possibility that the sample was not large enough for this economic evaluation (a Type II error; Howell, 1999). However, this is unlikely as the differences were small, and not suggestive of any trends. Also, participating in a research study can be stressful for some, and inclusion of a number larger than needed in order to conduct an economic evaluation might not always be considered to be ethical. There are also the additional costs which would be involved to consider. The study presented here found the services used to be relatively low. However, it could be that the participants were using more services, but that these were not included in the CSRI. Costs data were not collected for 40 participants involved in the study of this intervention, described in Chapter 4.
This was due to some managers finding the CSRI too time-consuming to complete, and others perceiving this information as inappropriate to disclose. Hence, this might have had some effect on the results.

**Conclusion**

The results from this study showed that conducting an evidence-based psychological group therapy programme did not make any significant difference to the costs for its participants relative to controls receiving traditional care. This study used QoL as the outcome variable, which has been called for in the literature (Witthaus, 1998). As the results showed a significant improvement in QoL for the people with dementia partaking in the groups, the conclusion can be drawn that this intervention was cost effective. A significant correlation between baseline QoL and cost of medication was detected, as was a significant correlation between improvement in QoL and decrease in cost of medication.