Quality Of Life In Dementia

Thesis submitted in 2007 for the degree of Doctor of Philosophy

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Abstract

Background: Quality of Life (QoL) is now an important outcome for people with dementia but the nature of the illness means that there may be difficulty in measuring it. Aims: This thesis, using an established dementia specific outcome measure, the QOL-AD, aims to assess the validity of measuring QoL in severe dementia and to investigate determinants both of QoL and of change in QoL in dementia. Method: In the first study, 224 people with Alzheimer's disease living in community and institutional settings and their caregivers were interviewed. In the second study, 238 people with dementia living in residential homes and staff were interviewed with a follow up assessment at 20 weeks. Results: People with a MMSE scores of <12 and ≥3 could provide valid and reliable ratings of their own QoL and mood, functional ability and psychosocial factors were associated with QoL in this group. Secondly, the person with dementia's self-ratings of QoL were independently predicted by current mood, cholinesterase inhibitor treatment and living environment, whereas family caregiver ratings of the person with dementia's QoL were predicted by mood and neuropsychiatric symptoms. Similarly, in residential homes, mood was the strongest predictor of self-rated QoL but staff ratings of resident's QoL were predicted by levels of dependency. Lastly, cognition, mood; function and behaviour were investigated as putative factors influencing change in QoL over 20 weeks. Change in QoL was predicted by changes in mood and cognition. Conclusion: People with severe dementia (MMSE>2) can comment on their QoL. People with dementia's perception of QoL differs from their caregiver's perception of it. Many people with dementia experience a decline in QoL and this may be linked to deterioration in mood or cognitive function. This suggests that psychological and pharmacological interventions aimed at improving mood or cognition may also benefit QoL.

Acknowledgements

The investigation was undertaken and submitted as a thesis for the Ph.D in Mental Health Sciences at University College London (UCL).

First of all, I would like to express my gratitude to my supervisors Professor Martin Orrell and Professor Gill Livingston, Centre for Ageing and Mental Health Sciences, Department of Mental Health Sciences, UCL. They have been a constant source of inspiration, motivation and guidance throughout the past 4 years and I thank them for their endless patience, support and encouragement without which this thesis would have never been completed.

The investigations within my thesis have been undertaken as part of two larger studies within which I was involved with the recruitment, data collection, data analysis and writing up and dissemination of the findings, in particular those related to Quality of Life. The first was a longitudinal study of people with Alzheimer's disease (AD) and their caregivers recruited from within London and the South East Region (LASER-AD) of the UK. The LASER-AD study was led by Professor Gill Livingston and Professor Cornelius Katona and was funded through a grant from Lundbeck. The second study was a randomised controlled trial examining the needs of older people with dementia living in residential homes using the Camberwell Assessment of Need in the Elderly (CANE). The CANE study was led by Professor Martin Orrell, Professor Bob Woods, Professor Gill Livingston, Professor David Challis and Professor Martin Knapp and was funded through a grant from the Wellcome Trust. I worked as a member of both research teams and interviewed many of the study participants, and I would like to thank the research teams who assisted with the data collection. I would especially like to thank all the people with memory problems and their families, friends and other carers who participated in the studies together with all the staff of the residential homes for all their help and cooperation.

I am also particularly grateful to the charity *for dementia* that supports Admiral Nursing and the North East London Mental Health Trust for the funding of my joint post as Clinical Research Fellow/Admiral Nurse Practitioner at UCL, which has enabled me to continue with my studies.

Undertaking this thesis has been both challenging and stimulating and my interest in further study has been generated by the support and encouragement received at various stages in my career as a mental health nurse working in Leicester, Essex and London. I would like to thank my colleagues both past and present, for all their support, in particular Dr Geraldine Hancock who has been a great source of help.

Lastly, I am also grateful to my family and friends who have always sought to encourage me in my endeavours and celebrated my accomplishments, as they did throughout the time spent working towards my Ph.D and I dedicate this thesis to the memory of my friend Liz Young.

Statement of contribution

As a result of the viva examination, I have been asked to prepare a statement regarding my contribution in respect of this thesis. The investigations within this thesis have been undertaken as part of two larger studies within which I was involved with the recruitment, data collection, data analysis and writing up and dissemination of the findings, in particular those related to Quality of Life. The first study, a longitudinal study of people with Alzheimer's disease (AD) and their caregivers recruited from within London and the South East Region (LASER-AD) was designed and led by Professor Gill Livingston and Professor Cornelius Katona. The data were collected by a research team of nine staff, consisting of a range of disciplines (medicine, nursing and psychology) who conducted all the interviews. The second study, a randomised controlled trial examining the needs of older people with dementia living in residential homes using the Camberwell Assessment of Need in the Elderly (CANE) was designed and led by Professor Martin Orrell, Professor Bob Woods, Professor Gill Livingston, Professor David Challis and Professor Martin Knapp. The data were collected by a research team of five staff, consisting of nurses and a psychologist. I was employed as a member of both research teams and directly interviewed approximately a third of the study participants in both studies. In addition, I provided training and advice to the other researchers on administrating the instruments and co-interviewed some of the participants. I was the research lead for the QoL studies and wrote the research protocol including the hypotheses, designed and conducted the analyses, and drafted the research papers which led to my position as first author on all the four QoL papers written so far (3 in press, 1 in draft). The analysis for this thesis was undertaken by myself with supervision from the Principal Investigators.

Statement of Originality

I hereby certify that the work embodied in this Thesis is the result of original research that I carried out and has not been submitted for a higher degree to any other University or Institution. To the best of my knowledge it contains no material previously published or written by another person except where due acknowledgment is made in the thesis itself.

12.9.07

Date Juanita Hoe

11.9.07

Date Professor Gill Livingston

Principal Investigator (Study 1)

5.9.07

Date Professor Martin Orrell

Principal Investigator (Study 2)

Ethical Considerations

Ethical approval was obtained from the relevant ethical committees. For Study 1, ethical approval was granted by all the appropriate Local Research Ethics Committees for North Essex Mental Health Partnership NHS Trust, Camden and Islington Community Health Services NHS Trust, and Barnet, Haringey & Enfield Mental Health Trust. For Study 2, ethical approval was granted by the London Multicentre Research Ethics Committee and all the appropriate Local Research Ethics Committees for Camden and Islington Community Health Services NHS Trust, North East London Mental Health Trust, Manchester Mental Health and Social care Trust, and North West Wales NHS Trust.

The consent of all the people with dementia and their caregivers who were involved in these studies was sought. Both people with dementia and their caregivers were given a verbal explanation about what the study involved and how, if in any way, it would affect their care and that at any time they could withdraw from the study.

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6.c. British Journal of Psychiatry Press Release 406
6.d. Hoe et al., (2007) 'Care Recipient and Carer Perceptions of Quality of Life in Dementia: The LASER-AD Study'. *International Journal of Geriatric Psychiatry,* (In Press). 407

ABBREVIATIONS

AChEI	-	Acetylcholinesterase inhibitors
AD	-	Alzheimer disease
ADCS-ADL	-	Alzheimer's Disease Co-operative Study – Activities of Daily Living Inventory
ADL	-	Activities of daily living
ADRQL	-	Alzheimer's Disease-Related Quality of Life
ANOVA	-	Analysis of variance
APA	-	American Psychiatric Association
BMA	-	British Medical Association
BNF	-	British National Formulary
CANE	-	Camberwell Assessment of Need for the Elderly
CAPE-BRS	-	Clifton Assessment Procedures for the Elderly–Behaviour Rating Scale
C-BS	-	Cornell-Brown Scale for Quality of Life in Dementia
CBS	-	Challenging Behaviour Scale
CDR	-	Clinical Dementia Rating
CG	-	Caregiver
CI	-	Confidence interval
CQoL	-	Carer rated QoL
DCM	-	Dementia Care Mapping
DEMQOL	-	Measure of health related quality of life for people with dementia
D.F.	-	Degrees of freedom
Diff	-	Difference
DLB	-	Lewy body dementia
DOH	-	Department of Health
DQOL	-	Dementia Quality of Life
DSM	-	Diagnostic and Statistical Manual of Mental Disorders.
EMI	-	Elderly Mentally Infirm
EQ-5D	-	EUROQOL health status measure

EURODEM	-	European Community Concerted Action Epidemiology of Dementia
EUROQOL	-	European QoL group
FTD	-	Frontotemporal dementia
GP	-	General Practitioner
HADS	-	Hospital Anxiety and Depression scale
HRQoL	-	Health-related quality of life
HSQ-12	-	12-item Health Status Questionnaire
HUI:2	-	Health Utilities Index Mark II
IADL	-	Instrumental activities of daily living
ICC	-	Intraclass correlation
ICD-10	-	International Classification of Diseases (10th revision)
IFA	-	Institute of Phonetic Sciences
IHQL	-	Index of Health-Related Quality of Life
LASER-AD	-	London and the South East Region Alzheimer Disease Study
LEILA75+:	-	Leipzig Longitudinal study of the Aged
MCI	-	Mild Cognitive Impairment
MMSE	-	Mini Mental State Examination
MSP	-	Malignant social psychology
NHS	-	National Health Service
NICE	-	National Institute of Clinical Excellence
NINCDS-ADRDA	-	National Institute of Neurological and Communicative Diseases and Stroke/Alzheimer's Disease and Related Disorders Association
NINDS-AIREN	-	National Institute of Neurological Disorders and Stroke – Association Internationale pour la Recherche et l'Enseignement en Neurosciences
NISW	-	National Institute of Social Workers Noticeable Problems checklist
NMDA	-	N-methyl-D-aspartate
n	-	Number
NPI	-	Neuropsychiatric Inventory
NS	-	Non-significant
Pearson's *r*	-	Pearson's product-moment correlation coefficient
PWB-CIP	-	Psychological Well-Being in Cognitively Impaired Persons

QALY	-	Quality adjusted life years
QoL	-	Quality of life
QOL-AD	-	Quality of Life - Alzheimer Disease
R^2	-	R square
RAID	-	Rating of Anxiety in Dementia
RCPsych	-	Royal College of Psychiatrists
RCT	-	Randomised controlled trial
RDC	-	Research diagnostic Criteria
PQoL	-	Person with dementia rated QoL
S.D.	-	Standard deviation
SEM	-	Structural equation modeling
SF-12	-	Short Form 12-item Health Survey
SF-36	-	Short-Form 36 Health Survey
Spearman's *Rho*	-	Spearman's rank correlation coefficient
SPSS	-	Statistical Package for the Social Sciences
SQoL	-	Staff rated QoL
SSI	-	Social Services Inspectorate
UK	-	United Kingdom
USA	-	United States of America
VaD	-	Vascular dementia
VAS	-	Visual analogue scales
VS	-	Versus
WHO	-	World Health Organisation
WHOQOL	-	World Health Organisation Quality of Life Group

QUALITY OF LIFE IN DEMENTIA

1.0. CHAPTER 1: INTRODUCTION

> *"But worse than all bodily failing is the weakening mind which cannot remember names of slaves, nor the face of a friend he dined with last evening, cannot remember the names of offspring begotten and reared..."*
>
> *(Juvenal, 2nd century AD; cited in Mahendra, 1984)*

1.1. OVERVIEW

The maintenance of physical and cognitive functioning and the avoidance of disease are associated with well-being and quality of life (QoL) in old age, as poor health can lead to loss of control, autonomy and independence (Bowling, 2005; Bond & Corner, 2004). QoL has become a fundamental, though controversial, area of study in dementia, and is considered to be at the early stages of its development when compared to other areas of medicine (Whitehouse et al, 2003). With the growth of the ageing population however, and predicted rise in numbers of people experiencing dementia the need to focus on QoL has become more evident. Whereas the traditional focus of research in dementia has been on the cognitive domains of the disease this has overlooked other aspects of the phenomenology of the disease that underpin QoL. Moreover, QoL measures are becoming a focus within dementia care and have increasing political, moral and ethical significance as an outcome measure for treatment and interventions and as a determinant of future care needs (Mack & Whitehouse, 2001; Jonnson et al, 2000). As has been evident in the recent NICE guidelines for the prescription of Acetylcholinesterase inhibitors (AChEI) that emphasises the need for QoL measures to demonstrate the efficacy of the medication (NICE, 2006). There are two major concerns that relate to QoL which are: how it is defined, and whose perspective is measured. The concept of QoL is considered to be a mostly subjective experience and the credence and value of perceptions of QoL within dementia have been questioned largely due to the nature of the disease (Selai & Trimble, 1999; Walker et al., 1998). Nonetheless, research undertaken in recent years has established the validity and reliability of a number of QoL measures within mild to moderate dementia (Selai et al., 2001a; Logsdon et al., 1999; Brod et al., 1999), but further exploration is needed of their application in severe dementia. This chapter aims to provide an introduction to understanding the nature of dementia and the conceptualisation and measurement of QoL. The different factors associated with dementia that may impact on QoL will be reviewed such as comorbidity, functional ability and environment. Then lastly, the conceptualisation and measurement of QoL in dementia generally and the issues surrounding how QoL is assessed will be discussed.

1.2. AIMS FOR THE INTRODUCTION

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

- To discuss the conceptualisation and measurement of QoL

- To explore factors associated with dementia that may impact on QoL

- To discuss the conceptualisation and measurement of QoL in dementia.

1.3. THE NATURE OF DEMENTIA

> *'... a notable forgetfulness of all things almost, that heretofore a man hath knowen, or of their names: so that such one often times forgetteth also his owne name, calleth any thing by a wrong name, and beginning to speake, forgetteth what he had saide afore, and what hee meant to say after. This distemperature and weakenes commeth by some blowe, sickenes, or age'.*
>
> *(Cosin, 1592)*

1.3.1. HISTORICAL CONTEXT OF DEMENTIA

The concept of dementia has evolved over time as a medical diagnosis, although the condition itself has been described for thousands of years sometimes with symptoms and aetiology (Berrios, 1987; Mahendra, 1984). Historically, the earliest use of 'demented' in English was recorded in the Oxford English Dictionary as 1644, although Berrios & Freeman (1991) traced its origins to the Latin works of Lucretious 'demens' translated as 'being out of one's mind'. Becoming more clearly defined throughout the 18th century, dementia became more commonly used and was included in the 1726 edition of Blanchard's 'Physical Dictionary' as being equivalent to 'anoea' or 'extinction of imagination or judgement' (Berrios, 1987). With increased knowledge of anatomy and disease, and the opinion that senility was an extreme form of ageing, dementia had become clinically differentiated from other psychiatric disorders by the mid 19th century (Adams, 1997). Furthermore, in 1894 both Emil Kraepelin and Alois Alzheimer's distinguished between senile and arterioslerotic dementia (Mahendra, 1984). New histological techniques in the early 20th century led to Alzheimer's now classical case-study of a 51 year old woman with a distinctive neuropathology (Alzheimer, 1907). Neurologically, atrophy of the brain; arteriosclerotic changes; senile plaques and neurofibrillary tangles were found post mortem. The clinical presentation described morbid jealousy, loss of memory, capricious behaviour, spatial and temporal disorientation, persecutory ideas and speech difficulties. Dementia was considered a chronic, irreversible and untreatable condition until the mid 1960's, when scientific advances led to recognition that there were clinically reversible causes of intellectual decline (Mahendra, 1984). Of importance was the acceptance of dementia as a disease which could be researched and treated medically, and a clearer typology from 'senile dementia', to 'senile dementia of the Alzheimer type' to 'Alzheimer's disease' (Burns & Hope, 1997). However into the 21st century dementia has continued to be used, as a broadly generic term for describing the process of cognitive impairment and neuropathological disease.

1.3.2. DEFINITION OF DEMENTIA

Lishman (1987) described dementia as 'an acquired global impairment of intellect, memory and personality'. The term dementia is therefore considered to be a collective term that refers to a clinical syndrome rather than a specific disease entity and also describes a variety of pathological processes with common features. In brief, the presence of dementia implies a global deterioration of a person's mental abilities due to underlying brain disease which is usually progressive and chronic in nature (Cooper, 1997). Or more specifically 'Dementia is the global impairment of higher cortical function including memory, the capacity to solve the problems of day-to-day living, the performance of learned perceptuo-motor skills, the correct use of social skills and control of emotional reactions, in the absence of gross clouding of consciousness. The condition is often irreversible and progressive.' (Royal College of Physicians, 1981).

1.3.3. PREVALENCE OF DEMENTIA

Demographic changes in the older population have led to increased interest in the study of the disease as the incidence of dementia is expected to rise. Over the past century the older population (≥65) within Britain has grown from 5% to 16% and it is projected that 23% of the UK population will be ≥65 in 2031 (Tomassini, 2005; Mann, 1997). The UK has a current population of nearly 60 million people of which 9.5 million are ≥ 65 years of age (ONS 2004; cited in Tomassini, 2005). Those aged 85 and over are the fastest growing age group in the population of many developed countries and within the current UK population, of those aged 65 and over, 12% are aged ≥ 85 (Tomassini, 2005). Dementia is present in around 1-2% of the population of those aged 60 – 69 years, rising to approximately 20% in those aged 80 – 84 and reaching around 50% in those aged 90 years and older (Ferri et al., 2005; Fratiglioni, 1998). Worldwide it is estimated that 24 million people have dementia and that this will double every 20 years to 42 million in 2020 and 81 million in 2040 (Ferri et al., 2005). Several meta-analyses have provided answers about the prevalence of dementia (Gao et al., 1998; Jorm & Jolley, 1998; Hofman et al., 1991; Jorm et al., 1987). The prevalence rate of dementia was found to double every 5.1 years from the age of 65 years and with a higher increase for vascular dementia (VaD) than for Alzheimer's disease (AD) (Jorm et al., 1987). Similar findings were observed in the European meta-analyses (Eurodem: Hofman et al., 1991) and although no gender difference was found in prevalence, there were higher rates of AD in women and higher rates of VaD in men. The evaluation of disease incidence rather than prevalence is preferred when studying risk factors for dementia due to differences in duration of disease or incidence between groups (Jorm & Jolley, 1998) and their meta-analysis showed that the log incidence of dementia and AD was found to rise linearly with age up to the age of 90 years. Significantly, Fratiglioni et al., (2000) found the incidence of dementia and AD continued to increase with age, but only in women after the age of 85 years. The differences in gender survival rates were attributed to endocrine or genetic, and environmental factors; such as head trauma, occupational toxicity and smoking (Fratiglioni et al., 2000; Lobo et al., 2000).

1.3.4. DIAGNOSING DEMENTIA

The diagnosis of dementia demands a broad range of clinical skills and relies on accurate clinical evidence gained through personal history, medical examination and investigation of the person (Burns & Hope, 1997). Dementia needs to be distinguished from other conditions which may overlap or present similarly including delirium and depression, as both of these conditions can improve with appropriate treatment (Adams, 1997). There are two main classification systems for the diagnosis of dementia the Diagnostic and Statistical Manual (DSM IV; APA, 1994) and International Classification of Diseases (ICD-10; WHO, 1992). DSM IV diagnostic criteria describes dementia as the development of multiple cognitive deficits manifested through memory impairment, with one or more cognitive disturbance which cause significant impairment in social or occupational functioning – aphasia (language disturbance), apraxia (impaired ability to carry out motor activities), agnosia (failure to recognize or identify objects) and disturbance in executive functioning (i.e. planning, organising, sequencing, abstracting). The course is characterised by gradual onset and continuing cognitive decline (APA, 1994). The ICD-10 diagnostic criteria defines dementia as a syndrome due to disease of the brain, usually chronic or progressive in nature, with disturbance of multiple higher cortical functions, including memory, thinking, orientation, comprehension, calculation, learning capacity, language and judgement. Consciousness is not clouded and cognitive impairments are commonly accompanied by deterioration in emotional control, social behaviour, or motivation which has occurred for a period greater than 6 months (WHO, 1992).

1.3.5. TYPES OF DEMENTIA

Dementia can be differentiated into four most common types. Alzheimer's disease (AD) is the most common cause of dementia characterised by a history of gradual onset and decline in function incorporating amnesia, apraxia, agnosia and aphasia (NINCDS-ADRDA: McKhann et al. 1984). Vascular dementia (VaD) is characterised by cognitive impairment resulting from cerebrovascular disease (ischaemia or stroke) defined by the presence of focal neurological signs: gait disturbance, incontinence and mood lability (NINDS-AIREN: Roman et al., 1993). Lewy body dementia (DLB) is characterised by fluctuating cognition, recurrent visual hallucinations and spontaneous features of Parkinsonism (McKeith et al., 1996). Frontotemporal dementia (FTD) is characterised by behavioural disorder and affective symptoms: personal neglect, disinhibition, perseveration and apathy, with intact visual and spatial abilities (Lund & Manchester Groups, 1994). These four subtypes account for the majority of total dementia cases, with AD being diagnosed in 50 – 60 % of all cases; VaD is found in 10 – 20% of cases; DLB accounts for a further 10 – 15% of cases and FTD is discovered in 8 – 15% of cases (Clark & Karlawish, 2003; Friedenberg, 2003; Stevens et al., 2002; Knopman et al., 2001; Lobo et al., 2000; Fratiglioni et al., 2000).

1.3.6. DEMENTIA AND THE INDIVIDUAL

> *Dementia is the fourth depth of dissolution. Such a person may have a highly developed brain, but not the full use of it . . . he may have many fine thoughts, and yet no system of thinking; his brain soon falls out of gear when dealing with complex subjects. At the bottom . . . there is no person, but only a living creature*
>
> *John Hughlings Jackson, (1894)*

1.3.6.1. DEMENTIA AND PERSONHOOD

The symptoms and disabilities of dementia often mean that it is seen to lead to destruction of the individual through loss of autonomy and personhood. Kitwood is possibly the best known exponent of the theory of personhood in dementia (See Figure 1, Kitwood, 1997:82). Personhood is defined as a 'standing or status that is bestowed upon one human being, by others, in the context of relationship and social being' (Kitwood, 1997:8). Personhood implies recognition, respect and trust' and Kitwood suggests that the key associations of personhood are with self-esteem; the place of the individual in a social group; the performance of given roles; and with the integrity, continuity and stability of the sense of self. Whilst the importance of accurate diagnosis of dementia is essential, the experience of the individual must also be understood. The adoption of person-centred approaches to dementia care allows for a psychological interpretation of the experience of the person with dementia (Kitwood, 1996; Miesen, 1993). Due to its nature, dementia is considered to offer the greatest challenge for investigation of self-perception and identity with respect to the disabilities of ageing (Coleman, 1996). Fundamentally the preservation of personhood becomes the central factor in caring for people with dementia. Jenkins & Price (1996) discuss how dementia can undermine the concept of self that contributes to personhood: ecological self (distorted body image); interpersonal self (limited communication); extended self (memory and capacity to plan); private self (erosion of identify); conceptual self (reduced status and increased dependency on others). Furthermore, the care provided in dementia is considered meaningless if aspects of personhood are diminished and care is delivered in a repetitive and unemotional way. It is therefore important that the person with dementia is recognised and accepted as an individual and a positive self-image reinforced. Memories of the person's life, achievements and personal characteristics give value to the person and their family and help map perceptions of who the person is (Jenkins & Price's, 1996).

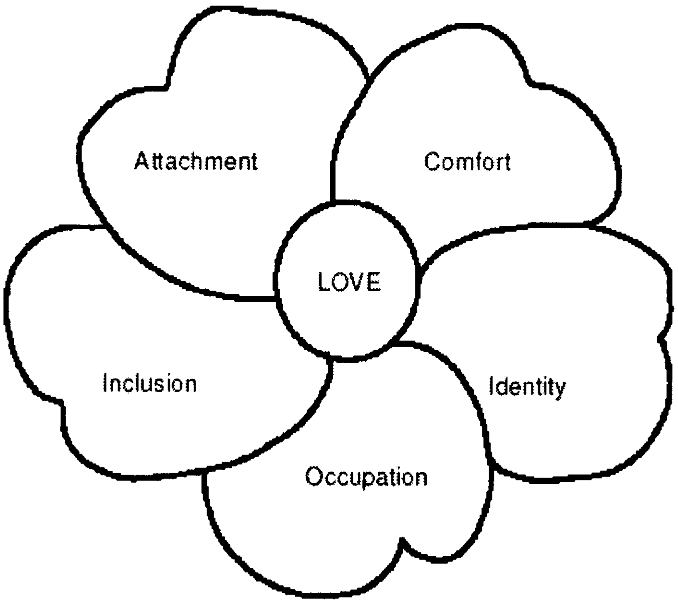


Figure 1: The main psychological needs of people with dementia (Kitwood, 1997)

1.3.6.2. WELL-BEING IN DEMENTIA

Kitwood & Bredin (1992) conceptualised the idea of a social-psychological theory of dementia in response to perceived inadequacies of the biomedical model which focused on the brain rather than personhood. The dementia process was argued to be an outcome of a dialectical interplay between two tendencies: neurological impairment causing limitations on performance and the personal psychology of the individual. Challenging the negative view of cognitive impairment, it was argued that through increased social interaction a process of 'rementia' occurs and that positive indicators of wellbeing not related to cognition, could be observed in all severities of dementia. Kitwood (1996) discusses the proposed dialectical framework for dementia (D) in more detail and identifies 5 key factors which are included in the equation (D = P + B + H + NI + SP). Personality (P) is the first factor, and a psychological kitbag of 'resources' and 'hang ups' is described which dictate the individuals coping style. Biography (B) explains the importance of life story in understanding the person and their behaviour. Physical health (H) relates to possible underlying medical conditions and disabilities which may contribute. Neurological impairment (NI) is the limitations resulting from neuropathological changes within the brain. Finally, social psychology (SP) is the impact of daily interactions on the person with dementia both positive and negative. Whilst three factors were considered to be fixed (P, B, NI), two (H, SP) are open to positive change. Negative interactions are described as malignant social psychology (MSP), which impact on wellbeing. The nature of well-being in dementia was argued to be due to 'four global sentient states' which incorporate a sense of personal worth, a sense of agency, social confidence and hope (Kitwood & Bredin, 1992). Fulfilling the psychosocial needs of the person with dementia; comfort; attachment; inclusion; occupation; identity (See Figure 1, Kitwood, 1997:82), allow the person to feel love (unconditional acceptance), as meeting one need can lead to satisfaction in others. The measure of a person's wellbeing is an important contributor to the QoL of the person with dementia, as it reflects the level of their interaction with others and engagement with their environment.

1.3.7. IN CONCLUSION

To summarise, dementia is a degenerative and chronic disease, the course and duration of which can vary. The theoretical understanding of dementia has been very much influenced by the historical perspective of its formulation that focused on the neurological aspects of the disease. Interest in studying the nature of dementia outside the neuropathology has however allowed for additional dimensions of the disease to be explored, namely the psychosocial aspects of the dementia process. Moreover, incorporating a more person-centred approach has influenced how the dementia process is perceived. Consequently, dementia is now viewed in a more humanistic and phenomenological way that emphasises the feelings and emotions of the individual and examines how they see things. Understanding the disease process and the individuals' experience of dementia is important, which may be conceptualised and measured as QoL. Alongside of this is the need to recognise what factors influence the dementia process and how this impacts on QoL. But first how QoL is conceptualised and then measured needs to be understood and this is discussed in the next section of this thesis.

1.4. CONCEPTUALISING AND MEASURING QUALITY OF LIFE

> *Quality of life is defined as an 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, expectations, standards and concerns. It is a broad ranging concept affected in a complex way by the person's physical health, psychological state, level of independence, social relationships and their relationships to salient features of their environment*
>
> *(WHOQOL Group 1993)*

1.4.1. THE MEANING OF QoL

QoL has become a popular and broadly used expression, a term that is frequently taken for granted and for which the meaning is not always clear. There is debate about the true definition and meaning of QoL, particularly in respect of whether ratings are objective or subjective, what criteria should be used and what is actually being measured 'the quality of an individual's life, state of life, or the meaning of life in general' (Oliver et al, 1996). Thus a debate around the theoretical concepts of QoL has emerged over recent years (Sarvimaki & Stenbock-Hult, 2000; Muldoon et al, 1998; Orley et al, 1998; Oliver et al, 1996). Moreover, conceptualising QoL has become a multidisciplinary enterprise which brings together the perspectives of sociologists, psychologists, philosophers, clinical and social scientists, statisticians and economists (Bond & Corner, 2004). Human needs and need satisfaction are considered the foundation of QoL and have been compared to Maslow's (1954) hierarchy of needs. At the bottom is physiological needs (warmth, shelter, food) and this continues up the hierarchy to the following: security needs (protection from danger); social needs (love, friendship, comradeship); ego needs (self respect, personal worth, autonomy); self actualization needs (achieving full potential). QoL is however argued to be less related to basic needs but to individual expectations and experiences of life, which include individual perceptions of wellbeing, happiness, goodness and satisfaction with various aspects of their lives and environment (Franklin et al, 1986; Lehman, 1983; Dalkey & Rourke, 1972). What is apparent is that QoL is a multidimensional concept 'just as is life itself' (Lawton, 1991). With a wide range of domains being suggested for inclusion as QoL indicators which incorporate physical and mental health, intellectual and emotional function, social and role function, activities of daily living, economic aspects, job and life satisfaction (Pearlman & Uhlmann, 1988; Ochs et al., 1988; Spitzer et al., 1981). Although all components are considered to be relevant indicators of QoL the risk of 'disunification' means there is a need to introduce order to the construct of QoL (Oliver et al., 1996; Lawton 1991). The expression QoL may also overlap with the terms health status and functional status which have been considered interchangeable (Guyatt et al, 1993). Perceptions of wellbeing may however be influenced by psychological factors unrelated to health and differing criteria (Muldoon et al, 1998). This may therefore be misleading (Farquhar, 1995) and the context for measuring QoL should be made specific i.e. health related or research specific QoL.

1.4.2. DEFINITIONS AND CONCEPTUALISATIONS OF QoL

As indicated there are several meanings of the term QoL which remains a vague and elusive concept for which there is no single widely accepted definition. The definitions that are provided are broad and varied; indeed, there may be as many QoL definitions as there are people (Liu, 1976). QoL is viewed as 'a concept which incorporates all aspects of an individual's existence' (Torrance, 1987) and is considered 'an abstraction which integrates and summarises all those features of our lives that we find more or less desirable and satisfying' (Bigelow et al, 1982). The inclusion of the terms life satisfaction, morale and happiness are debated but may be considered to be transient states which should be distinguished from QoL as they differ in their degree of subjectivity (Gentile, 1991). Alternatively, life satisfaction, self-esteem, and physical health are argued to be key dimensions of QoL (George & Bearon, 1980). Further definitions have been proposed and similar themes emerge within them, which incorporate physical, psychological and social components as well as including global ratings of QoL. Lawton (1983) defines QoL as 'the multidimensional evaluation, by both intrapersonal and social-normative criteria, of the person-environment system of an individual in time past, current and anticipated' and hypothesises four dimensions of QoL, behavioural competence, perceived QoL, objective environment, and psychological well-being. Each sector is intrinsic and considered core to the concept of QoL and also interlinked (See Figure 2; Lawton, 1983). Fundamentally, QoL is perceived as being continuous and dynamic in nature and may be evaluated negatively or positively depending on the individuals own internal perceptions and response to their environment.

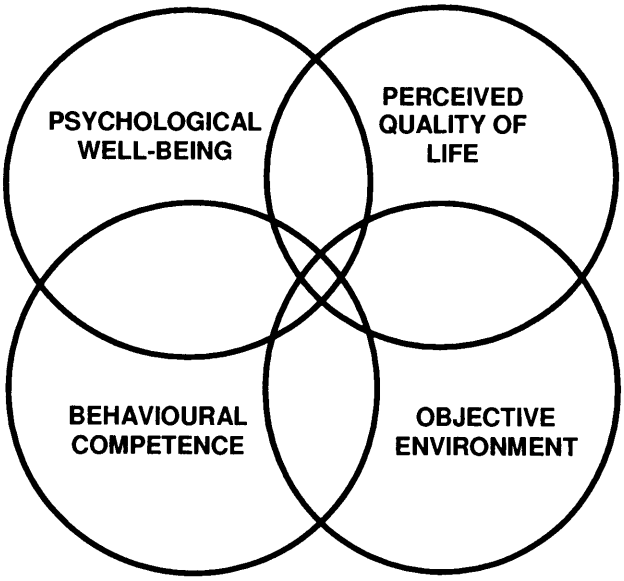


Figure 2: Four sectors of the good life (Lawton, 1983)

1.4.3. HEALTH RELATED QoL

The way QoL has been conceptualized and measured within the social sciences has been influenced by social indicators research and QoL outcomes in health and social policy research. Both traditions are criticised for focusing on issues of measurement rather than establishing the necessary theory to underpin its concept and use (Bond & Corner, 2004). Outcomes of treatment have traditionally been evaluated in terms of mortality and symptom assessments, but there is now increasing recognition that a more important outcome measure is the patient's perspective (Bowling, 2001). The emergence of QoL as a fundamental principle of evaluating and monitoring health outcomes may be due to the increasing number of people experiencing chronic illness and disability, particularly in the older population, when a treatment may alleviate disease symptoms but lead to worsening of how the patient feels. Criticism of the traditional medical model has also demanded a more humane approach which systematically assesses patients' perceptions (Bowling, 2001; Gentile, 1991).

Within the context of health, QoL is further defined as a reflection of patients' perception and response to their health status and to other non-medical aspects that have an impact on patient's lives and within health-related quality of life (HRQoL) this includes physical, psychological and social perspectives (Cheater, 1998; Gill & Feinstein, 1994). This definition is in keeping with that given by the World Health Organisation Quality of Life Group (WHOQOL), that QoL is "the individuals' 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, expectations, standards and concerns" (WHO, 1991). This broad description encompasses the complex nature of the person's physical, psychological and social wellbeing in relation to their environment. The recognition of cultural factors is particularly important when considering the QoL of the ageing population and especially those people with dementia. Memory impairment may not be regarded as so important in all cultures (Chiu and Zhang, 2000). Similarly, functional disability may seem less important in cultural contexts where independence and autonomy in activities of daily living are a less central part of the older person's role (Gureje et al., 2006). Older people are frequently marginalised as society holds a negative view of their QoL, and health and social research tends to focus on decline and disability (Gabriel & Bowling, 2004). There are both positive and negative elements that impact on an older person's QoL and Hughes (1990) lists the key domains that should be evaluated when measuring older people's QoL (see Table 1). These characteristics are also considered pertinent to people with dementia and as observed by Whitehouse (1998) definitions of HRQoL differ little from more generally accepted QoL definitions. Farquhar (1995) argues that no gold standard measure of QoL exists because there is no consensus definition of QoL. She further argues that use of the concept 'QoL is ambiguous when only measuring health and functional status and that the term 'health related QoL' should be assumed instead (Farquhar, 1995). Whilst there is no agreed single definition of health-related QoL, there is general agreement on the components. The agreed domains of HRQoL include: physical health and functioning; emotional health, cognitive functioning; role performance and work productivity; sexual functioning and life satisfaction (Kane, 2003).

Table 1: List of key domains including positive and negative aspects of ageing

(Hughes, 1990)

Subjective satisfaction	Global quality of life assessed by individual olde person.
Physical environmental factors	Standard of housing or institutional living arrangements, control over physical environment, access to facilities such as shops, public transport and leisure providers.
Social environmental factors	Family and social networks and support, levels of recreational activity and contact with statutory and voluntary organizations.
Socio-economic factors	Income and wealth, nutrition and overall standard of living.
Cultural factors	Age, gender, ethnic, religious and class background.
Health status factors	Physical well-being, functional ability and mental health.
Personality factors	Psychological well-being, morale life satisfaction and happiness.
Personal autonomy factors	Ability to make choices, exercise control and negotiate own environment.

1.4.4. MEASURING QoL

> *The difference in value between the sum of pleasures........ and the sum of pains'*
>
> *Jeremy Bentham (1834)*

1.4.4.1. MEASURING QoL IN HEALTH

Lerner (1973) argued that 'health is more than just a biomedical phenomenon; it involves a social human-being functioning in a social environment with social roles they need to fulfil'. For this reason it is important to measure health related QoL. From the viewpoint of health, QoL measures the social, emotional and physical wellbeing of patients following treatment (Greer, 1984). The use of QoL as an outcome measure focuses the impact of the patient's condition and treatment on their emotional and physical functioning and lifestyle (Bowling, 2001). Hence health related QoL has become important in measuring the impact of chronic disease (Guyatt et al., 1993). This is of particular significance as patients with the same clinical symptoms often have considerably different responses. Known as the 'disability paradox', patients with significant health and functional problems may have QoL scores which do not seem commensurate with their health status (Carr & Higginson, 2001). The use of a phenomenological approach in measuring QoL is advocated, being 'through the eye of the experiencer', as QoL is dependent upon the interpretation and perception of the individual (Ziller, 1974). Thus through assessing change in physical, functional, mental and social health, QoL measures can be used to evaluate human and financial costs and benefits of the interventions and care provided (Testa & Simonson, 1996).

Calman (1984) suggests that people perceive QoL in terms of their past experiences, current life-style, hopes and ambitions for the future. QoL measures the gap between the individual's present experience and their expectations for the future and that by narrowing this gap through improving experience or by lowering expectations, QoL could be improved (Calman, 1984). Importantly, the model recognises the highly individual nature of QoL and the influence of culture and past experience (Higginson, 2000). Carr et al., (2001) further propose a model of the relation between expectations and experience and identify three areas of difficulty in measuring QoL: people have different expectations; people are at different stages of their illness when QoL is measured and expectations may change over time. By providing health education, information and increasing awareness of risks, patients are helped to adapt to their disability through changing their expectations of health. The person's expectations are thereby matched by current experience and the impact of the disability on their QoL may be reduced (Carr et al., 2001).

Several factors must be considered when measuring QoL. Whilst there is consensus that QoL measurements are multidimensional and cover several domains, disagreement exists about what domains to include and the best methods for rating QoL remain unclear (Mack & Whitehouse, 2001; Muldoon et al, 1998; Farquhar, 1995; Gill & Feinstein, 1994). Structured lists of QoL domains are considered unsatisfactory without knowing which domains are important. Testa & Simonson (1996) recommend that measures of QoL should cover the objective and subjective components important to the relevant patient group that may be affected positively or negatively by interventions. Whilst health status is defined through the objective components, QoL is determined through subjective perception and expectations (Testa & Simonson, 1996: see Figure 3). The subjective perceptions thus translate that objective assessment into the actual QoL experienced (Testa & Simonson's, 1996). Nevertheless, Bowling (2001) cautions that subjective measures are not designed to be used as substitutes for traditional measures of clinical endpoints but are intended to complement existing measures and provide a fuller picture of health state.

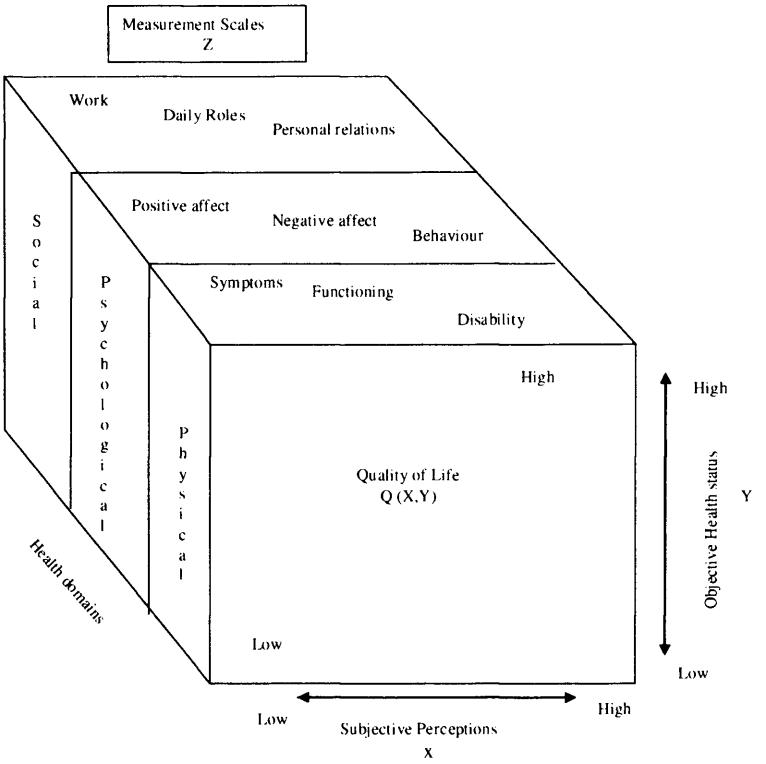


Figure 3: Conceptual Scheme of the Domains and Variables Involved in a Quality-of-Life Assessment (Testa & Simonson, 1996).

1.4.4.2. SUBJECTIVE AND OBJECTIVE DIMENSIONS OF QoL

Objective and subjective measures are both important in measuring QoL. Objective factors are defined as overtly measurable characteristics whereas subjective factors cover individual perceptions and interpretation (McSweeney & Creer, 1995). Objective factors are further elaborated as being primarily needs–based and incorporating basic needs that determine people's well-being in society such as environment and material resources which include levels of income, crime, pollution, transport, housing type, access to amenities and employment (Bond & Corner, 2004; Delhey et al., 2002). Whereas subjective factors include evaluations of life satisfaction and psychological well-being, morale, individual fulfilment, happiness and self-esteem and are expressed in terms of satisfaction, values and perceptions of individual life circumstances (Bowling, 2005). Muldoon et al., (1998) and Whitehouse (1998) argue that although objective components may be easier to measure than subjective components, both are important as individuals experiencing the same objective components may perceive their QoL differently. Moreover a subjective and objective assessment of QoL can be achieved by comparing individual perceptions with the perception of an external observer (Lawton, 1997). Variation among QoL scales is often due to the different emphasis placed on objective and subjective dimensions, which domains are covered and the question format rather than differences in how QoL is defined (Testa & Simonson, 1996). As extreme views on QoL are rare, an inclusive rather than exclusive approach should be used with determinants drawn from demographic, objective or environmental and subjective characteristics (Oliver et al., 1996). Oliver et al., (1996) devised a list of the main categories and contents for measuring QoL, based on consensus about the components which should be included when measuring QoL (see Table 2). As no single, direct measure of life quality exists, it is inferred through its constituents. Thus life quality is best observed as a sum total of its determinants (Oliver et al., 1996). The overall satisfaction an individual has with life is argued to be the most important domain of QoL (Bond & Corner, 2004; Logsdon & Albert, 1999). This means the importance of the individual's personal sense of satisfaction with various areas of life is recognised which includes physical comfort, emotional well-being, and interpersonal connections (Logsdon & Albert, 1999).

Table 2: Categories of commonly acknowledged life quality determinants and examples of their contents (Oliver et al., 1996)

Category	**Contents**	**Examples**
Personal Characteristics	Demographic variables	Age, gender, ethnicity, socio-economic status
Objective quality of life	Social/economic indicators	Social contact, income, housing, employment etc
	Behavioural competence/role performance measures	Social skills. functional ability, life events, activities
	Biological factors	Physical health status and mental state (psychopathology – signs)
Subjective quality of life	Subjective satisfaction	Perceived quality of life (satisfaction with social indicators in life domains) and general satisfaction (congruence between desired and attained goals)
	Mental Health	Positive affect, negative affect (psychopathology – symptoms), affect balance, stress
	Happiness and morale	
	Personality	Self-concept, locus of control, extroversion/introversion
	Adjustment, social adaptation and personal growth	Mastery, independence, values

1.4.4.3. VALIDITY AND RELIABILITY

1.4.4.3.1. Validity of QoL measures

QoL scales should be able to demonstrate validity in that they measure what they intended to measure (Testa & Simonson, 1996). Validity can be difficult to assess as no scale can provide a full picture of people's life quality or be relevant to all individuals (Hickey et al. 1996; Hankiss, 1983). Criteria for assessing the validity of QoL scales are suggested by Feinstein (1987) which includes evaluating the applicability of the questionnaire, its clarity, simplicity, comprehensiveness and likelihood of bias. Scales need to be relevant and also have predictive validity, sensitivity and responsive to change in QoL, particularly for clinically important changes (Haywood et al., 2004; Bowling, 2001; Higginson & Carr, 2001; Testa & Simonson, 1996). This ensures the areas relevant to the patient's QoL are measured and that scales are responsive to the different stages of the disease and interventions or treatment given. Fallowfield (1990) recommends that QoL measures should discriminate between patient groups and identify those patients experiencing good QoL and those that are not. Moreover Higginson & Carr (2001) argue that QoL measures used in clinical practice must be appropriate and acceptable for their intended use and the results meaningful and amenable to clinical interpretation.

1.4.4.3.2. Reliability of QoL measures

Reliability tests the reproducibility of the measure (Bowling, 2001; 1997). Different forms include test-retest reliability and inter/intra rater reliability when the same results are indicated on two different occasions or by two different raters on the same occasion (Cheater, 1998). Orley et al., (1998) argues that QoL is influenced by a broad range of facets and is therefore unlikely to alter markedly from day to day. Longer measures and those administered to a larger sample tend to show higher reliability (Arnold, 1991). Internal consistency involves testing for homogeneity and assumes that there are correlations between items in a scale which reflect a real pattern as to how the questions are answered overtime e.g. mood & life quality. Low correlations may reflect genuine change in health status rather than poor reliability.

1.4.4.4. GENERIC V DISEASE SPECIFIC MEASURES

1.4.4.4.1. Generic measures

A further area of importance and debate in measuring QoL is the use of generic versus disease-specific instruments. Generic instruments offer broader measures of health status and are useful for making comparisons with other conditions, whilst disease specific instruments are used for assessing disease related attributes when greater sensitivity to the clinical condition is required (Bowling, 2001; Testa & Simonson, 1996). Generic measures include single indicators, health profiles, and utility measures. Health profiles attempt to measure all aspects of health related QoL and can be applied across a variety of areas and populations irrespective of the underlying condition. Whilst this may be beneficial in making wider comparisons of the impact of interventions, generic instruments may be unresponsive to changes in specific conditions. Therefore in order to detect significant clinical changes Guyatt et al., (1986) argues that generic measures may need to be supplemented with disease specific measures.

1.4.4.4.2. Disease specific measures

Disease specific instruments aim to be more discerning between levels of a particular disease severity and have increased sensitivity towards clinical outcomes. Orley et al., (1998) argue that disease specific instruments are needed to reflect the issues contributing to that disease. They are more concise and should be able to reflect any clinically significant change in health status or disease severity. The use of disease specific instruments for evaluating therapeutic interventions within clinical trials is therefore recommended (Testa & Simonson, 1996). The use of disease specific measures may however be limited as their narrow focus may not assess the impact of disease or interventions upon wider aspects of life (Cheater, 1998). Furthermore, Guyatt et al., (1993) argue that disease specific measures may be of little use in surveys measuring the range of disability. This view is supported in Mack & Whitehouse (2001) who caution that using disease specific scales may also disadvantage arguments for additional resources. However, Gill & Feinstein (1994) recommend the use of disease specific scales to ensure good face validity, which should include specific domains of measurement that reflect QoL rather than purely health status. As QoL measures should indicate the range of normal activities potentially affected by a condition or its treatment, domain specific or generic instruments tend to be lengthy to ensure sensitivity and adequate psychometric properties (Bowling, 2001). The use of disease specific instruments therefore may avoid asking irrelevant questions and increase the chances of detecting clinically significant changes. It is important that the QoL instruments are chosen to reflect the most relevant outcomes to be measured to satisfy the aims of a study (Cheater, 1998). Essentially the use of both generic and disease specific measures are recommended to ensure assessment of both disease specific and wider aspects of life and to detect positive or negative impacts of intervention (Bowling, 2001; Cheater, 1998; Guyatt et al., 1993).

1.4.4.5. METHODS OF QoL MEASUREMENT

1.4.4.5.1. Self-assessment scales

The use of visual analogue scales (VAS) is a common method for measuring subjective experiences such as QoL, where respondents are asked to indicate the intensity of the attribute being measured (Polit & Hungler, 1995). The VAS consists of a straight line which is anchored at each end with a descriptive label representing the extremes of what is being measured e.g. worst, best. The use of VAS scales are criticised as they are time consuming to complete and may not be relevant to the experience being considered (Fallowfield, 1990). The variables being measured may also lack weighting and the clinical significance of changes in scores may not be obvious.

Self reports can also be obtained using standardised measures that have response formats with closed questions in a categorical dichotomous format (e.g. yes/no) or sequences of categorised responses (e.g. strongly agree, agree, disagree, strongly disagree). Brod & Stewart, (1994) and Jaeschke et al., (1990) found people with dementia prefer multiple rating scale points to dichotomy responses and Likert categorical scales are considered easier to administer, analyse and interpret (Brod & Stewart, 1994; Jaeschke et al., 1990). Standardised measures have fixed questions and a range of answers and Carr & Higginson (2001) caution that these may not measure patients QoL unless scores are weighted for the individual patient. Individual weightings are important for obtaining a true assessment of QoL and being responsive to change. Scores may be calculated for each domain separately or combined to provide a composite or index score. The disadvantage of scales that are calculated to produce an overall score is that the total may result from several combinations of responses thus leading to a lack of information about the individual components of the scale (Bowling, 1997).

1.4.4.5.2. Utility assessments

Utility measures of QoL originate from economic and decision theory and are considered to reflect the health status and value of that health status to a patient (Guyatt et al., 1993). They are used to assess cost-effectiveness in health care. When applying utility measures, values are placed on different health states and the preference of a particular health outcome is determined through calculating a single summary score (Bowling, 2001). Health related QoL is depicted as a single number along a continuum that stretches from full health (1.0) to death (0.0) or less for states considered worse than death. A common utility measure is quality adjusted life years (QALY) which are used as indicators of health gain for health service resource allocation. QALYs integrate two concepts, life expectancy and life quality that offer a mathematical outcome for rationing the allocation of health service resources (Oliver et al, 1997). Although offering a utilitarian argument for determining the greatest health gain for the greatest number, QALYs are criticised as being ageist and for focusing on cure rather than care and their use courts controversy as this marginalises the most disabled, elderly and chronically ill (Bowling, 1997). Older people have a shorter life expectancy in comparison to younger people. A further criticism of using QALYs is that the ‘disability paradox’, where QoL scores do not appear commensurate with the patient’s health status, prevents direct comparisons of different patient groups for allocating resources (Higginson & Carr, 2001).

1.4.4.5.3. Composite scores

Overall satisfaction with life can be determined through a global (or composite) rating of QoL, however this is controversial as QoL is an inherently multidimensional concept (Bowling, 2005; Lawton, 1991). Farquhar (1995) questions who should decide which dimensions are weighted or indeed who decides which dimensions define QoL. Subjective indicators of well-being or health are considered more influential than objective, economic or socio-demographic components in accounting for variance within QoL measures (Bowling et al., 2002). Gill & Feinstein (1994) advocate the use of a global rating through aggregating the scores of individual QoL domains as this explains QoL more comprehensively and they encourage more explicit criteria or weighting of the different components that construct QoL. Furthermore global ratings have been considered more acceptable for use in clinical trials as change in QoL could be more easily distinguished. In addition, the use of a global QoL rating as a dependent variable is considered logical for establishing causal relationships influencing QoL (Fayers & Hand, 2002; Beckie & Hayduk, 1997). Alternatively Muldoon et al., (1998) and Lawton (1997) both argue that the use of a composite score fails to recognise QoL measures as being multi-dimensional and that it is illogical to aggregate scores that combine appraisals of objective measures of behaviour, function and subjective wellbeing and there is a need to evaluate individual domains separately within research and clinical practice (Lawton, 1997; Lawton, 1991; Hughes, 1990).

1.4.4.6. QoL ASSESSMENTS IN HEALTH

If outcome measures in health must take into account the patients' perspective, QoL measures that are based on practitioner or expert perspectives may not adequately reflect the views of patients (Cheater, 1998). Significantly it is the patients own perceptions of their symptoms and feeling that are most closely associated with their use of health services (Bowling, 2001). Furthermore it is possible that a person may feel unwell without any medical abnormalities being detected. Slevin et al., (1998) argue that if health professional assessments of QOL are to be meaningful and reliable they should reflect patient perceptions. Their study of 108 patients with cancer showed that doctors did not accurately measure patients QoL, suggesting they have insufficient knowledge of the patients' feelings. Guyatt et al., (1993) also discuss discrepancies between self and proxy responses to health related QoL measures. They note that perceptions of QoL varied depending on the domains being assessed and the choice of proxy. Here the evidence is conflicting as some studies show higher agreement between spousal proxy and self ratings, whilst others studies suggest that subject/proxy relationship is not a significant predictor of agreement (Magaziner, 1992). Higher levels of agreement have been detected for observable domains of QoL such as physical function and cognition. Whereas proxy respondents tend to rate patients as being more impaired for measures of functional ability (Yasuda et al., 2004; Rothman et al., 1991). Guyatt et al., (1993) advise that clinicians should focus on patient perceptions and limit the influence of caregiver proxy perceptions. Nevertheless, Yip et al., (2001) argue that there is a need for reliable proxy respondents. They examined the level of agreement between proxy and self-respondents using the Short-Form 36 (SF-36) health related QoL instrument in a community sample of 32 pairs of subjects over 65 years and their proxies. The proxy responses were based on ‘how the subject would rate their own QoL’ rather than the proxies perception of the subjects QoL. The proxies were found to underestimate the subjects’ perceptions of QoL although higher agreement was observed in those proxies and subjects who were co-resident. The validity of asking a proxy to suggest how another person perceives their QoL is questionable as it can be argued the proxy is still providing their own perception. Individual self-reports are considered the ideal for assessing health related QoL (Bowling, 2001; Muldoon et al., 1998; Gill & Feinstein, 1994). Proxy measures may however be needed for those respondents unable to complete QoL measures.

Individuals change with time and the basis on which they perceive their QoL may change, this phenomenon is known as response shift. Response shift refers to a change in the meaning of a person’s self-evaluation of QoL due to a change in their internal standards of measurement, their values, or conceptualisation of QoL

(Sprangers & Schwartz, 1999). A model to explain the impact of response shift on health-related QoL is offered which has 5 major components: catalyst (change in health status); antecedents (individual characteristics); mechanisms (behavioural, cognitive and affective processes); response shift (redefining QoL) and perceived QoL. The use of downward or upward social comparisons can influence the individuals interpretation of the situation and impact on their perception of QoL through comparisons with others more or less fortunate than themselves. The antecedents and mechanisms therefore bring about the response shift and the subsequent perception of reduced, maintained or improved QoL (Sprangers & Schwartz, 1999). Beaumont & Kenealy (2004) examined the influence of social comparisons and perceptions of QoL and their study assumed that judgments of QoL are perceived through making positive or negative social comparisons with others and outlined four social comparison strategies: upward identification, upward contrast, downward identification and downward contrast. There were 190 healthy older adults included in the study which found perceptions of higher QoL were associated with downward contrasts where judgements are made with reference to individuals viewed as having a poorer quality of life (Beaumont & Kenealy, 2004). Schwartz et al., (2007) recommend that the design of new QoL scales should incorporate the assessment of response shift and that focusing on the appraisal processes and comparing measures between patient and healthy control groups may lead to a better understanding of the disability paradox.

1.4.4.7. MEASURING QoL IN MENTAL ILLNESS

Orley et al., (1998) discuss the use of QoL measures in psychiatric patients and consider how QoL ratings may be affected by the impact of the disorder through disturbed affect or thinking and through institutionalisation. It is argued that whilst psychiatric symptoms such as depression may affect a persons' QoL they do not distort it or make their perceptions invalid. In addition, whilst the impact of institutionalisation may mean psychiatric patients perceive a good QoL due to lowered expectations their assessments are still considered valid. Proxy ratings have been advised for those patients with cognitive impairment but Orley et al., (1998) caution that whilst these may be useful for planning and evaluating care they should not be taken as a measure of perceived QoL. Difficulties are routinely assumed in people with dementia providing subjective assessments of their QoL or care, owing to limitations of comprehension and reliability (Stewart et al., 1996). Feinberg & Whitlatch, (2001) investigated the decision-making capacity of 51 people with mild to moderate dementia and their family caregivers. Their study found that people with dementia could provide accurate and reliable responses to questions about preferences, choices and their own involvement in decisions about daily living. A good level of agreement with family caregiver responses was also observed but they conclude that the perceptions of the person with dementia are preferred and can be used to influence care provision.

1.4.4.8. MEASURING QoL IN OLDER AGE

Individual perceptions are essential in assessing health related QoL in people of all age groups. A fifth of older adults living in the community and half of those living in institutions are reluctant or unable to be interviewed (Magaziner, 1992). Studies have looked at the ability of older people to rate their own QoL. Livingston et al., (1998) administered the Index of Health-Related Quality of Life (IHQL; Rosser et al., 1992) to a community sample of 782 older people aged 65 years and older. Their study found that three quarters of the respondents were able to complete the IHQL and the other measures used, and interestingly this also included those people with dementia. Those experiencing somatic symptoms or subjective memory impairment were less likely to complete the questionnaires. Pettit et al., (2001) administered the

12-item Health Status Questionnaire (HSQ-12; Radosevich & Pruitt, 1996) or the 12-item Short Form Health Survey (SF-12; Ware et al., 1996) to a community sample of 1085 older people over 65 years of age. They found that both Health-Related QoL measures were acceptable and valid for use within this population. Completion rates were lower in those subjects with dementia and the SF-12 was found not to distinguish between those people with dementia and those without. It is clear therefore that most older people and those experiencing dementia are able to complete instruments assessing their own QoL.

1.4.5. IN CONCLUSION

To summarise, QoL lacks a standard definition but it is agreed to be a multidimensional concept which overall is subjective in nature. Whilst the conceptualisation of QoL involves both objective and subjective domains emphasis is placed on the individual subjective ratings of overall QoL. Within health, HRQoL provides a global measure of wellbeing in patients and is an appropriate outcome measure for the assessment of disease impact and interventions provided. A debate surrounds the measurement of QoL and as discussed there are several methodological factors to consider when undertaking QoL assessments within research, particularly whether measures should be disease specific or global; informant or subject completed, and leading to a composite score or domain scores. The consensus opinion indicates where possible individual perceptions should be sought in preference to the views of others as they often differ and this has implications for the application of QoL measures in dementia. Measures of QoL in dementia need to consider factors in dementia that may have positive and negative influences on QoL. These will be discussed in the next section of this thesis.

1.5. FACTORS AFFECTING QUALITY OF LIFE IN DEMENTIA

> *'Men are disturbed not by things, but by the view which they take of them'*
>
> *(Epictetus, 1st century AD)*

1.5.1. QoL AND CHRONIC DISORDERS

Interest in the conceptualisation of QoL and its measurement is attributed to the ethical and economic concerns associated with the ageing population and the concomitant increase in chronic illness and disability. Birren & Dieckmann (1991) identify three main areas of concern, first is the impact on health service resources and the potential financial burden anticipated, second is the intrusive use of medical technologies and third is the QoL for people in institutions. In chronic illness, people can suffer both from the disability and from the treatment (Velarde-Juradon & Avila-Figuero., 2002). Moreover treatment can often result in limited gains in terms of survival, or absence of cure, which poses a challenge as to whether they should be offered. Aggressive interventions and those with side-effects may have therapeutic benefits that are overshadowed by the negative effects, thus leading to reduced QoL overall. Therefore the detrimental impact on QoL needs to be weighed against the advantages offered through treatment (Fayers & De Haes, 1995). It is the individual's perception that predicts whether they seek help, accept treatment or regard themselves to be well and recovered, and therefore measures of outcome should take account of individual's self-assessments (Bowling, 1991). The use of subjective health measures can be used to help provide a fuller picture of the individual's health state.

1.5.2. QoL IN DEMENTIA

Human needs are the basis for QoL and Hornquist (1982) suggests that QoL is the degree of fulfilment of those needs (such as psychological, social, physical, activity, marital and structural). Therefore it is pertinent to examine the importance of QoL within dementia. Dementia is a complex disorder, the course of the disease is not straightforward and it has multiple causes and domains. Accordingly, dementia can have significant psychological and social consequences. As a wide range of therapeutic interventions and possible outcomes are available in the management of dementia, QoL is considered to offer a common language for evaluating the effectiveness of treatment (Mack & Whitehouse, 2001). The concept of QoL in dementia is a comparatively recent occurrence and within the context of dementia is defined as 'the integration of cognitive functioning, activities of daily living, social interactions and psychological well-being' (Whitehouse et al., 1997). Psychological well-being was identified as the most important element of QoL measurement in dementia due to its subjective nature, and the need to include patient perceptions has been highlighted (Walker et al., 1998). Brod & Stewart (1999) stated that the behaviour and emotions associated with the QoL domains are determined by the presence of the disorder, and devised a conceptual model of dementia-specific QoL (see Figure 4). For the concept of QoL to have any value as an outcome measure it must be 'operationalised', in that decisions are made as to what is to be measured and the agreed concepts defined and translated into an observable form (Bowling, 2001).

A similar conceptual framework of health related QoL specific to people with dementia was devised by Smith et al., (2005a). Based on reports from people with dementia and their caregivers five domains were identified: activities of daily living and looking after yourself, health and well-being, cognitive functioning, social relationships and self-concept. Caregiver proxies had difficulty separating the impact of dementia on their own lives from the impact on the person with dementia. In addition, several differences were observed between self and proxy reports and concerns were expressed regarding the appropriate use of proxy reports. Caution should therefore be exercised when substituting proxy ratings for self ratings of QoL for people with dementia.

The need for a conceptual model of QoL in people with severe dementia was identified by Volicer et al., (1999). Due to difficulties with communication and comprehension, they used observational methods using visual analogue scales. The three components of psychological well-being included positive and negative affect and were seen as being on a continuum: happy-sad mood, engagement-apathy, agitation-calm. The use of 'outwardly' expressed characteristics was considered to offer easily recognisable indicators of the person with dementia's emotional state. Engagement in appropriate and meaningful activity was considered to be the best way to achieve optimal psychological well-being in people with severe dementia.

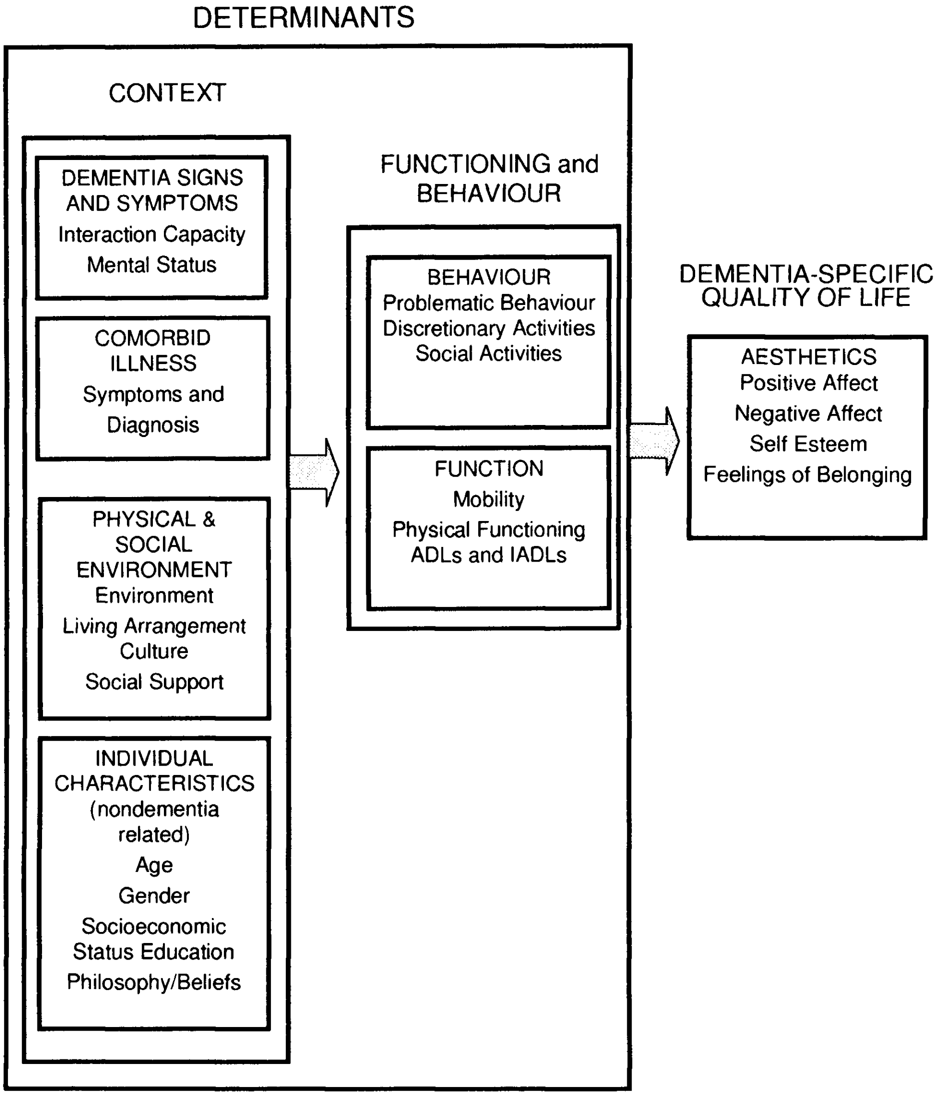


Figure 4: Conceptual Model of QoL in Dementia and its Determinants (Brod et al., 1999)

1.5.3. COMORBIDITY AND DEMENTIA

Mental and neuropsychiatric behavioural disturbances are a common occurrence affecting most people with dementia, irrespective of the cause and stage of the disorder (Lyketsos et al., 2000). Recent studies found that delusions, depression, aberrant motor behaviour and irritability were the most persistent neuropsychiatric symptoms (Ryu et al., 2005; Steinberg et al., 2004). Increased neuropsychiatric disturbances especially apathy and visual hallucinations, add to caregiver burden and are associated with advancing age and poorer cognition (Craig et al., 2005; Cummings et al., 1994). Of these apathy and depression are the two neuropsychiatric symptoms most frequently associated with dementia, and apathy is considered the most common neuropsychiatric symptom in AD, increasing with dementia severity and impairment in activities of daily living (ADL) (Assal & Cummings, 2002). Apathy may be an indicator of distress in dementia which overlaps with depression and Starkstein et al, (2001), found apathy in AD was associated with impaired activity of daily living and cognitive skills, older age and lack of insight, which was irrespective of the presence of depressive symptoms. A recent study found depression was prevalent across 25% of people with dementia living in the community and those that took exercise were less likely to be depressed (Regan et al., 2005). In contrast, anxiety levels were associated with feelings of generalised anxiety; disturbed sleep patterns and worry over somatic complaints were observed to decline with dementia severity (Forsell et al, 1993). Treatment of both depression and anxiety in dementia can be effective and may help increase functional ability, improve QoL and decrease caregiver burden (Shankar & Orrell, 2000; Tekin & Cummings, 2001).

1.5.4. FUNCTIONAL ABILITY AND DEMENTIA

There are four domains of functional competence: cognition, motor behaviour, biological health and sensation-perception (Whittle & Goldenberg, 1996). Competence in activities of daily living (ADL) can be divided into instrumental activities of daily living (IADL) or basic ADL. IADL refer to complex and demanding tasks that include household chores (cooking, cleaning, laundry); mobility (shopping, using transport); cognitive activities (managing finances, using the telephone, taking medications). Basic ADL refers to common everyday tasks such as: bathing, dressing, using the toilet, transferring, continence and feeding. Whilst basic ADL are a measure of physical function, IADLs reflect measures of physical functional performance and social activity (Aguero-Torres et al., 2001).

Andersen et al's (2004) study found that HRQoL in people with dementia was significantly affected by their dependency status, based on their ability to perform ADL. Global measures of dependency were thus suggested as an indirect evaluation of QoL as levels of functional ability are known to decrease as cognition worsens. For people with dementia an inability to perform activities of daily living (ADL) was associated with the progression of the disorder, loss of QoL and increased resource use (Kurz et al., 2003). A decline in instrumental ADL is usually observed before the reduction in basic ADL skills in people with dementia (Galasko et al., 1995). A recent study examined levels of cognition, function and caregiver time and found a marked increase in dependency status for people with a MMSE <16 (Feldman et al., 2005). The study included 331 people with AD living in community and institutional settings and the amount of formal caregiver time was observed to double in the proceeding 12 months from baseline for people with MMSE of 15. However, agreement between family proxy ratings, observed performance and self-ratings of functional health are considered poor (Yasuda et al., 2004). Family proxy ratings show greater disability levels for physical, instrumental and affective functioning and less disability in cognitive function. Furthermore, in a study of physical and instrumental function in people with dementia, over two years, proxy and self ratings of ability were observed to become increasingly discordant over time (Kiyak, et al., 1994).

1.5.5. ENVIRONMENTAL FACTORS AND DEMENTIA

Advancing dementia is one of the principal indicators for placement in long-term care settings and up to 90% of people with dementia are reported to enter an institution prior to death (Yaffe et al., 2002). Other predictors influencing placement into long-term care include caregiver burden and depression, living alone, reduced independence; behavioural disturbances such as physical and verbal aggression; perseveration and incontinence, (De Jonghe et al., 2003; Yaffe et al., 2002; Dunkin & Anderson-Hanley, 1998; Levin et al., 1994; Jerrom et al., 1993; Brodaty et al., 1993). The choice of setting (nursing or residential care), is influenced by level of cognitive impairment, functional dependency; age and location prior to admission e.g. own home or hospital. Nursing home choice is influenced more by age, increased cognitive deficits and hospitalisation prior to admission (Lee et al., 2001). The prevalence of dementia is estimated to be between 50-74% in nursing homes, and 23-42% for residential and assisted living facilities (Zimmerman et al., 2003; Macdonald et al., 2002).

Behavioural disturbances are a common feature in care home residents, but particularly in those with dementia and may be due to environmental as well as physical and psychological difficulties (Moniz-Cook et al., 2001; Allen-Burge et al., 1999; Alexopolous et al., 1998a). Gonzalez-Salvador et al's., (2000) study found QoL was higher for residents with dementia in assisted living facilities compared to those living in nursing care, and lower ratings of QoL by staff were associated with disorientation, physical dependence and anxiolytic treatment.

Health and functional status are influenced positively and negatively by the care provided, which in turn will affect QoL (Kane, 2003). In comparison to people with physical impairment Gessert et al., (2005) found paid caregivers of long-term care rated all aspects of QoL less important in people with dementia, which they also perceived as being more difficult to influence. The needs of people with dementia in care homes are complex and daytime activities, behavioural problems and company are the most common unmet needs identified for residents with dementia (Hancock et al., 2006; Martin et al., 2002). Kane (2003) challenges the stereotypical perception of nursing homes as: sterile; disciplined; lacking in privacy and meaningful activities; unable to meet individual needs and preferences; or sustain QoL; and cites examples of reforms in care including increasing resident choice, participation and independence. Eleven outcomes of long-term care provision were identified by Kane (2001), which related to the physiological, functional, cognition, affect, social activities and satisfaction dimensions of QoL (see figure 5). The residents self rating was considered the gold standard and scales were completed satisfactorily in 60% of nursing home residents with dementia. The need for privacy and enjoyment was found difficult to measure reliably in the more cognitively impaired residents (Kane et al., 2003). These findings do suggest however that QoL can be measured in residents with dementia living in care settings.

Outcome measures such as individual need or QoL are important for care settings, despite being given a low priority (Gessert et al., 2005; Kane et al., 2003; Gonzalez-Salvador et al., 2000). The needs of people with dementia in care homes are significantly higher than for people in sheltered accommodation, or living in the community (Hancock et al., 2006). Leon et al., (1998) examined the relationship between AD severity, care setting and health-related QoL (using Health Utilities Index), caregiver time and burden, health status and service utilisation, across all dementia severities and care settings. Little variance in QoL ratings was found across the care settings, or the range of disease severity, although poorer health status was evident in the caregivers of community patients. Lower QoL was associated with increased dementia severity but was scored higher for community patients.

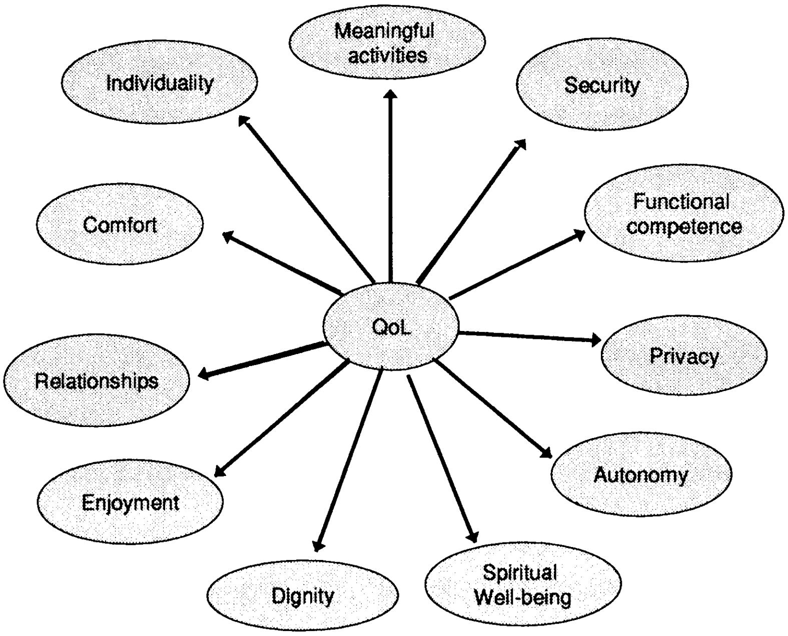


Figure 5: QoL domains pertinent to long-term care provision (Kane et al., 2003)

1.5.6. CAREGIVERS AND DEMENTIA

The majority of people with dementia live in the community and are cared for by a relative or friend (Rabins, 1998). Caregivers are a diverse group which can make investigating their needs particularly difficult. Most caregivers provide support to a relative; usually a parent or spouse although not all caregivers are related to the person they care for (BMA, 2004). Caregivers are essential in supporting people with dementia to remain in the community and lack of a caregiver is a predictor of nursing home placement (Brodaty et al., 1993). Whilst caring takes place within the context of love, duty and obligation (SSI, 1995), caregivers can experience adverse psychological, physical, social and financial consequences known as caregiver burden (George & Gwyther, 1986). It is the non-cognitive features of dementia such as psychotic symptoms and depression which are associated with increased difficulty for caregivers and behavioural disturbances are identified as the most consistent predictor of caregiver burden (Banerjee et al., 2006; Coen et al., 1999; Donaldson et al., 1997). Caregivers of people with dementia have higher stress levels than other caregivers and their psychological well-being influences the ability to continue caring for the person with dementia (Rosenvinge et al., 1998; Dunkin & Anderson-Hanley, 1998; Levin et al., 1994). The risk of depression is higher in caregivers of people with dementia and its prevalence is estimated at between 40-60%, with spousal caregivers and females being identified at most risk (Livingston et al., 1996; Redinbaugh et al., 1995; George & Gwyther, 1986). A recent UK study found higher incidence of anxiety caseness than depression in caregivers of people with dementia and suggested this may be because caregiver depression is being effectively targeted (Mahoney et al., 2005). Moreover, the study identified risk factors for both anxiety and depressive symptoms that included poor caregiver health, irritability in the person with dementia and the quality of the relationship between the caregiver and care recipient. Conversely, Waite et al's (2004) investigation of social factors and depression in caregivers found associations with; depression in the person with dementia, and living together. Depression in caregivers was not related to life events, the availability of a confidant, or the quality of the relationship. The availability of formal support from health and social services and informal support from family and friends can be of benefit in reducing caregiver burden, although increased use of services is associated with higher levels of stress in caregivers (Jerrom et al., 1993). Brodaty et al., (2005) investigated the reasons for non-use of community services such as home help, community nurses, meal services, transport and respite services, in caregivers of people with dementia in Australia. The main reasons for non-use of services were a perceived lack of need for services and the person with dementia's reluctance to accept help. Brodaty et al., (2005) found that 1 in 3 caregivers were not receiving any services whilst 1 in 4 had only one; most caregivers denied a need for services despite the presence of caregiver burden.

1.5.7. INTERVENTIONS IN DEMENTIA

1.5.7.1. ACTIVITIES

Non-pharmaceutical interventions include the provision of therapeutic activities, education and psychological support and there is increasing evidence to support the benefits of psychosocial and behavioural interventions in dementia (Burns, 2004). Therapeutic activities are undertaken in dementia to maintain or enhance cognitive functioning, promote independence and increase QoL, alongside providing enjoyment, meaningful activity and encouraging interaction with others and the environment (Marshall & Hutchinson, 2001). Three broad categories of therapeutic interventions are described, namely social and diversional, cognitive, and alternative therapies (Pulsford, 1997). Social and diversional activities incorporate recreational pursuits; current events; entertainment and physical exercise. Cognitive based therapies include reality orientation; life-review; reminiscence and validation therapy. Alternative therapies include multi-sensory environments; drama, art and music therapy. The literature regarding activities in dementia has been examined (Marshall & Hutchinson, 2001; Pulsford, 1997). Whilst the effectiveness of undertaking activities were apparent, criticism of the studies included methodological weakness such as lack of theoretical frameworks, profiling of disease diagnosis and severity, inadequate sample size and appropriate outcome measurement. However, more robustly designed studies have been undertaken which showed the positive benefits of activities for people with dementia (Teri et al., 2003; Spector et al., 2003). Teri et al., (2003) implemented a randomised exercise plus behavioural management programme for people with AD and their caregivers over 3 months. The success of the programme was indicated by improvements in physical health and depression for the person with dementia, caregiver benefits were not however measured. Spector et al., (2003) examined the effectiveness of a randomised controlled trial of a cognitive stimulation therapy programme that incorporated reality orientation and was undertaken twice weekly for seven weeks. Significant improvements in cognition and QoL were observed and considered comparative to the benefits of taking anticholinesterase medication. The lack of provision of therapeutic activities within care settings for people with dementia is an area of major concern and considered dependent on the attitude and skills of staff (Perrin, 1997; Pulsford, 1997). Perrin (1997) used dementia care mapping to assess occupational need for people with severe dementia in care settings. A distinct lack of occupation was apparent within the 9 hospital and residential settings assessed which resulted in reduced interaction, increased withdrawal and aimless wandering. The only significant active behaviour evident was food related. Perrin (1997) suggests that people with severe cognitive impairment have reduced awareness of the environment other than their immediate surroundings and that the quality of the environment has less impact on their psychological well-being. This concurs with Kane (2003) who states that QoL is not influenced by care or care environment but by the characteristics known to affect QoL.

1.5.7.2. CAREGIVER INTERVENTIONS

The British Medical Association (BMA, 2004) identified that the needs of Carers were for respite; reliable and satisfactory services; information; recognition of their role and contribution, care of their own health and someone to talk to. Psychosocial interventions and support for caregivers of people with dementia are paramount in reducing caregiver stress and burden and include education and information; skills training; support groups and counselling (Burns, 2004). The benefits of peer support include shared experiences and reduced isolation which most caregivers find helpful (Zarit et al., 2004). However group interventions were found less effective than individual interventions at reducing caregiver distress (Brodaty et al., 2003a; Coen et al., 1999; Knight et al., 1993). Unsuccessful interventions included short educational programs, single interviews and support groups alone. Marriot et al., (2000) undertook a randomised cognitive-behavioural family intervention incorporating caregiver education, stress management and coping skills training, implemented over 14 session at two-weekly intervals. The model was effective in significantly reducing burden in caregivers and behavioural disturbances in the people with dementia. Providing information only to caregivers had no effect on burden.

Several reviews of interventions with caregivers of people with dementia have been undertaken and the evidence found to be conflicting (Brodaty et al., 2003a; Sorensen et al., 2002; Schulz et al., 2002; Cooke et al., 2001; Pusey & Richards, 2001). Methodological criticisms include design weakness such as inadequate samples, limited power and effect size; insufficient information regarding procedures and the people delivering interventions; the broad range of outcome measures and multiple statistical comparisons; definitions of a caregiver vary widely making generalisation difficult and caregiver burden measures are insensitive to change. Cooke et al., (2001) found little evidence of consistent benefits for caregiver's except for improving caregiver knowledge of dementia, which was considered unrelated to psychological and social outcomes. Sorensen at al., (2002) and Schulz et al., (2002) conclude interventions are successful in alleviating burden and depression with benefits to caregiver knowledge and ability, but spousal caregivers benefit less than adult children. Individual interventions are more effective at improving caregiver well-being whereas interventions in groups help improve the symptoms of dementia (Sorensen at al., 2002; Pusey & Richards, 2001). Pusey &

Richards (2001), conclude the best evidence of efficacy was interventions closest to the psychosocial intervention model of expressed emotion, stress-vulnerability model and cognitive behavioural approaches (Baguley & Baguley, 1999), most specifically problem solving and behavioural management approaches.

1.5.7.3. PHARMACOLOGICAL INTERVENTION

The principal aims of treatment in dementia are to improve cognition; mood and behaviour thereby promoting optimum functional performance and improving QoL (Small et al., 1997). Four medications are currently approved for the treatment of AD in the UK; there are 3 Acetylcholinesterase Inhibitors (AChEI): Donepezil a reversible inhibitor of acetylcholinesterase; Galantamine a reversible inhibitor of acetylcholinesterase that has nicotinic receptor agonist properties and Rivastigmine a reversible non-competitive inhibitor of acetylcholinesterases and Memantine an N-methyl-D-aspartate (NMDA) antagonist (BNF, 2005). AChEI's help delay the progression of AD in people with mild to moderate dementia and reduce neuropsyschiatric symptoms and functional impairment (Trinh et al., 2003; Clark & Karlawish, 2003; Francis et al., 1999) and in the UK their use is restricted to people with moderate dementia (NICE, 2006). Whilst Memantine has shown improvements in functional ability and decreased care dependence in people with severe dementia (Forstl, 2000). The benefits of AChEI's are considered important as neuropsychiatric symptoms contribute to the loss of autonomy, morbidity and need for long-term care placement (Trinh et al., 2003). The treatment effects observed in Donepezil have been maintained over long periods of at least 2 years and Francis et al., (1999) recommend a 3 month trial on AChEI's for anyone diagnosed with AD, particularly as prediction of responders/non-responders is not possible. The guidelines for prescribing of AChEI's have recently been revised as their cost effectiveness is questioned and improved evidence of how AChEI's impact on QoL is needed (NICE, 2006; Overshott & Burns, 2005). Simpson et al., (2005) argue that AChEI's have shown benefits for people with dementia both within and outside of the established criteria and stopping AChEI medication increases the risk of mortality and a marked deterioration in patients.

Antipsychotic medications are a common treatment for the reduction of behavioural disturbance in dementia and are commonly used in care homes (Smith & Beier, 2004; Macdonald et al., 2002). Non pharmacological (psychosocial) interventions are considered the preferred option and pharmacological options should only be introduced when these prove ineffective (Small et al., 1997). Use of antipsychotic medication in non-EMI (Elderly Mentally Infirm) nursing homes was strongly linked with the presence of dementia in residents but was only prescribed for 15.3% of the population surveyed and did not seem inappropriate (Macdonald et al., 2002). Antidepressants were observed to be prescribed for 25% of the population and the treatment of depression in dementia is encouraged. An increased risk of cerebrovascular adverse events has been associated with antipsychotic use in people with dementia and their prescription has now become limited (Smith & Beier, 2004; Brodaty et al., 2003b; Katz et al., 1999). AChEI's are known to reduce neuropsychiatric symptoms in AD and there use as an alternative treatment for the management of behavioural disturbances is indicated (Trinh et al., 2003; Clark & Karlawish, 2003).

1.5.8. IN CONCLUSION

To summarise, dementia is a complex disorder with significant psychological and social consequences that can affect the well-being of both the individual and their caregiver. Difficulties persist due to the presence of concomitant mental disorder and physical frailty, and whilst their manifestation helps shape the decisions about the person's care and treatment, these too can subsequently have as significant an impact on the person with dementia. Moreover dementia is a disease that not only affects the individual but significantly impinges on the lives of their family and friends too. Conversely the experience of dementia can be influenced more positively by the provision of appropriate interventions, including activities, medication and caregiver support which are not currently provided consistently. Further evidence is however needed to show the influence of the different factors identified and to demonstrate the efficacy of the interventions available and their impact on QoL. The next section of this thesis will explore how QoL can be measured within dementia and examine its application within this field.

1.6. ASSESSING QUALITY OF LIFE IN DEMENTIA

> *'But to say that existence is not sufficient reason for an individual to be recognized as human is to totally exclude the physical dimension of man'*
>
> *(Weber, 1973)*

The number of people with dementia is increasing and so is its impact. The progression of dementia is non-linear and has multiple causes and outcomes and is a complex disorder when compared with other health states (Mack & Whitehouse, 2001). The debilitating and degenerative nature of dementia affecting cognition and function means assessing QoL in dementia offers a unique challenge to health professionals. Logsdon & Albert (1999) argue that QoL assessments are needed for evaluating the effectiveness and impact of the therapeutic interventions available for AD. They further suggest that QoL measures could also be used to refine measures of disease severity and predict time to disease end points as assessment of QoL varies in people with dementia who have comparable levels of cognitive impairment. In addition, measuring QoL can assess how disabling dementia is and indicate the anticipated benefits of slowing disease progression or delaying its onset. Moreover, Walker et al., (1998) argue that measuring QoL in dementia is as important as measures of disease severity and progression, symptom response, cognition, behavioural disturbance and activities of daily living for assessments of disease impact. Measures of QoL are fundamental for not only reflecting the impact of the disease on the individual but also on those providing care for the person with dementia. Cost is another significant factor as the increase in incidence of dementia has implications for health resources and caregiver burden. Jonnson et al., (2000) discuss how studies involving the cost of care in dementia have focused on cognition, when it is behavioural and psychological symptoms that impact on patient and caregiver QoL and influence decisions around care provision, particularly long term care placement. Banerjee et al., (2006) also argues that QoL in dementia is more strongly linked to behavioural and psychological disturbance rather than limitations in cognition and function and recommend that QoL measures be included when assessing the effectiveness of interventions in dementia. The use of QoL as an outcome measure in assessing the impact of interventions and treatment in dementia may therefore be of benefit in supporting arguments for resource allocation. There are several key areas for consideration in the assessment of QoL in dementia. Firstly, what are the best ways to measure QoL in dementia? Second, is how does QoL change as the dementia progresses and third is how to best measure the effects of interventions in dementia and their impact on QoL?

1.6.1. METHODS FOR MEASURING QoL IN DEMENTIA

1.6.1.1. SELF-RATINGS OF QOL IN DEMENTIA

Whitehouse (1999) describes assessment of QoL as the principal area for development in QoL research in dementia and states there are three complementary approaches, which are self ratings, caregiver proxy ratings and direct observation. The ability of people with dementia to assess their own QoL of life has been questioned due to its subjective nature. Difficulties are loss of cognitive ability, lack of insight and awareness of deficits (anosognosia) and reduced language and communication skills which may affect the person with dementia's ability to comprehend and provide appropriate responses (Selai & Trimble, 1999; Walker et al., 1998; Kerner et al., 1998). Providing an answer does not mean that the question is necessarily understood, QoL may also be perceived differently as the disease progresses (Ettema et al., 2005). However, Lawton et al., (1999) say it is logical to assume that they will have likes and dislikes. Even in the more profound stages of dementia it is possible to display preferences and aversions through emotional expression. Lawton (1997) reasons that although subjective measures demand a degree of cognitive skill people with dementia can provide reliable assessments of their mood and QoL. Brod & Stewart (1994) found that people with dementia were able to complete structured short items scales and showed a preference for multiple rating scale point to dichotomy responses. Several studies have now shown that QoL can be reliably measured in people with mild to moderate dementia using self rating QoL scales (Logsdon et al., 1999; Brod et al., 1999; Selai et al., 2001a) and one of these studies included people with severe dementia (Thorgrimsen et al., 2003). What is not clear is the stage of dementia when self-report of QoL is no longer possible.

1.6.1.2. PROXY RATINGS OF QoL IN DEMENTIA

Proxy ratings involve a judgement of the person with dementia's QoL being made by another person to whom they are known and may be provided by a formal or informal caregiver. Due to the debilitating nature of dementia, proxy ratings are frequently used alongside or as an alternative to the person with dementia's own rating of QoL. Proxy reports may be the only source of information available, particularly for those people experiencing severe levels of cognitive impairment (Magaziner, 1997). Rabins et al., (1999) maintain that the use of a proxy for rating QoL in dementia is the best way to ensure personhood is respected throughout the illness and that the influence of caregiver characteristics on responses is reduced by requesting objective rather than subjective judgments about observable behaviours. Kane et al., (2003) contests that proxy judgement should be the sole source of QoL assessment as discrepancies exist between caregiver and people with dementia's own perceptions of QoL. Proxy ratings have however been shown to be a reliable and valid indicator of patient QoL (Karlawish et al., 2001; Albert et al., 1999). Nevertheless, proxies impose there own judgment on QoL ratings, and in dementia these are thought to be influenced by feelings of caregiver burden and depression (Karlawish et al, 2001; Logsdon et al., 1999). Several studies have examined caregiver proxy ratings in comparison to self ratings for people with dementia and will be discussed in more detail in Section 1.6.2. of this Thesis. Whilst proxy ratings may be considered necessary as dementia progresses the inclusion of the individual's own rating of QoL is often considered most valuable and the preferred method for assessment of QoL in dementia, as QoL ultimately reflects the person's with the disease experience (Brod & Stewart, 1999; Walker et al., 1998).

1.6.1.3. DIRECT OBSERVATION OF QoL IN DEMENTIA

Observational methods are undertaken either through direct observation of the person with dementia which records the frequency that certain behaviours present or by applying attribute ratings of observed affect states over time. Direct observation is time consuming and costly, but provides the most objective method of rating QoL in dementia as the subjective component is removed (Whitehouse, 1999; Lawton, 1997). Observation requires a degree of interpretation by the rater and training to ensure they do not influence the behaviour observed. In addition, multiple observations of the same individual are needed to achieve a consistent result and cannot be limited to the 'working day' of the observer (Kane, 2003). Observational tools have however been devised that can be used to reliably measure health related QoL and well-being in people with dementia (Lawton et al., 1999; Kitwood & Bredin, 1992). The use of Dementia Care Mapping (DCM: Kitwood & Bredin, 1992) is being increasingly used to assess the well-being of people with dementia in care settings and well-being scores were found to be closely associated with QoL (Fossey et al., 2002). However, Lawton et al., (1999) found that the amount of training provided to observers was a significant factor in the accuracy of reports. Observational methods are needed where communication difficulties exist for the individual and are of particular benefit in measuring QoL for people with severe dementia and within institutions (Fossey et al., 2002; Brod & Stewart 1999; Lawton et al., 1999; Lawton, 1997).

1.6.2. PROXY V SELF RATINGS OF QoL IN DEMENTIA

Alongside of the question what is the best way to measure QoL in dementia is the key question who should rate QoL? Individual subjective ratings are considered the gold standard for measuring QoL but these may be difficult to elicit and their validity may be questionable particularly in more severe dementia where observational ratings may be of more benefit (Novella et al., 2001a; Brod et al., 1999; Whitehouse, 1998). Studies in people with mild/moderate dementia living in the community, found that lower QoL ratings by the person with dementia were predicted by the presence of depressive symptoms, whilst lower QoL ratings of them by caregivers were associated with caregiver depression and burden (Sands et al., 2004; Karlawish et al., 2001; Logsdon et al., 1999). Moreover, in studies which compared patient and proxy ratings, QoL has been consistently rated lower by caregivers than patients with mild-moderate dementia (Vogel et al., 2006; Fuh & Wang, 2006; Ready et al., 2004; Logsdon et al., 2002; Selai et al., 2001a). The relationship between the proxy and the person with dementia is significant and the response agreement and bias may be influenced by age, gender, the relationship to the subject and the level of caregiving assistance needed (Magaziner, 1997). A study that investigated caregiver, staff and individual perceptions of QoL for people with dementia in institutional care found poor agreement between patient and proxy ratings other than for observable measures of function such as physical health and disability (Novella et al., 2001b). The spouse and qualified nursing staff were found to have closer agreement with the patient's ratings of QoL than other family and staff members. Coucill et al., (2001) also investigated people with mild/moderate dementia rating their QoL and compared these with caregiver and physician ratings. The study found there were differences between the two proxy ratings but it was unclear who the preferred proxy was. Magaziner (1997) advises that only proxies who are familiar with the aspect of health being studied should be used. Concordance between proxies and subjects responses can be improved by minimising interpretation, judgement and opinion. Caregiver proxy perspectives may alter over time and be influenced by their own health status and circumstances. Attention should therefore be given to the health and cognitive status of the proxy and their availability to provide a consistent proxy for longitudinal studies (Magaziner, 1997). The inclusion of both proxy and self-ratings rather than depending solely on one or the other ensures both subjective and objective perceptions of the person with dementia's QoL are collected (Selai & Trimble, 1999; Ready et al., 2002).

1.6.3. QoL MEASURES IN DEMENTIA

The past decade has seen several QoL measures devised for use in dementia (Smith et al., 2005b; Ready et al., 2002; Rabins et al., 1999; Logsdon et al., 1999; Brod et al., 1999: see Table 3, Section 1.6.4.2.). In addition generic scales have been modified for use in dementia (Selai et al., 2001a; Novella et al., 2001a; Kerner et al., 1998). This proliferation of instruments has led to a number of reviews being undertaken of the scales available to determine the reliability, validity and responsiveness of the scales in measuring QoL in people with dementia (Moniz-Cook et al., 2008; Ettema et al., 2005; Ready & Ott., 2003; Walker et al., 1998; Salek et al., 1998; Howard & Rockwood, 1995). Despite having a common purpose the instruments vary widely with differences in scale content, respondent, administration methods and target population. Whilst reliability, validity and sensitivity are considered the essential attributes of QoL measures other issues are also important, which include applicability; feasibility; acceptability and burden (Walker et al., 1998). Multidimensionality is recognised as being a common feature of the scales available and the most apparent similarity is that their conceptualisation and development has been strongly influenced by Lawton's model of QoL (Ettema et al., 2005; Ready & Ott, 2003; Howard & Rockwood, 1995). Lawton (1983; see Section 1.4.2) identified four dimensions of QoL: behavioural competence (cognitive and functional abilities), objective environment (living situation and presence of a caregiver), psychological well-being (positive and negative affect) and perceived QoL. It is important to include individual items that are relevant to dementia and responsive to changes in the condition (Ettema et al., 2005; Walker et al., 1998; Howard & Rockwood, 1995). The validity of existing scales is shown by correlations with depression and mood, cognition and functional ability and satisfactory reliability is reported (Ettema et al., 2005). The concerns regarding the validity and reliability of people with dementia to provide self-ratings are raised as a challenge and possible complication in the assessment of QoL (Howard & Rockwood, 1995; Walker et al., 1998; Ettema et al., 2005). The use of both proxy and self-ratings has been advised as the best strategy to determine construct validity in the absence of a gold standard (Ready & Ott, 2003). Salek et al., (1998) previously argued that of the available QoL measures none can be considered gold standard and should therefore be further developed and refined. However, Ready & Ott (2003) now consider that the preliminary data is encouraging on the range of instruments available, and Ettema et al., (2005) suggest that the instrument showing the highest reliability and validity should be the scale of choice, but question whether one instrument can assess QoL across each dementia severity.

1.6.4. REVIEW OF QoL MEASURES IN DEMENTIA

1.6.4.1. DEMENTIA SPECIFIC QoL INSTRUMENTS

A search of the literature was undertaken for this thesis of QoL scales and reviews of QoL instruments in dementia. The search strategy was for studies measuring QoL in people with dementia and the main medical and social science databases: Medline, Ovid, Psychinfo and Embase were searched. The key terms used were quality of life, dementia and Alzheimer's disease. Within the current literature reviewed for this thesis the most commonly used dementia specific QoL scales were highlighted and are examined below (Smith et al., 2005b; Ready et al., 2002; Rabins et al., 1999; Logsdon et al., 1999; Brod et al., 1999). Each of these instruments have been included in previous literature reviews examining the validity and reliability of QoL scales and their use is supported (Moniz-Cook et al., 2008; Schölzel-Dorenbos et al, 2007; Ettema et al., 2005; Ready & Ott., 2003; Walker et al., 1998; Salek et al., 1998; Howard & Rockwood, 1995). However, none of the reviews can conclusively identify a QoL scale for use with people with dementia and Schölzel-Dorenbos et al, (2007) state that no QoL scale can be used across all stages of dementia.

1.6.4.1.1. Alzheimer's Disease-Related Quality of Life (ADRQL: Rabins et al., 1999)

The ADRQL was developed to assess health related QoL across all severities in dementia and the scale measures positive and negative behaviours in 5 domains: social interaction, awareness of self, feeling and mood, enjoyment of activities and response to surroundings. The scale uses family caregiver proxy reports administered by a trained interviewer. The scores are calculated using a preference-based weighting approach and can be totalled into a single score. The ADRQL was developed in the USA using a Delphi process of consultation, focus groups and an expert panel with family caregiver, voluntary sector and health professionals. The ADRQL showed acceptable internal consistency (0.77-0.91 range), content and convergent validity (Black et al., 2002; Gonzalez-Salvador et al., 2000) and has shown sensitivity to change in QoL over a two year period (Lyketsos et al., 2003). Although a reliable measure the ADRQL does not seek the person with dementia's own view of QoL.

1.6.4.1.2. Dementia Quality of Life (DQOL: Brod et al., 1999)

The DQOL was developed to assess direct subjective individual experience explicitly and the scale measures 5 domains: positive affect (6 items), negative affect (11 items), feelings of belonging (2 items), self-esteem (4 items), sense of aesthetics (5 items) and a global QoL rating. The scores are calculated for each subscale with no overall score. The DQOL was developed in the USA through a review of the literature and focus groups that included family caregivers, health care providers and people with dementia. The DQOL showed acceptable internal consistency (0.67-0.89 range) and test-retest (0.64-0.90). Convergent validity was indicated by correlations with the geriatric depression scale. This scale is only completed by the person with dementia and no proxy view can be obtained.

1.6.4.1.3. Quality of Life - Alzheimer Disease (QOL-AD: Logsdon et al., 1999)

The QOL-AD was developed to assess perceived QoL in people with AD and caregivers and the scale measures 13 items encompassing physical and mental health, personal relationships, finance and overall life quality. The domain items are rated as poor, fair, good or excellent and separate scores are calculated for the patient and caregiver reports which can be combined into a single QoL score. The QOL-AD was developed in the USA through a review of the literature and consultation which included people with dementia, family caregivers and experts in dementia. The QOL-AD has high internal consistency for patients and caregivers

(0.84 to 0.88) and test-retest reliability (ICC 0.76 and 0.92 respectively). Construct validity was indicated by correlations with measures of cognition, activities of daily living, depression and engagement in pleasant events. The QOL-AD has also been shown to be a valid and reliable instrument for use in the UK (Selai et al., 2001b; Thorgrimsen et al., 2003) and has been used with a small number of people with severe dementia MMSE ≥3 (as discussed in Chapter 2, Section 2.10.1.1., Page 98, of this Thesis). The QOL-AD has shown sensitivity to change in QoL over a one year period (Selwood et al., 2005).

1.6.4.1.4. Cornell-Brown Scale for Quality of Life in Dementia (C-BS: Ready et al., 2002)

The C-BS is a modification of the Cornell scale for Depression in Dementia developed to assess QoL in dementia and the scale measures positive and negative affect, self esteem, physical and psychological satisfactions. The scale uses self and family caregiver proxy reports administered by a trained interviewer. The scores range from -2 (negative affect) to +2 (positive affect) and a total score is calculated. The C-BS had good internal consistency (0.81) and strong inter-rater reliability (ICC 0.90). Criterion validity was indicated by positive correlations with a visual analogue dysphoria scale.

1.6.4.1.5. Measure of health related quality of life for people with dementia (DEMQOL: Smith et al., 2005b)

The DEMQOL was developed to provide a psychometrically rigorous measure of heath related QoL in people with dementia and the scale measures 5 domains: health and well-being, cognitive functioning, social relationships and self-concept. The domain items are rated as a lot, quite a bit, a little and not at all with scores calculated from 1 (a lot) – 4 (not at all) and summed to produce a total score. The scale uses self rated reports of QoL administered by a trained interviewer; there is also a separate scale for family caregiver reports, the DEMQOL-proxy. The DEMQOL was developed in the UK through a review of the literature, qualitative interviews and consultation which included people with dementia, family caregivers and experts in dementia. The DEMQOL had high internal consistency (0.87) and acceptable inter-rater reliability (ICC 0.84) and indicates concurrent validity through moderate associations with the QOL-AD and DQOL.

1.6.4.2. SUMMARY OF DEMENTIA SPECIFIC QoL INSTRUMENTS

In summary, these are five dementia specific QoL instruments that demonstrate acceptable psychometric properties. Of these only two have both self-report and caregiver proxy ratings. All but one has a single score and individual domain score. The instrument that covers every aspect for target population, respondents and scoring, the QOL-AD, is also the shortest and quickest to administer (see Table 3). The European Interdem collaboration recommends the QOL-AD as the measure of choice in their review of outcome measures in dementia, as it is brief and has demonstrated sensitivity to psychosocial interventions (Moniz-Cook et al., 2008). The review also favours using the DQOL when more detail about QoL is required but caution this may be more burdensome to complete and is limited to those people with mild or moderate dementia.

Table 3: Dementia-specific quality of life instruments

QoL Measure	Target population	Respondent	Item No	Domains	Single score	Time taken
ADRQL Rabins et al., (1999)	Mild/moderate & severe dementia	Caregiver - proxy Formal & informal	47	Social interaction Awareness of self Feeling & mood Enjoyment of activities Response to surroundings	Yes	Not specified
DQOL Brod et al., (1999)	Mild/moderate dementia MMSE ≥12	Self-report	29	Self-esteem Positive affect Negative affect Feeling of belonging Sense of aesthetics	No	15 - 20 mins
QOL-AD Logsdon et al., (1999)	Mild/moderate dementia Severe dementia MMSE ≥3	Self-report Caregiver - proxy	13	Physical health Mental health Personal relationships Finances Overall life quality	Yes	10 mins
C-BS Ready et al., (2002)	MCI Mild/moderate dementia MMSE ≥ 9	Self-report Caregiver - proxy	19	Negative affectivity Positive affectivity Self esteem Physical complaints Satisfactions	Yes	15 mins
DEMQOL Smith et al., (2005b)	Mild/moderate dementia MMSE ≥ 10	Self-report	28	Health Well-being Cognitive functioning, Social relationships Self-concept	Yes	Not specified

1.6.5. PREDICTORS OF QoL IN DEMENTIA

The identification of predictors allows for the relationship between QoL and other characteristics associated with dementia to be explored. At present the evidence is conflicting, possibly due to the limited number of studies that have examined this factor. Demographics factors have been identified as a predictor of QoL in dementia. Banerjee et al., (2006) identified increased age of the person with dementia as the strongest predictor of better QoL. Age was also found to be a factor when change in QoL was measured over one year, as was female gender (Selai et al., 2001a), and increased age was associated with improved QoL. It is somewhat counterintuitive to assume that if QoL improves as the person with dementia ages, then QoL increases as the disease progresses. Besides, the evidence is contradictory and studies have shown QoL both increases and decreases as dementia advances in severity (Terada et al., 2002; Logsdon et al., 2002; Rabins et al., 1999). Woods et al., (2006) examined the relationship between demographic variables, cognition, psychological symptoms and QoL in people with dementia. QoL was self-rated and increases in QoL were found to be mediated by improvements in cognition which was influenced by participation in cognitive stimulation therapy. Other studies have identified cognition and dementia severity as a predictor of QoL in dementia (Albert et al., 2001; Karlawish et al., 2001; Kerner et al., 1998); but all were based on caregiver proxy ratings of the person with dementia's QoL. In contrast, more recent studies found caregiver proxy ratings of QoL were not associated with cognition or dementia severity but were strongly associated with depression and neuropsychiatric symptoms (Banerjee et al., 2006; Shin et al., 2005; Ready et al., 2004). Indeed, depressive symptoms have most consistently been identified as a predictor of lower QoL in dementia (Fuh & Wang, 2006; Ready et al., 2004; Karlawish et al., 2001 Selai et al., 2001a). In a study comparing caregiver and self-ratings of people with dementia's QoL, Logsdon et al, (1999) found lower incidence of depression and functional dependency, plus continued education were determined as predictors of higher QoL scores. Alternatively, Burgener & Twigg's (2002) study found that ongoing social contact and activity were factors influencing QoL for people with dementia. Of note, Ready et al., (2004) observes that many of the studies exploring predictors of QoL in dementia are cross-sectional in design and suggests that longitudinal predictors of QoL may be different. Studies about predictors would therefore need to be replicated with longitudinal data to be interpreted with confidence.

1.6.6. MEASURING CHANGE IN QoL AND DEMENTIA

Measures of QoL in dementia need to be able to detect changes in QoL in response to both interventions and the progression of the disease, in order to show benefits to patients and/or caregivers. There is currently limited evidence available although two studies have measured change in QoL over time (Selwood et al., 2005; Lyketsos et al., 2003). Lyketsos et al., (2003) followed up a sample population of 120 people with dementia in assisted living and nursing home accommodation (Gonzalez-Salvador., 2000) and used the ADRQL to measure change in QoL from baseline. Although an overall decline in mean QoL scores was detected, nearly half the ADRQL scores remained unchanged or were higher at follow up. This study suggests that QoL is preserved in people with advanced dementia over time despite the progression of the disease. Lyketsos et al., (2003) speculated that stability in the domain 'feelings and mood' showed depressive symptoms improved in residents over the course of 2 years. Selwood et al., (2005) followed up a sample of 60 people with dementia (Thorgrimsen et al., 2003) over one year, using the QOL-AD, DQOL and EQ-5D. The EQ-5D is a generic QoL utility scale (EUROQOL, 1990). No significant difference was found in any of the QoL scores between baseline and follow up, further suggesting that QoL does not decline over time. Selwood et al., (2005) identified baseline QoL as being the only predictor of future QoL in people with dementia. Both studies called for further longitudinal studies with larger samples to further investigate the impact of change in QoL in dementia over time.

1.6.7. IN CONCLUSION

To summarise, the literature shows evidence that QoL can be measured in dementia. The instruments available use different methods for measuring QoL in dementia and it is evident that QoL can be assessed using proxy and self ratings. In general individual perceptions of QoL should be sought in preference to the views of others; however proxy ratings have a role to play particularly in severe dementia. The ability of people with severe dementia to rate their own QoL still remains unclear. Due to the varied approaches in measurement and sample populations several associates of QoL have been identified and the evidence suggests depression in dementia is a significant contributory factor which decreases QoL. Furthermore it may be that QoL changes over the course of dementia but this evidence is limited. This thesis will therefore contribute to the existing research by initially investigating the ability of people with severe dementia to rate their own QoL. Secondly, the role of proxy ratings in QoL will be examined to determine which factors influence perceptions of QoL in dementia and how these contrast to those of the person with dementia. Both family and formal caregiver proxies will be examined. The final investigation in this thesis will determine how QoL changes over the course of dementia.

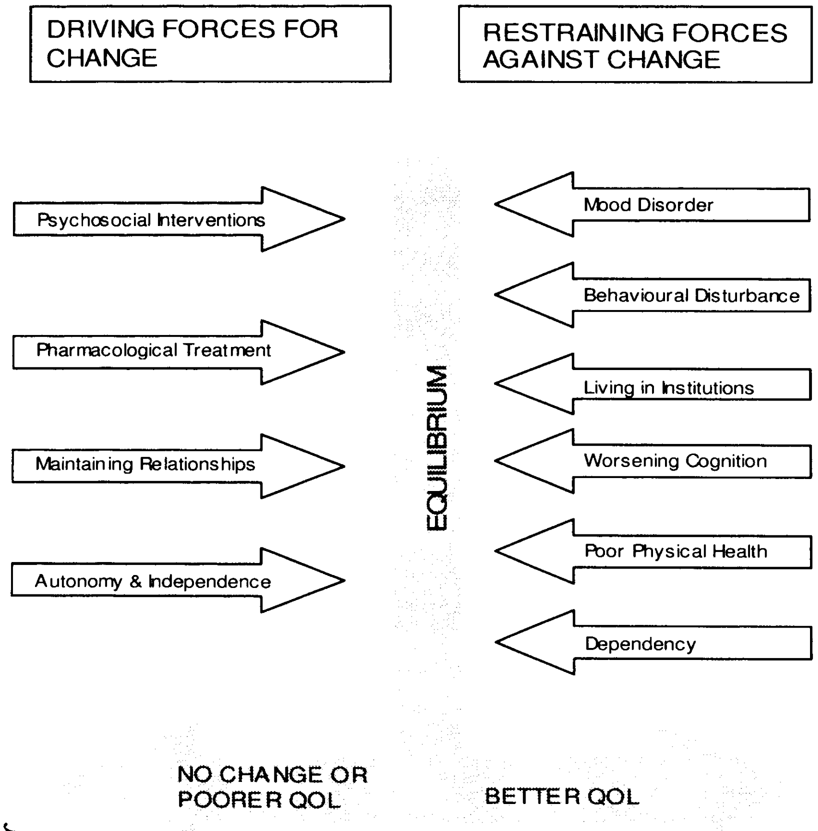
1.7. AIMS AND HYPOTHESES

'Only ill-health, recurring, inevitable,
Can teach the taste of what it is to be well'
(Lerner, 1964)

1.7.1 CONCEPTUALISING CHANGE IN QUALITY OF LIFE

QoL is now an established outcome measure for people with dementia. The subjective assessment of QoL in dementia is shown to have good validity. Moreover QoL does not necessarily change as dementia progresses (Selwood et al., 2005; Lyketsos et al., 2003). Dementia is a degenerative disease process characterised by worsening cognition, behavioural disturbance, mood disorder, increased dependency and physical frailty which may lead to institutionalisation. There is a need to understand what factors influence QoL in dementia and in particular to understand what factors can bring about change in QoL in dementia in order to plan future rational interventions. I have devised a new model to conceptualise the relationship between the factors influencing change in QoL in dementia (See figure 6). To theorise change in QoL the concept of force field analysis was applied as QoL is dynamic in nature (Lawton, 1983) which means there is a dynamic balance or equilibrium of forces working in opposite directions. Lewin (1951) argued that 'an issue is held in balance by the interaction of two opposing sets of forces – those seeking to promote change (driving forces) and those attempting to maintain the status quo (restraining forces)'. For any change to occur, the motivating forces must exceed the preventive forces, thus altering the equilibrium. The model is underpinned by Lawton's theory that QoL is interlinked by four dimensions, behavioural competence, perceived QoL, objective environment, and psychological well-being that may be evaluated negatively or positively depending on the individuals own internal perceptions and response to their environment. From the literature it is evident that QoL in dementia may be improved through enhancing mood and cognition, increased engagement, maintaining relationships, and promoting independence and autonomy in the person with dementia (Logsdon et al., 1999; Burgener & Twigg's, 2002; Thorgrimsen et al., 2003; Spector et al., 2003; Woods et al., 2006). In addition, with the current availability of treatment, cognitive stimulation, psychosocial interventions and application of person centred care to maintain personhood, it is feasible to assume change in QoL is possible. This thesis will attempt to determine the relationship between the driving and restraining factors influencing changing perceptions of QoL as suggested in the model proposed (see Figure 6).

Figure 6: Model conceptualising the relationship between the factors influencing change in QoL in dementia (Hoe, 2007)



1.7.2. OVERALL OBJECTIVE OF THESIS

The overall objective of this thesis is to assess the validity of measuring QoL in severe dementia and to investigate the factors associated with QoL and change in QoL in dementia as measured by the QOL-AD (Logsdon et al., 1999). The QOL-AD has been used to measure QoL in people with dementia across the disease severity (Selwood et al., 2005; Thorgrimsen et al., 2003, Logsdon et al., 1999). The reliability and validity of the QOL-AD for people with severe dementia to self-rate their own QoL will be investigated. Factors influencing individual and caregiver perceptions of the person with dementia's QoL will be explored; this will include both family and paid caregivers across community and institutional settings. Lastly, how QoL changes over time from the viewpoint or perspectives of the person with dementia and the caregivers will also be examined and factors identified which are associated with such changes including cognition; mood; functional ability; behaviour, unmet needs; living situation and treatment. The overall project has been carried out as two separate studies and the research design and methodology will be explained for both studies within the relevant chapters. This will include descriptions of the sample population, study procedure and instruments used.

1.7.3. AIMS

Aim 1: To investigate the reliability and validity of self-rated QoL in people with severe dementia.

Aim 2: To investigate the association between clinical and demographic factors and QoL in dementia including cognition; mood; behaviour, function, environment and unmet need, by comparing the person with dementia and the caregiver ratings of QoL in dementia.

Aim 3: To assess the sensitivity to change of the QOL-AD and to investigate which change in baseline clinical and demographic factors predict changes in QoL in dementia: namely cognition; mood; behaviour, function, environment and unmet need.

1.7.4. HYPOTHESES

1.7.4.1. PRIMARY HYPOTHESES

Lower QoL as rated by the person with dementia will significantly correlate with higher levels of depression and anxiety symptoms.

1.7.4.2. SECONDARY HYPOTHESES

Hypothesis 1: The majority (two thirds) of people with severe dementia will not be able to provide valid and reliable assessments of their QoL.

Hypothesis 2: QoL as rated by the person with dementia will not significantly correlate with clinical factors, namely cognition, behavioural disturbances or activities of daily living

Hypothesis 3: Caregiver perceptions of QoL in dementia will not differ from the person with dementia's rating of QoL.

Hypothesis 4: There will be no significant relationship between change in QoL and change in any clinical or demographic factors.

2.0. CHAPTER 2: MEASURING QUALITY OF LIFE IN PEOPLE WITH SEVERE DEMENTIA

2.1. AIMS AND HYPOTHESES:

Aim 1: To investigate the reliability and validity of self-rated QoL in people with severe dementia.

Hypothesis 1: The majority (two thirds) of people with severe dementia will be able to provide valid and reliable assessments of their QoL.

2.2. METHODOLOGY

This Chapter will describe the design and methods undertaken for the first study forming part of this investigation and will be referred to as Study 1. Descriptions of the sample population, study procedure and instruments used are given. This Chapter will explore the validity and reliability of QoL ratings provided by people classed as having severe dementia <12 MMSE. This cutpoint was selected as it reflects that used within the UK national guidelines for the prescribing of Acetylcholinesterase Inhibitors for the treatment of dementia (NICE, 2001) and QoL measures have not been validated in this group of people with dementia (Selai et al., 2001a; Ready et al., 2002; Brod et al., 1999; Logsdon et al., 1999).

2.3. STUDY DESIGN

This study formed part of a larger epidemiologically representative project that involves people with Alzheimer's disease (AD) and their caregivers recruited from within London and the South East Region of the UK; the LASER-AD study (Regan et al., 2005; Paton et al., 2004; Livingston et al., 2004). The overall study design was a longitudinal study with a 6 months follow up of a cohort of 224 people with AD. Purposive sampling was used and the participants were recruited from urban, suburban and semi-rural districts and were selected to be epidemiologically representative of the people with AD in terms of gender, dementia severity and living situation (Schneider et al., 2002; Fratiglioni, 1998; Fratiglioni et al., 1997: see Section 2.5. of this Thesis). There was an initial baseline assessment with data collection that included the person with dementia and the caregiver's health status, QoL and resource use (see Section 2.10. of this Thesis). A follow-up assessment was undertaken at 6 months.

2.4. RATIONALE FOR DESIGN

The current design allowed for a cross sectional study of the clinical data as it was collected at a given point of time in the given population. The QOL-AD scale could therefore be examined in terms of concurrent validity by testing convergent and discriminant validity and the ability to discriminate between clinical populations (across dementia severity and living situations). Reliability was investigated through examining internal consistency. This was appropriate for the overall objective and for assessing the relationships between scales. Having a second assessment 6 months later was necessary to obtain data for measuring the sensitivity to change and predictive validity of the QOL-AD scale and the other rating instruments.

2.5. SAMPLE POPULATION

All of the participants recruited had AD (DSM-IV; American Psychiatric Association, 1994; McKhann et al., 1984), whatever the age of onset and their treatment status. There was stratification on severity of dementia in order to balance the sample for mild (30%), moderate (40%) and severe (30%) patients (Fratiglioni, 1998). No upper limit was set for Mini Mental State Examination (MMSE) scores. The recruitment of participants was balanced regarding their disease severity using the MMSE (Folstein et al., 1975) score. Dementia severity was considered mild when MMSE > 20, moderate when MMSE < 20 and >10, and severe when MMSE < 10 (Ashford, 2000). In addition 60-70% of the participants included were female (Fratiglioni et al., 1997). This gender proportion was applied for the three groups of dementia severity level. The participants were also balanced regarding their living settings: 65% were community-based and 35% were institutionalised (Schneider et al., 2002). The stratification on living status was independent of severity and gender, i.e. the proportion of 65%/35% was not applied to the three groups of severity, as people with severe dementia were more likely to live in institutions. The caregivers were defined by the time per week they spend in close contact with the person with dementia and a minimum of 4 hours/week was required. This ensured that the caregiver was able to observe the participants ability to cope with the dementia. There was no condition on the nature of the relationship they had with the participant e.g. spouse/partner, relatives, friend or neighbour. One person only was considered the caregiver and where possible, this person was the same throughout the whole study. If there were no family or friend identified as a caregiver, then a statutory caregiver was used and this included wardens, regular home helps and care assistants.

2.6. SAMPLE SIZE RATIONALE

A sample size of 220 people with dementia was calculated for the overall project and was based on the known psychometric properties of the HSQ-12 to be able to show a 10% difference (Pettit et al., 2001) between the three groups of severity level as defined by MMSE score. The numbers predicted for each group were as follows: 44 people with mild AD (MMSE > 20), 99 people with moderately severe AD (MMSE < 20 and >10), and 77 people with severe AD (MMSE < 10).

2.7. INCLUSION CRITERIA

- Age of participants was more than or equal to 50 years old at inclusion.

- A diagnosis of Alzheimer's disease according to DSM-IV revised interim version (APA, 1994).

- A MMSE score <24 that indicated the presence of cognitive impairment.

- Participants had to have a caregiver / informant, willing to participate in the study.

- The caregiver / informant had to spend at least 4 hours a week with the person with dementia.

2.8. EXCLUSION CRITERIA

- Participants who presented with dementia other than AD. This included Vascular dementia, and other significant neurological disease (e.g. Dementia with Lewy body, Parkinson's disease, Huntington's disease, Normal Pressure Hydrocephalus, sequelae of brain surgery, brain trauma).

- A history of other severe and enduring mental illness not associated with AD.

- Those participants unable to comply with the study assessment, either due to another disease or inability to understand the English language that interfered with, or prevented their participation.

2.9. PROCEDURE

The participants were either identified through the local psychiatric services (North Essex Mental Health Partnership NHS Trust, Camden and Islington Mental Health Services NHS Trust, and Barnet, Haringey & Enfield Mental Health Trust), through managers of local nursing and residential homes, or through the voluntary sector (e.g. the local Alzheimer's Society). The caregiver was initially sent an information letter (see Appendix 3.a.iii) which outlined the background to the project, what it involved, and its main objectives. This information was then followed up with a phone call to the caregiver a week later, to enquire about their possible interest and to discuss any concerns regarding participation in the study. The time, date and venue for interviews were then arranged at the person with dementia and their caregiver's convenience. This was usually in the participant's or the caregiver's home, within the residential or nursing home and inpatient settings. When visited a brief summary of the research protocol was provided verbally and questions answered about the study. Consent was then obtained from the person with dementia and the caregiver before starting the interview (see Section 2.12. of this Thesis). Standardised interviews were conducted collecting information on the person with dementia's sociodemographic details; mental and physical health (including a medical examination); cognition; activities of daily living; QoL; medication and resource use. Information was also collected of the caregivers sociodemographic details; QoL and health status (see Section 2.10. of this Thesis). A follow-up assessment was then undertaken repeating all the same measures at 6 months. No specific order for the assessments was followed, but if there was evidence of performance anxiety then the briefer cognitive tests i.e. MMSE were undertaken first to allay any concerns and build confidence. Encouragement was offered throughout the interview and reassurance provided as necessary. Two hours was allowed for each interview and the person with dementia and the caregiver were usually interviewed at the same time by two separate interviewers. On the rare occasions that the person with dementia became distressed and agitated or found the interview procedure too tiring, arrangements were made to continue the interview at another time. The interviews were all conducted by a range of trained experienced health professionals from medicine, nursing and psychology. The same researcher completed the follow up interview where possible.

2.10. DATA COLLECTED

2.10.1. INSTRUMENTS USED FOR THE PERSON WITH DEMENTIA

2.10.1.1. QUALITY OF LIFE IN ALZHEIMER'S DISEASE (LOGSDON ET AL., 1999)

The QoL in Alzheimer's disease (QOL-AD) is a disease specific scale that measures QoL in dementia and is completed by both patient and caregivers (Logsdon et al., 1999). There are 13-items that include domains relevant to physical and mental health, personal relationships, finances and overall life quality. The items listed are physical health, energy, mood, living situation, memory, family, marriage, friends, self as a whole, ability to do chores, ability to do things for fun, money and life as a whole. Ratings are given on a scale of Poor (1); Fair (2); Good (3); Excellent (4) and there is a total possible score between 13 and 52. Higher scores indicate better QoL. In addition, where 1 or 2 items are missing the mean QOL-AD score can be calculated and substituted for the missing data, as described in Logsdon et al's., (2002) paper. QOL-AD scales with 3 or more items missing were excluded. The patient and caregiver scales can be used separately to assess QoL from each perspective. The ratings may also be combined with the scores given by the person with dementia which are given twice the weight of the caregiver's rating and a total score calculated to provide a weighted composite score as outlined by Logsdon et al., (1999). The QOL-AD was found to have good reliability for rating patient and caregiver responses (Logsdon et al., 2002). Thorgrimsen et al., (2003) studied 261 participants with dementia in the UK and found the QOL-AD was a reliable scale: all of the intraclass correlations were 0.75 or above ($p<0.001$) and Cronbach's alpha was 0.82; convergent and divergent validity was reported as the QOL-AD was negatively correlated with depression (-0.20, $p<0.01$), but was not correlated with cognition (-0.09, $p=0.19$). The QOL-AD could be satisfactorily used to rate QoL by patients with dementia, some of whom had MMSE scores as low as 3. However, Thorgrimsen used 2 separate samples in her study and most of the participants experienced a moderate degree of cognitive impairment: sample 1 (n=60) had a mean MMSE of 16.1 (s.d. 6.5, range 3-28) and sample 2 (n=201) had a mean MMSE of 14.4 (s.d. 3.8, range 7-24). Therefore few participants experienced a severe degree of dementia with a MMSE ≤10. The QOL-AD was included in this thesis as a disease specific QoL scale. It is a short, easily administered and acceptable assessment of QoL in people with dementia, which has proven validity, reliability and sensitivity to change (Selwood et al., 2005; Thorgrimsen et al., 2003; Logsdon et al., 1999).

2.10.1.2. HEALTH STATUS QUESTIONNAIRE – 12 ITEM (RADOSEVICH & PRUITT, 1996).

The Health Status Questionnaire – 12 item (HSQ-12 item) is a generic scale derived from the short form 36 (SF-36) (Radosevich & Pruitt, 1996; Ware et al., 1996, 1993). It is a short instrument used to measure the impact of illness on health status and comprises 8 domains, each scoring a range of 0 – 100. Higher scores indicate increased functioning and better QoL. The HSQ-12 has been shown to be suitable for use with older populations experiencing chronic disease and provides a brief and acceptable measure of health related QoL (Bowling and Windsor, 1997). The HSQ-12 has also been shown to be suitable for monitoring QoL in patients with mild-moderate dementia (Pettit et al., 2001). Three domains were found to be particularly likely to be impaired in severe dementia: Mental Health (mood state - calmness, sadness, happiness); Role-physical (role limitation due to physical health problems); Role-mental (role limitation due to emotional health problems) and were used in the analysis. The other domains e.g. pain, energy, fatigue, physical functioning and health perception are less related to AD. The HSQ-12 was included as a generic QoL measure and the scale has acceptable psychometric properties and is relevant and practical to use (Radosevich & Pruitt, 1996).

2.10.1.3. MINI MENTAL STATE EXAMINATION (FOLSTEIN ET AL., 1975)

The MMSE was included as an accepted and widely used screening instrument of cognitive function, it is easy to administer and assesses the major cognitive domains affected in AD (Clark et al., 1999; Kim & Caine, 2002). The Mini Mental State Examination (MMSE) is a brief standardised test of cognitive function that measures orientation, memory and attention (Folstein et al., 1975). There is a maximum score of 30, with scores of 0 – 10 commonly described as severe dementia, 11-20 moderate dementia, and 21-24 mild dementia (Ashford, 2000). The MMSE is a clinical measure and has been widely used in epidemiological studies. Tombaugh & McIntyre's (1992) review of existing studies showed the MMSE had good validity: correlations with other cognitive screening tests range from -0.66 to -0.93; in terms of reliability: internal consistency had alpha levels ranging from .96 for mixed medical patients and .54 to .77 for community samples. Sensitivity of the MMSE in measuring change in cognition has also been demonstrated: reliability coefficients generally fall between .80 and .95. It is quick and easy to use and is acceptable to both the person with dementia and the assessors and was completed with all participants where possible. Fillenbaum et al., (1988) suggest that refusal to answer questions probably indicates an inability to answer correctly, so unanswered questions were scored zero.

2.10.1.4. CORNELL SCALE FOR DEPRESSION IN DEMENTIA (ALEXOPOLOUS ET AL., 1988b)

The Cornell Scale for Depression in Dementia (Cornell) is an assessment of depression in people with dementia. Depressive signs and symptoms are divided into five categories in the Cornell scale: mood related signs: behavioural disturbance; physical signs; cyclic functions; ideational disturbance. There are 19 items rated on a three-point scale ranging from absent (0); mild or intermittent (1);

severe (2) and a total score of 8 and over indicates significant depressive symptoms. Within institutional settings the Cornell has good validity showing high correlation co-efficients with research diagnostic criteria (RDC) depression subtypes for hospitalised patients ($r^2 = 0.89$, $p < 0.0001$) and nursing home residents ($r^2 = 0.80$, $p < 0.0001$). It also has good reliability (coefficient alpha 0.84) and sensitivity to measuring the severity of depressive symptoms for all levels of cognitive impairment has been shown but only at the level of significance ($p < 0.05$) for nursing home residents (Alexopolous et al., 1988b). Ratings are made on the level of depressive symptoms after assessment of all relevant information (i.e. self and caregiver reports and through rater observation). Information is elicited through direct interview with the person with dementia and their caregiver, the researcher then makes an overall rating for each subsection. The Cornell was included as it has a psychobiological orientation and includes a broad range of depressive symptoms incorporating cognitive, somatic, affective and behavioural domains (Kurlowicz et al., 2002). The Cornell provides an objective rather than a subjective assessment. Designed primarily to be scored on behavioural observation rather than using an elaborate interview the Cornell is less dependent on the person with dementia's self-report of internal states. The Cornell has a high level of concurrent validity relative to other measures of depression in people with dementia and previous studies have evaluated the psychometric properties of the Cornell in both cognitively intact and dementia patients and showed high internal and interrater reliabilities in both populations (Kurlowicz et al., 2002).

2.10.1.5. NEUROPSYCHIATRIC INVENTORY (CUMMINGS ET AL., 1994)

The Neuropsychiatric Inventory (NPI) measures psychopathology in people with dementia and assesses 12 neuropsychiatric symptoms common in dementia: delusions, hallucinations, agitation/aggression, depression/dysphoria, anxiety, apathy/indifference, irritability, elation/euphoria, disinhibition, aberrant motor behaviour, sleep disturbance and appetite. Where positive responses are given to the screening questions, the frequency (score 1-4) and severity (score 1-3) of the behaviour is rated, and these are multiplied to give a score for each symptom. This instrument is completed with the caregiver. The NPI was included as it allows symptom-specific analysis and can be used across all dementia severities (Wood et al., 2000). As an outcome measure the NPI can also provide a distinctive profile of neuropsychiatric symptoms in a variety of neurological disorders. The level of caregiver distress is also rated for each neuropsychiatric disorder. The NPI calculates scores for the individual symptom domains and an overall total NPI score, which is scored between 0 and 144. Higher scores indicate increasing severity. The NPI has good validity: severity and frequency were significantly correlated for all items (p=0.0001). It also has good reliability: Cronbach's alpha for overall reliability was 0.88. In addition it has demonstrated sensitivity to change over the course of the dementia: test-retest had overall correlations of 0.79 for frequency (p=0.0001) and 0.86 for severity (p=0.0001) and all scored measures were significantly correlated (Cummings et al., 1994).

2.10.1.6. ALZHEIMER'S DISEASE CO-OPERATIVE STUDY – ACTIVITIES OF DAILY LIVING INVENTORY (GALASKO ET AL., 1997)

The Alzheimer's Disease Co-operative Study – Activities of Daily Living Inventory (ADCS-ADL) provides an evaluation of individual performance and autonomy in activities of daily living, either basic or instrumental (Galasko et al., 1997). There are 23 items measured through informant-based observation of each action or behaviour. These items are related to eating, walking, toileting, bathing, grooming, dressing, telephone use, watching television, conversation, clearing dishes from a table, finding belongings, preparing food and drinks, garbage disposal, travel, shopping, keeping appointments, being left alone, knowledge of current events, reading, writing, participation in hobbies, using household appliances. Items 1 – 5 (eating, walking, toileting, bathing, grooming) provide a choice of best response and the remaining items consist of a either a yes, no or don't know response followed by sub questions, e.g. did the patient select their first set of clothes for the day? If yes, which best describes their usual performance: 3. without supervision or help; 2. with supervision; 1. with physical help. The ADCS-ADL can be used to determine levels of functional ability across the range of dementia severity, which is scored between 0 and 78. Higher scores imply fuller functioning with a score of 78 indicating full function. This instrument was completed with the caregiver. The ADCS-ADL was included as a measure of ADL and can be used to demonstrate change in levels of dependency in all stages of the dementia process (Galasko et al., 1997).

2.10.2. INSTRUMENTS USED FOR THE CAREGIVER

2.10.2.1. HOSPITAL ANXIETY AND DEPRESSION SCALE (ZIGMOND & SNAITH, 1983).

The Hospital Anxiety and Depression scale (HADS) is a self-assessment scale, which provides a valid measure of mood disorder (Zigmond & Snaith, 1983). The HADS is divided into two 8-item subscales that differentiate between the different aspects and severity of mood disorder related to anxiety and depression. The overall severity of each item is rated on a five point scale (0-4) and a score of 8-10 implies borderline cases, whilst a score of 11 and over on either subscale indicates caseness. The scale is able to reflect the individual's present mood state and HADS scores are not affected by physical illness. The HADS can reliably assess for clinically significant symptoms of anxiety or depression and is easily understood and acceptable to patients (Bowling, 2001). The HADS is a popular and widely used self-report measure and was included as its psychometric properties allow for its use across a range of ages from adolescents to older adults (Martin, 2005; White et al., 1999). In this study the HADS was used with caregivers. It has been used in caregivers of people with dementia before (Clare et al., 2002). The study of anxiety and depression in family caregivers in this population found higher levels of anxiety caseness (23.5%, n=36) to those of depression (10.5%, n=16) when the HADS was used, with 13 caregivers experiencing both anxiety and depression at the level of caseness (Mahoney et al., 2005).

2.10.2.2. HEALTH STATUS QUESTIONNAIRE – 12 ITEM (RADOSEVICH & PRUITT, 1996).

The HSQ-12 was rated by the caregiver to provide a measure of their health-related QoL (As described above in *Instruments used for the person with dementia* see Section: 2.10.1.2.)

2.10.3. ADDITIONAL DATA COLLECTED

2.10.3.1. DEMOGRAPHIC DATA

Demographic data was collected regarding the participant and caregiver's age; gender and marital status: being single, married, divorced or widowed. Ethnic status was self-defined and recorded using the same categories as the 2001 UK Census (UK, 2001); and whether their first language was English or not. Information was also collected on living situation: whether they lived alone, with a spouse or cohabited, lived with relatives or within institutions (residential or hospital settings); and the type of accommodation: such as own home, private rent, social housing, warden controlled, residential or nursing home. Employment status was recorded: being employed full or part time, unemployed or retired. Years of education and the highest academic level of study attained were recorded: primary, secondary or tertiary. The relationship between the person with dementia and the caregiver was also determined: spouse, child, other relative, friend or paid caregiver.

2.10.3.2. ACETYLCHOLINESTERASE INHIBITORS

The prescription of acetylcholinesterase inhibitors (AChEI) was recorded for individual participants. AChEI drugs are used in the treatment of mild to moderate Alzheimer's disease and have been shown to improve cognitive functioning (NICE, 2001). The AChEIs include Donepezil a reversible inhibitor of acetylcholinesterase; Galantamine a reversible inhibitor of acetylcholinesterase that has nicotinic receptor agonist properties and Rivastigmine a reversible non-competitive inhibitor of acetylcholinesterase (BNF, 2005).

2.11. ETHICAL APPROVAL

Ethical approval was granted by all the appropriate Local Research Ethics Committees for North Essex Mental Health Partnership NHS Trust, Camden and Islington Community Health Services NHS Trust, and Barnet, Haringey & Enfield Mental Health Trust (Appendix 2.a.).

2.12. CONSENT

Both caregivers and the person with dementia were asked for their written informed consent (Appendix 3.a.). If the person with dementia was unable to give informed consent, they were asked for assent and the caregiver gave their written agreement. The interview was stopped if the person with dementia asked to withdraw or showed distress.

2.13. ANALYSIS

For this analysis only those people with a severe degree of dementia (MMSE <12) were selected. The data were analysed and descriptive data, relevant associations and correlations between QoL, clinical and demographic information are reported. The analysis was undertaken using SPSS 12.0. (SPSS, 2004). It was decided that only those people who completed all 13 items on the QOL-AD were considered able to complete the scale. Therefore, those cases with ≤2 missing items did not have mean values imputed for this part of the investigation. The descriptive data was analysed and t-tests were used to explore differences between those people with dementia who were and were not able to complete the QOL-AD. The scores on the MMSE at which participants were able to complete the QOL-AD were then examined. As there is no gold standard for criterion validity in measuring an individual's QoL, construct validity of the QOL-AD was assessed by correlating the scale with measures of cognition, mood, neuropsychiatric symptoms, activities of daily living and the relevant domains in health related QoL (MMSE, Cornell, NPI, ADCS-ADL and HSQ-12 respectively). Analysis was undertaken, as appropriate using Pearson's *r,* Spearman's *Rho* and Cronbach's alpha. Following the conventions of Dunn and Everitt (1995), correlations of 0.4 and above were considered as possibly clinically significant and as there were multiple univariate analyses $p<0.01$ was used as the level for significance. The caregiver's HADS scores were then correlated with the person with dementia's QOL-AD score to examine the relationship of caregiver mood to the person with dementia's QoL.

2.14. RESULTS

2.14.1. DEMOGRAPHIC CHARACTERISTICS

Seventy-nine of the people with dementia from the original study population of 224 participants had a MMSE score <12 (see Table 4 for all demographic characteristics). Of these participants, the majority were female (73.4%) with a mean age of 81.0 (s.d. 8.3) years ranging from 55 – 98 years. They were a largely white population (93.7%) and although all spoke English, this was not the first language for 8 (10.1%) participants. The participants had a mean of 9.1 (s.d. 1.9) years of education spanning 1 – 14 years, and most had achieved a secondary level of schooling (n=54, 68.4%). Just over half were widowed (n=43, 54.4%) and the remaining where either married (n=29, 36.7%), or single (n=4, 5.1%) and divorced (n=3, 3.8%). Over half of the participants 49 (62.0%) lived within a 24 hour care setting, this being either a residential or nursing home, or a hospital type setting. Of the remainder, 25 (41.8%) lived with someone else and 5 were living alone (6.3%). The majority of the caregivers were children (35.4%) followed closely by a spouse (32.9%). There were 19 (24.1%) participants who had a paid caregiver.

Table 4: Demographic characteristics of the sample population

Demographic	**Characteristic**	**(n)**	**%**
Gender	Male	21	26.6
	Female	58	73.4
Age (years)	< 60	2	2.5
	60 – 69	3	3.8
	70 – 79	27	34.2
	80 – 89	35	44.3
	90 – 99	12	15.2
Ethnicity	White British	62	78.5
	White Irish	5	6.3
	White Other	7	8.9
	Black Caribbean	3	3.8
	Black Other	1	1.3
	Asian	1	1.3
First language	English	71	89.9
	Other	8	10.1
Years of education	1 – 5	3	3.8
	6 – 10	50	63.3
	11 - 14	11	13.9
	Not known	15	18.9
Highest level of education	Primary	2	2.5
	Secondary	54	68.4
	Tertiary	9	11.4
	Not known	14	17.7
Marital Status	Single	4	5.1
	Married	29	36.7
	Divorced	3	3.8
	Widowed	43	54.4
Living situation	Live Alone	5	6.3
	Live with Spouse	14	17.7
	Live as a Couple	2	2.5
	Live with other relatives	9	11.4
	Live with others	49	62.0
Accommodation	Owner occupier	21	26.6
	Private rent	1	1.3
	Local Authority	7	8.9
	Sheltered accommodation	1	1.3
	Residential	19	24.1
	Nursing home	14	17.7
	Other e.g. hospital	16	20.3
Caregiver relationship	Spouse	26	32.9
	Children	28	35.4
	Other relative	4	5.1
	Friend	2	2.5
	Paid caregiver	19	24.1

2.14.2. COMPLETERS AND NON-COMPLETERS OF THE QOL-AD

Of the 79 people with dementia who had a MMSE <12 there were 41 (52%) participants who could complete all 13 items on the QOL-AD. They had a mean QOL-AD score of 32.8 (S.D. 6.2). There were 38 (48%) participants who could not complete the QOL-AD and most of the non-completers were people with more severe dementia (see Table 5). Of those who did not complete the QOL-AD 25 (65.8%) did not answer any of its questions. Eight (21.0%) participants partially completed the questionnaire; two had one item missing, three had three items missing; one had six items missing and two had 12 items missing. Five (13.2%) QOL-AD questionnaires were answered by the person with dementia but not by the caregiver and were excluded as they could not be matched.

The baseline characteristics of those able to complete and those not able to complete the QOL-AD were examined (see Table 5). A comparison of means using *t*-test was undertaken and a significant difference between the two groups was observed for the MMSE and ADCS-ADL scores (see Table 6). Completers of the QOL-AD had a higher mean MMSE score of 7.0 (S.D. 3.2, n=41) compared with 2.9 (S.D. 3.4, n=38) for those unable to complete the scale. The ADCS-ADL showed a mean of 21.3 (S.D. 14.1) for completers of the QOL-AD and 7.9 (S.D. 8.60) for non-completers. The MMSE mean difference was –4.13 (95% CI –5.6 to –2.6) p<0.001, and the ADCS-ADL mean difference was –13.40 (CI –18.7 to –8.1) p<0.001.

Table 5: Characteristics of completers and non-completers of the QOL-AD

Variables	**Able to complete**				**Not able to complete**				
	Mean	S.D.	Range	(n)	Mean	S.D	Range	(n)	p<
Age	80.0	8.8	55–94	*(41)*	82.1	7.9	64 –98	*(38)*	0.52
MMSE	7.0	3.2	0–11	*(41)*	2.9	3.4	0–10	*(38)*	0.0001
CORNELL	5.6	5.6	0–21	*(41)*	4.0	4.8	0–24	*(38)*	0.19
ADCS-ADL	21.3	14.1	0–58	*(41)*	7.9	8.5	0–45	*(38)*	0.0001
NPI	24.9	20.6	0–79	*(41)*	19.6	15.7	0–69	*(38)*	0.36
HSQ-Mental Health	71.7	17.9	33–100	*(37)*	67.8	29.0	40–100	*(6)*	0.90
HSQ–Role mental	88.8	22.8	20–100	*(38)*	78.0	26.8	20–100	*(10)*	0.79
HSQ–Role physical	73.8	36.9	0–100	*(39)*	76.7	38.6	0–100	*(9)*	0.63

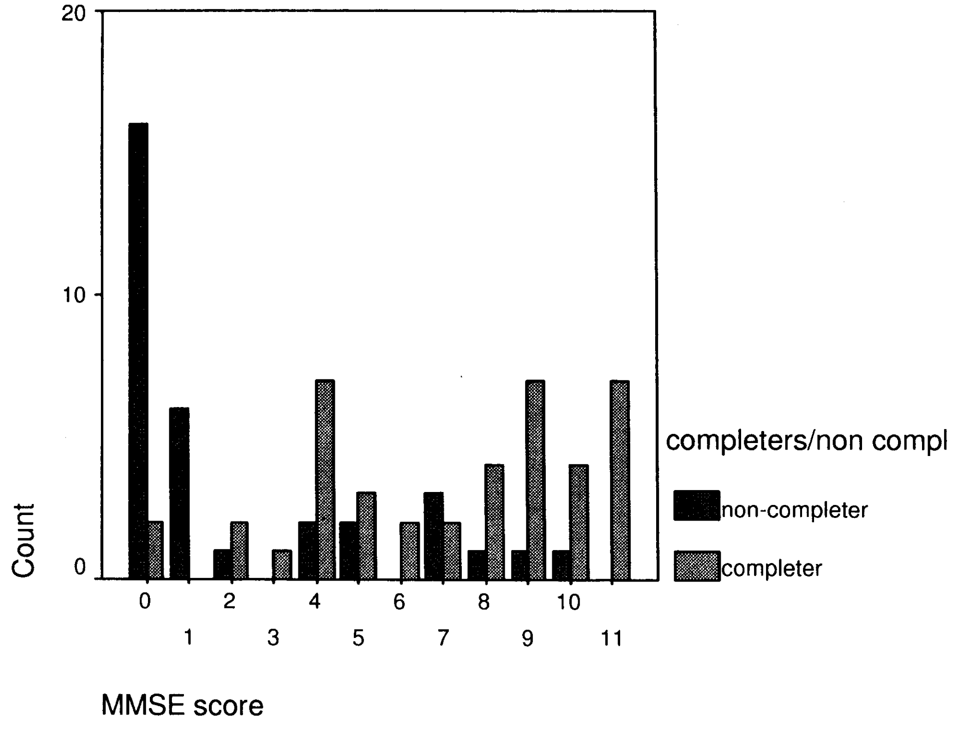
Table 6: Mean differences between completers and non-completers of the QOL-AD

Variables	**Mean difference**	**Significance** (2-tailed)	**Confidence Intervals** Upper	**Confidence Intervals** Lower
MMSE score	-4.1	.000	-5.6	-2.6
ADCS total score	-13.4	.000	-18.7	-8.1
NPI total score	-5.3	.203	-13.6	2.9
HSQ - Mental Health	-3.9	.651	-21.4	13.5
Age	2.1	.277	-1.7	5.8
Years of Education	-.07	.889	-1.0	0.9

2.14.3. MMSE SCORES FOR COMPLETERS AND NON-COMPLETERS OF THE QOL-AD

The MMSE scores of the completers and non-completers of the QOL-AD were then further examined. The completers of the QOL-AD were observed to have a MMSE score range of between 0 – 11. The majority of non-completers had a score of 0, with a MMSE score range of between 0 - 10. Figure 7 shows the MMSE scores for completers and non-completers of the QOL-AD. From Figure 7 it is clear that most completers (n=41) had a MMSE score ≥3 and the non-completers had a MMSE ≤ 1. As most people with a MMSE <3 could not complete the QOL-AD, the QoL of people scoring 3-11 (n=37, 71.2% completed) was examined to consider the validity and reliability of the measures.

Figure 7: The MMSE <12 scores for completers and non-completers of the QOL-AD



2.14.4. CORRELATIONS BETWEEN THE QOL-AD AND OTHER MEASURES

A subsequent analysis was undertaken for participants who had a MMSE ≥3 and <12. Table 7 shows the QOL-AD scores and their correlation with age and years of education, the Cornell, NPI (total score and individual items), ADCS-ADL, HSQ-12 and the HADS. No associations were observed between the QOL-AD and age, years of education, MMSE score, the Cornell, NPI total score or the NPI dimensions of anxiety, agitation, aberrant motor activity and disinhibition, the HSQ role-mental domain, or HADS rated depressive and anxiety features in caregivers. There was a significant correlation between the QOL-AD and the ADCS-ADL (p<0.001) and with the HSQ-role physical (p<0.01). In addition, higher levels of QoL were strongly associated with good mood status on the HSQ-mental health (p<0.001) domain. These results were the same if all 41 completers of the QOL-AD were considered.

Table 7: Correlations with the total QOL-AD score for people with MMSE <12 and ≥3

Variable	(n)	Value		p<
AGE	37	r	-0.08	0.63
EDUCATION	33	r	-0.06	0.73
MMSE	37	r	-0.02	0.99
ADCS-ADL	37	rho	0.55	0.0001
CORNELL	37	rho	-0.27	0.10
NPI-apathy	37	rho	-0.40	0.02
NPI-anxiety	37	rho	-0.18	0.30
NPI-agitation	37	rho	0.05	0.78
NPI-aberrant motor activity	37	rho	-0.21	0.22
NPI-disinhibition	37	rho	0.26	0.12
NPI total score	37	r	-0.11	0.19
HSQ Mental Health	34	r	0.58	0.001
HSQ Role Mental	35	rho	0.28	0.10
HSQ Role Physical	36	rho	0.48	0.003
HADS anxiety	31	rho	-0.05	0.65
HADS depression	31	rho	0.09	0.98

2.14.5. MEASURES OF INTERNAL CONSISTENCY

Three measures of reliability were undertaken which included item-item correlation and test-retest reliability. A reliability analysis examining internal consistency was undertaken using Cronbach's alpha, to calculate the mean inter-item correlation (see Table 8). The item-total correlation between each QOL-AD item and the QOL-AD total score varied between 0.35 and 0.81, Cronbach's alpha =0.78. The highest item-item correlation showing reliability coefficients ≥.70 were with the total QOL-AD score and fun (.81); life as a whole (.73); family (.72) and friends (.70), and the item-item correlations for life as a whole and family (.72) and friends and marriage (.70). Only 23 (62.2%) of the original participants were able to complete the QOL-AD at six months, six had died or refused follow up. The others were able to be interviewed but did not complete the QOL–AD. The mean QOL-AD scores for these 23 had at baseline been 37.5 and at follow up were 37.9. Test-retest reliability had correlations of 0.86 (95% CI -2.03 – 1.12). The Cronbach's alpha co-efficient for test retest reliability was 0.89.

Table 8: Reliability analysis of the QOL-AD

QOL-AD items	Physical Health	Energy	Mood	Living situation	Memory	Family	Marriage	Friends	Self	Chores	Fun	Money	Life
Physical Health	1.0												
Energy	.56	1.0											
Mood	.42	.38	1.0										
Living situation	.10	.22	.46	1.0									
Memory	.25	.35	.44	.34	1.0								
Family	.16	.58	.23	.16	.43	1.0							
Marriage	.08	.33	.15	.33	.11	.46	1.0						
Friends	.19	.40	.27	.21	.45	.57	.70	1.0					
Self	.27	.12	.41	.02	.40	.37	.19	.28	1.0				
Chores	.05	.33	.36	.33	.53	.38	.34	.40	.23	1.0			
Fun	.36	.60	.54	.14	.49	.58	.33	.64	.47	.58	1.0		
Money	.05	.08	.32	.38	.43	.30	.12	.40	.27	.29	.38	1.0	
Life	.17	.28	.27	.11	.44	.72	.47	.51	.68	.38	.52	.42	1.0
QOL-AD Total	.35	.62	.60	.43	.65	.72	.54	.70	.53	.61	.81	.50	.73
Cronbach's alpha = 0.78													

2.15. DISCUSSION

2.15.1. SUMMARY OF FINDINGS

This is the first study that has reported the results of a group of people with severe dementia and their ability to report their own QoL using standardised measures. This study found that it was possible for individuals with severe dementia to rate their own QoL and that these measures were valid and useful in identifying predictors of QoL. For the sample of 79 participants, just under three quarters (37 out of 52) of those people scoring from 3 to 11 on the MMSE were able to complete the QOL-AD and just over one sixth (4 out of 27) of those with a MMSE below 3 were also able to complete the QOL-AD. The main findings are that there is evidence for the validity and reliability of the QOL-AD in people with MMSE scores of 3 – 11, and that it was possible for most individuals with a score of 3 or more on the MMSE to rate QoL using the QOL-AD. Most of the non-completers did not complete any of the items on the QOL-AD and it was felt that the difficulty was in choosing from an abstract list to describe their feelings. In contrast they were able to answer some cognitive questions and so had a degree of comprehension. Some of those who answered were unable to retain the instructions of choosing a rating from the list of Poor / Fair / Good / Excellent and this had to be repeated with every question. The results for those people scoring 3 and above on the MMSE can be considered generalisable to this population group, which was representative of people with severe AD in different geographical and institutional settings. Just over half of those people with severe dementia included in this study were in institutionalised settings.

2.15.2. VALIDITY OF THE QOL-AD

The QOL-AD showed construct validity in that it correlated with ability to look after self, limitations due to physical health and overall mood status. The highest correlation co-efficient with other scales was with HSQ mental-health (mood state) and it is of interest that this seems to be such a large component of QoL even in severe dementia. The significant correlation with limitations due to physical health and of activities of daily living are more modest but still of the degree which would be regarded as clinically significant (Dunn & Everitt, 1995). It therefore successfully integrates information about mental and physical dimensions and their effects on health as is desirable from a QoL instrument. Evidence of convergent validity is therefore indicated as the QOL-AD correlated with related variables (Bowling, 1997). It was anticipated that QoL would not correlate with age, education or cognition as these are not measures of emotional state. As no correlations were shown with the variables age, education and cognition with QoL this indicates discriminant validity (Bowling, 1997). Despite being strongly linked to QoL in general, depression (as measured by the Cornell scale) was not found to be associated with the QOL-AD ratings. This may be partly because most of the participants were not clinically depressed. Or as the sample size was small it may be due to type II error as a link with depression has been found in other studies (Thorgrimsen et al., 2003; Logsdon et al., 1999). Mood did however contribute to the QoL measurement. The QOL-AD was not correlated with the caregivers' depression or anxiety symptoms. This was also anticipated as the intention was to measure the person with dementia's QoL not the caregivers' emotions, although it has been suggested that they contribute to the caregiver's assessment (Karlawish et al, 2001; Logsdon et al., 1999). The lack of correlation with other neuropsychiatric symptoms may be because, as previously shown and often observed in clinical practice and in other QoL instruments, they distress the caregiver more than the person with dementia (Banerjee et al., 2006).

The scores on the QOL-AD were found to be related to the person with dementia's mood but not to their caregivers.

2.15.3. RELIABILITY OF THE QOL-AD

The test-retest reliability was highly correlated. Good internal consistency and test-retest reliability are indicated at levels of 0.50 and above (Bowling, 1997). The QOL-AD scale therefore showed reliability and lack of redundancy in its high item total correlation scores. Interestingly the highest item-item correlations were between the items where participants rated relationships and overall QoL. The similarity of items regarding different relationships strongly suggests that the answers given were meaningful. The relationship to overall QoL again suggests that psychosocial items (relationship with family, friends and ability to have fun) rather than health are more important in this group.

2.15.4. LIMITATIONS

The study is limited by the small sample size, as many of the participants could not complete the scale. There were, however, enough participants to show significant correlations. In addition, there is the lack of an accepted gold standard of QoL. This issue has been raised in other dementia studies and the use of individual subjective ratings was suggested as the gold standard for measuring QoL in dementia (Kane et al., 2003; Novella et al., 2001a; Brod et al., 1999; Whitehouse, 1998). Definitions of severe dementia were also made according to the MMSE cutpoint of 12, and not to the MMSE cutpoint of 10 as is more widely accepted (Ashford 2000). As explained above this cutpoint was chosen to reflect that used by NICE (2001). This was considered an appropriate point to measure from, as treatment in dementia was only advised for people with a MMSE score of 12 and above. NICE do however now recommend that treatment with AChEIs is only available for those people with dementia scoring between 10 and 20 points on the MMSE (NICE, 2006). A MMSE of >12 is also the cutpoint at which there is existing evidence of the ability of people with dementia to reliably complete self-reported QoL scales (Selai et al., 2001a; Ready et al., 2002; Brod et al., 1999; Logsdon et al., 1999). In addition, the MMSE was selected to reflect dementia severity as opposed to a global rating. Thus some of the participants in this part of our study may have been less severe than would have been indicated by a global rating and conversely some with higher MMSE scores may have had a global rating of more severe dementia. The definition given is, however, considered clinically useful and easy to understand.

2.15.5. MEASURES OF QoL IN SEVERE DEMENTIA

For the population group able to complete the QOL-AD, QoL did not differ according to cognition. This finding is consistent with other studies of QoL in dementia (Selwood et al., 2005; Thorgrimsen et al., 2003), but not with Woods et al., (2006), and demonstrates how important it is to use the person with dementia to rate their QoL rather than relying solely on other raters' judgements. The QOL-AD contained both objective and subjective domains and ratings were obtained through direct questioning, which is considered a better method for obtaining QoL measures, rather than just using observation or proxy ratings. This method allowed both the individual and their caregiver to express personal opinions about QoL and to seek clarification or elaborate on answers if necessary. Consequently, direct questioning does not impose the professional's opinion on the person. As the need for QoL measures within old age psychiatric research becomes more important, it is essential that a range of reliable tools are available and that these can be used to consistently measure QoL across all severity of the disease. The disease specific QOL-AD scale also showed associations with relevant items on the HSQ-12, which is a generic scale for measuring QoL. It is also important that these tools are able to identify predictors of QoL relevant to the population group. This study suggests that in severe dementia, higher QoL was predicted by better functional ability, lack of disability, improved mood status and increased engagement with the environment.

2.15.6. IMPLICATIONS

The ability to measure QoL in severe dementia has implications for future research and clinical practice. QoL assessments are beneficial in determining the effectiveness and impact of therapeutic interventions and the QOL-AD has potential to be used routinely within surveys, intervention studies and clinical trials. The validity and reliability of self ratings using the QOL-AD for people with dementia scoring ≥3 MMSE is indicated and this instrument is relevant to measuring QoL in people with severe dementia. The sensitivity of the QOL-AD to measuring change does however need to be further investigated. This study has also shown, counter-intuitively, that QoL does not decrease as cognition worsens within the spectrum of severe dementia and throws into question most people's assumption that dementia worsens QoL. This finding has implications for the care and treatment offered for this patient group as people with severe dementia do still experience good QoL and the ability to influence their QoL is indicated. The finding that better mood is a predictor of QoL has implications for the treatment of depressive symptoms in dementia and this is encouraged. In addition, more engagement with the environment was also a predictor of higher QoL and demonstrates the usefulness of providing meaningful activities with this patient group.

Care provision in dementia for people at all stages of disease severity should routinely consider the impact of interventions on the individual's QoL. Furthermore the use of advanced directives is increasing within dementia care and clinical decision making must be underpinned by more robust evidence. The use of routine QoL assessments can assist clinicians in demonstrating more sound and balanced judgements regarding the impact of interventions in patient care.

2.15.7. CONCLUSION

The self-ratings of people with severe dementia (MMSE ≥3) have thus been shown to be valid and reliable, and this provides a basis for further investigation as it allows QoL to be explored in a wider population of people experiencing dementia. Establishing the validity and reliability of QoL measures in severe dementia has implications for both research and clinical practice and the routine use of the QOL-AD in studies is suggested. QoL is a highly subjective concept and people with severe dementia may still experience good QoL. Significantly QoL does not diminish as the disease progresses within severe dementia. It may be important to inform the wider public of this, as advanced directives and living wills become more part of our culture. QoL was also found to be influenced by a range of factors that included functional ability, lack of disability, improved mood status and increased engagement with the environment. The intention is therefore to further examine in more detail the factors influencing QoL in a larger sample of people with dementia and incorporate all levels of disease severity.

3.0. CHAPTER 3: PEOPLE WITH DEMENTIA AND FAMILY CAREGIVER PERCEPTIONS OF QUALITY OF LIFE IN DEMENTIA

3.1. AIMS AND HYPOTHESES:

Aim 2: To investigate the association between clinical and demographic factors and QoL in dementia including cognition; mood; behaviour, function, environment and unmet need, by comparing the person with dementia and the caregiver ratings of QoL in dementia.

3.1.1. PRIMARY HYPOTHESES

Lower QoL as rated by the person with dementia will significantly correlate with higher levels of depression and anxiety symptoms.

3.1.2. SECONDARY HYPOTHESES

Hypothesis 2: QoL as rated by the person with dementia will not significantly correlate with clinical factors, namely cognition, behavioural disturbances or activities of daily living

Hypothesis 3: Caregiver perceptions of QoL in dementia will not differ from the person with dementia's rating of QoL.

3.2. METHOD

The validity and reliability of people with severe dementia has been established in the previous Chapter. This Chapter will examine in more detail the factors influencing family caregiver proxy QoL ratings for people with dementia. This Chapter will describe the aims and results of this study undertaken as part of Study 1. Descriptions of the sample population, study procedure and instruments used are as detailed in Chapter 2 (see Section 2.2). The whole sample population for Study 1 will be included in this investigation. The aim of this Chapter is to compare the views of people with dementia and family caregivers about QOL in dementia. It will also attempt to identify factors associated with QoL in dementia as rated by the family caregiver and by the person with dementia.

3.3. STUDY DESIGN

Described in Chapter 2, see Section 2.3., Study Design, Page 93, of this Thesis.

3.4. RATIONALE FOR DESIGN

Described in Chapter 2, see Section 2.4., Rational for Design, Page 93, of this Thesis.

3.5. SAMPLE POPULATION

Described in Chapter 2, see Section 2.5., Sample Population, Page 94, of this Thesis.

3.6. INCLUSION CRITERIA

Described in Chapter 2, see Section 2.7., Inclusion Criteria, Page 95, of this Thesis.

3.7. EXCLUSION CRITERIA

Described in Chapter 2, see Section 2.8., Exclusion Criteria, Page 96, of this Thesis.

3.8. PROCEDURE

Described in Chapter 2, see Section 2.9., Procedure, Page 96, of this Thesis.

3.9. DATA COLLECTED

The data collected was as that described for Study 1 in Chapter 2 (see Section 2.10). The HSQ-12 was not analysed as part of this investigation, but all other instruments were included in the analyses.

3.9.1. INSTRUMENTS USED FOR THE PERSON WITH DEMENTIA

- Quality of Life in Alzheimer's disease (Logsdon et al., 1999), see Chapter 2: Section 2.10.1.1., of this Thesis.

- Mini Mental State Examination (Folstein et al., 1975), see Chapter 2: Section 2.10.1.3., of this Thesis.

- Cornell Scale for Depression in Dementia (Alexopolous et al., 1988b), see Chapter 2: Section 2.10.1.4., of this Thesis.

- Neuropsychiatric Inventory (Cummings et al., 1994), see Chapter 2: Section 2.10.1.5., of this Thesis.

- Alzheimer's Disease Co-operative Study – Activities of Daily Living Inventory (Galasko et al, 1997), see Chapter 2: Section 2.10.1.6., of this Thesis.

3.9.2. INSTRUMENTS USED FOR THE CAREGIVER

- Hospital Anxiety and Depression scale (Zigmond & Snaith, 1983), see Chapter 2: Section 2.10.2.1., of this Thesis.

3.9.3. ADDITIONAL DATA COLLECTED

- Demographic data, see Chapter 2: Section 2.10.3.1., of this Thesis.

- Acetylcholinesterase Inhibitors, see Chapter 2: Section 2.10.3.2., of this Thesis.

3.10. ETHICAL APPROVAL

Described in Chapter 2, see Section 2.11., Ethical Approval, Page 105, of this Thesis.

3.11. CONSENT

Described in Chapter 2, see Section 2.12., Consent, Page 105, of this Thesis.

3.12. ANALYSIS

The data were analysed using SPSS 12.0. (SPSS, 2004). For the QOL-AD, where one or two items were missing the mean QOL-AD scores were inserted. Using person mean methods of imputation (in comparison to other methods of mean imputation) gives better results for multi-dimensional data with respect to measures of discrepancy 'because the mean is taken across more than one trait' (Bernaards & Sijtsma, 2000). Descriptive data, relevant associations and correlations of clinical and demographic data with QoL ratings are reported. As the data was not normally distributed, the Mann-Whitney and Spearman's test were used for analyses. Following the conventions of Dunn and Everitt (1995) correlations of 0.4 and above were considered as possibly clinically significant. As there were multiple univariate analyses $p<0.01$ was used as the level for significance. Stepwise linear regression analyses were undertaken to determine independent predictors of QoL, for the person with dementia's QoL, and family caregiver views of the person with dementia's QoL. In step one demographic data was entered and included to examine whether the person with dementia lived in a 24 hour care settings or not to consider the effect of these variables. In step 2, the presence of Acetylcholinesterase Inhibitors (AChEI) was included, to examine whether taking AChEIs moderated or mediated this effect. In step 3, the person with dementia's morbidity data (cognition, dependency, neuropsychiatric symptoms, depression) were included to examine the effects of morbidity once demographics and treatment variables were considered and in step 4 the caregiver's morbidity (anxiety and depression) were included to consider the effects of caregiver mental health. For the regression analysis, series mean scores were also imputed for those subjects without HAD scores and for missing data on years of education.

3.13. RESULTS

3.13.1. DEMOGRAPHIC DATA

Overall, there were 224 people with AD who were interviewed and demographic data was analysed and are reported (see Table 9 for all demographic characteristics). The sample population were predominantly women (71.4%) and had a mean age of 81.0 (s.d. 7.4) years ranging from 55 – 98 years. The mean years of education was 9.4 (range 1-16) and the majority had achieved a secondary level (77.7%) of education. Ethnicity was mixed, and the majority were white British (79.5%), followed by white other (15.6%) and the remaining 11 (4.7%) were from non-white ethnic backgrounds. English was not the first language for 27 (12.1%) of the participants, although all could speak and comprehend the English language. Of the 224 people with dementia, 89 (39.7%) were currently married, 114 (50.9%) were widowed and 21 (9.4%) were single, separated or divorced. At interview there were 51 (22.8%) participants who lived alone, 91 (40.7%) lived with a spouse; partner or other relative and 82 (36.6%) participants were living in 24 hour care settings.

Table 9: Demographic characteristics of the sample population

Demographic	**Characteristic**	**(n)**.	**%**
Gender	Male	64	28.6
	Female	160	71.4
Age	<60	2	0.9
	61 - 69	12	5.4
	70 - 79	74	33.0
	80 - 89	108	48.2
	90 - 99	28	12.5
Ethnicity	White British	178	79.5
	White Irish	14	6.3
	White Other	20	8.9
	Greek	1	0.4
	Black Caribbean	5	2.2
	Black Other	1	0.4
	Asian	2	0.9
	Other	3	1.3
First Language	English	197	87.9
	Other	27	12.1
Years of Education	1 - 5	4	1.8
	6 - 10	159	71.0
	11 - 15	35	15.6
	16<	1	0.4
	Unknown	25	11.2
Highest level of Education	Primary	6	2.7
	Secondary	174	77.7
	Tertiary	26	11.6
	Other general education	1	0.4
	Not known	17	7.6
Marital Status	Widowed	114	50.9
	Married	89	39.7
	Single	12	5.4
	Divorced/separated	8	3.6
	Other	1	0.4
Living situation	Live Alone	51	22.8
	Live with Spouse	66	29.5
	Live as a Couple	2	0.9
	Live with other relatives	23	10.3
	Live with others	82	36.6
Living Accommodation	Owner occupier	104	46.4
	Private rent	2	0.9
	Local Authority	32	14.3
	Sheltered accommodation	12	5.4
	Residential home	35	15.6
	Nursing home	19	8.5
	Other	19	8.5
	Refused	1	0.4

3.13.2. CAREGIVER CHARACTERISTICS

All of the 224 participants had a caregiver identified and their characteristics were analysed (see Table 10). Most of the caregivers were women (69.6%). Spousal caregivers (37%) were the most likely to be caring for someone with dementia and interestingly there were similar numbers for husband (17.4%) and wife (19.6%) caregivers. Children (35.5%) caring for a parent were the next most likely to be caring for someone with dementia.

Table 10: Caregiver demographic characteristics for the sample population

Demographic	**Characteristic**	**(n)**	**%**
Caregiver Gender	Male	68	30.4
	Female	156	69.6
Caregiver relationship	Husband/partner	39	17.4
	Wife/partner	44	19.6
	Child	79	35.3
	Other relative	21	9.4
	Friend	10	4.5
	Paid caregiver	31	13.8

3.13.3. CLINICAL CHARACTERISTICS

The clinical characteristics of the 224 people with AD were examined and are reported (see Table 11). The participants included people with mild, moderate and severe dementia and there was a mean MMSE score of 14.7. The mean Cornell score was 4.5 and of the 224 participants 51 (22.8%) were depressed "cases". A significant degree of behavioural disturbance was shown with a mean NPI total score of 18.0 and the level of functional dependency varied with a mean ADCS-ADL score of 35.2.

Table 11: Clinical Characteristics of the sample population

Variable	**(n)**	**Mean**	**S.D.**	**Range**
Age	224	81.0	7.4	55 – 98
Years of Education	199	9.4	1.7	1 – 16
MMSE	224	14.7	8.3	0 – 29
CORNELL	224	4.5	4.8	0 – 24
NPI total	224	18.1	15.8	0 – 79
ADCS-ADL	224	35.2	22.0	0 – 78
QOL-AD - Patient total	192	36.5	6.7	17 – 52
QOL-AD - Caregiver total	222	30.2	6.3	17 – 49

3.13.4. ACETYLCHOLINESTERASE INHIBITORS

Within the overall sample population of 224 people diagnosed with AD there were 119 (53.1%) participants who were prescribed AChEI medication (see Table 12). Donepezil (43.8%) was the most commonly prescribed AChEI and just under half of the participants (46.9%) were not prescribed any antidementia medication.

Table 12: Prescription of AChEI medication

Anticholinesterase	**(n)**	**%**
Donepezil	98	43.8
Rivastigmine	19	8.5
Galantamine	2	0.9
Not Prescribed	105	46.9

3.13.5. QUALITY OF LIFE SCORES

Overall 192 (85.7%) of the 224 people with dementia were able to complete the QOL-AD. Of the 224 caregivers recruited, 222 (99.1%) caregivers completed the QOL-AD regarding the QoL of the person they cared for. Where one or two items were missing mean QOL-AD scores were inserted. This was done for 13 (5.8%) of the people with dementia QOL-AD completed scales and for 20 (8.9%) of the caregiver completed scales (Logsdon et al, 2002). A further 32 (14.3%) people with dementia and 2 (0.9%) caregivers had 3 or more items missing on the QOL-AD and were excluded. Of these, 25 people with dementia did not answer any of the questions on the QOL-AD, 2 participants answered 1 item, 1 participant answered 7 items and 4 participants answered 10 items. For the excluded caregiver items, 1 caregiver answered 10 items and 1 caregiver did not answer any questions on the QOL-AD. This left 191 matched QOL-AD scores for the person with dementia and the caregiver which the rest of the results report. For the 191 matched cases the people with dementia had a mean QoL score of 36.6 (s.d. 6.8) and the caregivers had a mean QoL score of 30.8 (s.d. 6.3).

3.13.6. FACTORS CORRELATED WITH INDIVIDUAL AND CAREGIVER RATED QoL

Correlations were calculated between the QoL scores and the pathological variables (see Table 13). The correlations were undertaken initially using the people with dementia's (PQoL) ratings and then repeated for all the caregiver (CGQoL) ratings. Of the 191 matched caregiver rated QOL-AD scales, there were 167 family-caregivers and 24 paid-caregivers. The correlations were subsequently repeated dividing the caregivers into family-caregiver (CQoL) and paid-caregiver (SQoL) ratings. All the correlations are presented in Table 13.

3.13.6.1. FACTORS CORRELATED WITH INDIVIDUAL QoL

For the people with dementia, higher PQoL ratings were significantly correlated with better cognition (p<0.005) and ADL functioning (p<0.001) and less depressed mood (p<0.001). No demographic variables (age, gender or years of education) were related to PQoL.

Table 13: Correlations with QOL-AD scores and pathological variables.

Variables	**PQoL** scores (n) 191	**CGQoL** scores (n) 191	**CQoL** scores (n) 167	**SQoL** scores (n) 24
	rho	*rho*	*rho*	*rho*
MMSE	.222 **	.242*	.219 **	**.574 ** **
CORNELL	-.361 *	-.378*	-.384 *	-.348
ADCS-ADL	.301 *	**.417***	**.420 ***	**.600 ** **
NPI Total	-.155	**-.444***	**-.460 ***	-.399
NPI – delusions	-.024	-.086	-.080	-.149
NPI hallucinations	-.066	-.029	-.004	-.254
NPI – agitation /aggression	-.060	-.267*	-.279 *	-.213
NPI – depression	-.147	-.254*	-.251 *	-.336
NPI – anxiety	-.067	-.169	-.187	-.047
NPI – elation	.134	-.009	-.047	.348
NPI – apathy	-.147	**-.451***	**-.491 ***	-.265
NPI – disinhibition	.056	-.041	-.029	-.105
NPI – irritability	-.084	-.273*	-.310 *	-.036
NPI – aberrant motor behaviour	-.039	-.238*	-.272 *	-.017
NPI – sleep	-.063	-.047	-.024	-.233
NPI - appetite	.068	-.024	-.031	-.060
HADS Depression	-.119	-.258*	-.264 *	
HADS Anxiety	-.077	-.278*	-.294 *	

p ≤0.001 = *; p ≤0.005 =**

3.13.6.2. FACTORS CORRELATED WITH CAREGIVER RATED QoL

No demographic variables (age, gender or years of education) were related to CGQoL for caregiver rated QoL. There was no significant difference observed between the total ratings of CQoL compared to SQoL (Median score = 30.0 versus 29.5 respectively; Mann-Whitney U = 1872.5). For family-caregivers, higher CQoL ratings were significantly correlated with better cognition (p=.005) and ADL functioning (p<0.001), less depressed mood (p<0.001) in the person with dementia and fewer neuropsychiatric symptoms (p<0.001). For the individual items on the NPI, negative correlations with CQoL were observed for agitation/aggression (p<0.001), depression (p<0.001), apathy (p<0.001), irritability (p<0.001) and aberrant motor behaviour (p<0.001). Higher CQoL ratings were also significantly correlated with fewer symptoms of caregiver depression (p<0.001) and anxiety (p<0.001). For paid caregivers, higher SQoL ratings were significantly correlated with better function (p<0.005) and better cognition (p<0.005).

3.13.7. QoL SCORES AND ACETYLCHOLINESTERASE INHIBITORS

Within the matched pairs, 116 people with dementia (60.7%) were prescribed an AChEI and 75 (39.3%) were not. The mean PQoL and CGQoL ratings were compared for those taking AChEI medication and those that were not (see Table 14). The differences in ratings were then compared using Mann Whitney U tests as the data were not normally distributed. Those people with dementia taking AChEI medication had higher rated PQoL (median score = 38.00 versus 35.0; U value = 3247.5, p<0.005). This was also true of the caregiver ratings, CGQoL (median score = 31.00 versus 29.0; U value = 3472.5, p<0.05).

Table 14: QoL scores and the presence of AChEI medication

AChEI	**AChEI prescribed**	**(n)**	**Median**	**Mean**	**S.D.**	**Range**
PQoL	Yes	116	38.0	37.9	5.7	24 – 49
	No	75	35.0	34.5	7.8	17 – 52
CGQoL	Yes	116	31.0	31.7	6.0	18 – 49
	No	75	29.0	29.4	6.6	18 – 47

3.13.8. QoL SCORES AND LIVING SITUATION

The person with dementia's living situation was examined and within the matched pairs, 56 people with dementia (29.3%) were living in a 24 hour care setting compared to 135 (70.6%) who were not (see Table 15). Of those not living in a care setting 51 (29.7%) lived alone and 85 (44.5%) lived with other relatives. The person with dementia had a mean PQoL score of 37.9 (s.d. 6.5) when living with relatives, 36.8 (s.d. 6.3) when living alone and 34.2 (s.d. 7.0) when living in 24 hour care. The person with dementia rated PQoL higher when they lived at home and lower when they lived in care (p=0.005).

Table 15: QoL scores and the person with dementia's living situation

Living situation	**Living in 24 Hour Care**	**(n)**	**Median**	**Mean**	**S.D.**	**Range**	**Sig**
PQoL	Yes	56	35.0	34.2	7.0	17 – 49	p<0.005
	No	135	37.0	37.6	6.4	23 – 52	
CGQoL	Yes	56	29.0	29.6	6.1	18 – 43	NS
	No	135	31.0	31.3	6.3	18 – 49	

3.13.9. REGRESSION ANALYSIS

Multiple regression analysis allows for the relationship between several independent or predictor variables and a dependent variable to be determined. Further analyses was therefore undertaken using stepwise linear regression to determine independent predictors of QoL, for the people with dementia's QoL (PQoL), and family caregiver views of the people with dementia's QoL (CQoL). People with dementia (191) and family-caregiver QOL-AD scores (167) were used as the dependent variables (see Table 16). Paid-caregivers were not included in the regression analysis as there were so few of them.

3.13.9.1. PREDICTORS OF QoL AND THE PERSON WITH DEMENTIA

When the people with dementia's rating of their own QoL was considered, in step one, 24 hour care was the only significant predictor ($p<0.001$) of lower PQoL. On step 2, both being in 24 hour care ($p<0.005$) and not taking AChEI ($p<0.05$) were significant predictors of lower PQoL. On step 3, more depressive symptoms ($p<0.001$), being in 24 hour care ($p=0.001$) and not taking AChEI ($p<0.01$) were all significant predictors of a lower PQoL. The model did not change on step 4.

3.13.9.2. PREDICTORS OF QoL AND THE FAMILY CAREGIVER

When family-caregiver ratings of QoL were considered, in step 1 the only significant predictor of lower CQoL was living in 24 hour care ($p<0.01$); in step 2 the model did not change. In step 3, CQoL was significantly lower when the person with dementia had more depressive symptoms ($p\leq0.01$), was more irritable ($p<0.001$), more apathetic ($p<0.001$), had lower ADL function ($p<0.05$) and lived in 24 hour ($p<0.05$). In step 4 the model remained the same.

Table 16: Identified predictors of people with dementia and family caregiver rated QoL using regression analysis

Variables	**PQoL** *(n = 191)*		**CQoL** *(n = 167)*	
	Beta	*p≤*	*Beta*	*p≤*
CORNELL	-.319	.001	-.181	.01
ADL			.182	.05
NPI – apathy			-.320	.001
NPI – irritability			-.215	.001
24 hour care	-.239	.001	-.182	.05
AChEI	.182	.01		
Model %	20		41	
F =	15.9		22	
p ≤	.001		.001	
Adjusted R^2	19		39	

3.14. DISCUSSION

3.14.1. SUMMARY OF FINDINGS

This study examined the people with dementia and caregiver components of the QOL-AD separately in an epidemiologically representative sample of people with AD, including gender, different living situations and all severities of the disorder. In keeping with earlier studies the caregivers rated the people with dementia's QoL lower than the people with dementia did (Sands et al., 2004; Selai et al., 2001a; Logsdon et al., 1999). It is evident from this study that although highly correlated there is discrepancies in QoL ratings between caregiver proxies and people with dementia. Having taken into account the demographic features and pathological variables in both the caregiver and people with dementia dyad, it has been possible to explore further the factors which contribute to these divergent assessments. This study showed differences between both the family caregiver and the QoL ratings of the people with dementia. Mood and living environment were the main predictors of the person with dementia's own rated QoL, whereas the family-caregiver ratings of QoL in dementia were predicted by the person with dementia's mood status and neuropsychiatric symptoms. Paid-caregiver's QoL ratings were most influenced by the person with dementia's level of dependency.

3.14.2. QoL AND ACETYLCHOLINESTERASE INHIBITORS

In a new, and potentially important, finding people with dementia taking AChEIs rated their QoL more highly than those who were not. While caregivers also rated the people with dementia on AChEI as having a higher QoL; the regression analysis suggested that this was accounted for by those participants taking AChEIs being less likely to be in 24 hour care. Taking AChEIs is predictive of higher QoL in dementia although the direction of causation is not clear. It is unclear whether those people with higher QoL are more likely to seek to take medication for their AD or whether it improves their QoL or both from this cross-sectional data. Whilst the link between AChEI and QoL in dementia needs to be investigated much further, these findings are the first in the literature that consider QoL using a validated scale for dementia and the use of AChEIs. Moreover this finding supports the argument that QoL may be better for people with dementia taking AChEIs (Overshott & Burns, 2005).

3.14.3. DISCREPANCIES BETWEEN PROXY AND SELF RATINGS IN DEMENTIA

Another discrepancy between caregiver and people with dementia was that for the caregiver's ratings of QoL, higher dependency and neuropsychiatric symptoms (apathy and irritability) were a predictor of reduced QoL in dementia. Greater levels of functional dependency and neuropsychiatric symptoms were not identified as a predictor for the people with dementia's own ratings of QoL. Increased neuropsychiatric disturbances have been found to be associated with caregiver psychological morbidity (Banerjee et al., 2006; Schulz et al., 2002; Donaldson et al., 1997; Coen et al., 1997) and low caregiver QoL. Banerjee et al., (2006) found correlations between QoL as measured by the DEMQOL-Proxy (see Chapter 1 Section 1.6.4.1.5. of this Thesis) and the NPI total score and the 5 NPI subscales: agitation ($p<0.001$); depression ($p<0.001$); anxiety ($p<0.005$); disinhibition ($p<0.05$); irritability ($p<.0001$). They further identified predictors of QoL in dementia as rated by the caregiver which were neuropsychiatric symptoms and the person with dementia's age. These findings are similar to the current study except no association with demographic characteristics was found in this study.

When the high levels of neuropsychiatric symptoms were considered, the caregiver's mood symptoms were no longer an independent predictor of their ratings for people with dementia's QoL. Caregiver mood is very strongly related to the person with dementia's neuropsychiatric symptoms and thus both may no longer be independent predictors although there is a strong correlation (Mahoney et al., 2005). In their study using the same sample as the present one, Mahoney et al., (2005) examined anxiety and depression caseness in caregivers of people with dementia as measured by the HADS. Anxiety caseness was most commonly found when the person with dementia was male, had increased functional dependency and neuropsychiatric symptoms were present, particularly irritability. Whereas, depression caseness in the caregiver, was associated with poor caregiver health and physical functioning where this interfered with daily living and the presence of irritability in the person with dementia (Mahoney et al., 2005). Previously caregiver depressive symptoms have been found to be a predictor of caregiver rated QOL-AD scores (Logsdon et al., 1999). In their study, Logsdon et al., (2002) found caregiver depression was significantly associated with caregiver QOL-AD ratings ($p<0.001$), but was not correlated with the person with dementia's QOL-AD ratings. The current study therefore shows that if the overall clinical picture is considered the caregivers low mood may not be an independent predictor.

3.14.4. PREDICTORS OF QoL IN DEMENTIA

The regression analysis showed that despite some differences in predictors of QoL in dementia, both the individual and caregiver's rated QoL as lower when the person with dementia was in a 24 hour care setting and if they had more depressive symptoms. Just over a third of the sample lived in 24 hour care. The association found between low QoL and living in 24 hour care setting may be related to those people with dementia living in institutions having higher levels of dependency and exhibiting more behavioural problems (Jagger & Lindsay, 1997; and as discussed in Chapter 4 of this Thesis and Appendix 6.b.: Hoe et al., 2006). It is of interest that the mean QoL score rated by the people with dementia in this study was higher than in an additional study undertaken in a residential care setting, which may also be because people generally prefer to live in their own homes (see Chapter 4 and Appendix 6.b.: Hoe et al., 2006). The findings suggest the continued provision of care at home could contribute to the wellbeing of people with dementia and maintenance of their QoL.

3.14.5. FACTORS INFLUENCING QoL RATINGS

Modest associations between QoL and cognition have been observed previously (Logsdon et al., 1999), as they were in this correlation analysis, but cognitive impairment was not in itself a predictor of QoL in regression. Low QoL scores were predicted by reduced ADL ability for family-caregiver QoL ratings but not for the people with dementia's own ratings of QoL, and dependency is related to cognition. This is similar to Andersen et al's (2004) study that showed that health-related QoL in people with dementia as measured by the EQ-5D (EUROQOL, 1990) is predicted by dependency status based on ADL ability. The EQ-5D is a generic QoL utility scale which does not consider cognition as a separate attribute. Andersen et al., (2004) also found that QoL in dementia diminished as disease severity and dependency increased, and when the person with dementia was institutionalised. In addition, as expected levels of functional ability were observed to decrease as cognition worsens and reduced function was also related to physical illness and depression. It is noteworthy that these findings are consistent with a further study of QoL in residents with dementia living in residential homes that showed staff perceptions but not the resident's QoL ratings were influenced by levels of functional dependency (as discussed in Chapter 4 of this Thesis and Appendix 6.b.: Hoe et al., 2006).

3.14.6. GENERALISABILITY OF THE FINDINGS

This study examined the people with dementia and caregiver components of the QOL-AD separately and was an epidemiologically representative sample of people with Alzheimer's disease, in terms of gender, dementia severity and living situation and therefore the results may be considered generalisable, at least in the UK. Many studies have looked at both family proxy and patient ratings of QoL in a range of people with mild/moderate dementia and severe dementia (MMSE>3) and shown them to be valid and this study fits with the literature (Thorgrimsen et al., 2003; Selai et al., 2001a; Logsdon et al., 1999, Brod et al., 1999) and as discussed in Chapter 2 of this Thesis (also see Appendix 6.a.: Hoe et al., 2005). Both Logsdon et al., (1999) and Thorgrimsen et al., (2003) used the QOL-AD to rate QoL in dementia and found depression in the person with dementia had the strongest association with QoL ratings.

3.14.7. LIMITATIONS

Limitations of this study include that there continues to be a lack of an accepted gold standard QoL measure to validate findings (Novella et al., 2001a; Brod et al., 1999; Whitehouse, 1999). In addition, a small number of people with dementia could not complete the QOL-AD, mostly those with a profound degree of dementia who had poor comprehension and communication ability and these findings may not be applicable to those with a MMSE<3 (as discussed in Chapter 2 of this Thesis and Appendix 6.a.: Hoe et al., 2005). Finally there were relatively few paid-caregivers and thus we cannot consider in detail the factors that predict QoL from their ratings.

3.14.8. IMPLICATIONS

This study has shown that discrepancies exist between the person with dementia and caregiver proxy ratings, they are therefore not considered to offer a perfect substitute for the person with dementia's own rating of QoL. This finding strengthens the argument that the person with dementia's own views should be sought where possible and the results show people with dementia at all levels of disease severity (up to MMSE≥3) do provide valid and meaningful perceptions of their own QoL.

The identification of depression in the person with dementia as a predictor of QoL in dementia reinforces the need to treat depressive symptoms in dementia more energetically. The association between higher QoL in dementia and treatment with AChEIs is potentially very significant and the benefits of AChEIs in improving cognition, behavioural disturbances and functional ability are known (Trinh et al., 2003; Clark & Karlawish, 2003; Francis et al., 1999). This finding also has implications for showing that the routine use of dementia specific QoL assessment within clinical trials to further investigate the relationship between AChEI medication and QoL in dementia is feasible. Overall this study indicates that QoL in people with dementia is higher when treating depression energetically, giving cholinesterase inhibitors and providing care in their own homes.

3.14.9. CONCLUSION

In conclusion this study showed differences between caregiver and people with dementia's ratings of their QoL. The findings suggest people with dementia's rated QoL is most predicted by current mood, taking AChEIs and living environment, whereas family-caregiver perceptions of people with dementia's QoL are predicted by the people with dementia's mood status, the presence of neuropsychiatric symptoms and living environment. Clinicians and researchers should be made aware that proxy ratings are different from the people with dementia's QoL and should not be substituted for self-ratings. Depression in people with dementia continues to be a predictor of low QoL and should be managed actively. Similarly, the management of neuropsychiatric disturbances may help caregivers as well as the person with dementia. Taking AChEIs and supporting people in the community where possible, may contribute to higher QoL.

3.14.10. FURTHER RESEARCH

This study has concentrated on comparing people with dementia and family caregiver proxy ratings of QoL in dementia. Not all people with dementia have an identified family caregiver; therefore further investigation that compares individual and formal or paid caregiver's perceptions of QoL in dementia would be of interest. Whilst further investigation into AChEI treatments of dementia is not within the scope of this thesis, the ability to investigate the impact of environment on QoL is. The next Chapter will therefore aim to examine the staff perceptions of QoL in dementia and the investigation will be undertaken for people with dementia living in residential homes.

4.0. CHAPTER 4: QUALITY OF LIFE OF PEOPLE WITH DEMENTIA LIVING IN RESIDENTIAL HOMES

4.1. AIMS AND HYPOTHESES:

Aim 2: To investigate the association between clinical and demographic factors and QoL in dementia including cognition; mood; behaviour, function, environment and unmet need, by comparing the person with dementia and the caregiver ratings of QoL in dementia.

4.1.1. PRIMARY HYPOTHESES

Lower QoL as rated by the person with dementia will significantly correlate with higher levels of depression and anxiety symptoms.

4.1.2. SECONDARY HYPOTHESES

Hypothesis 2: QoL as rated by the person with dementia will not significantly correlate with clinical factors, namely cognition, behavioural disturbances or activities of daily living

Hypothesis 3: Caregiver perceptions of QoL in dementia will not differ from the person with dementia's rating of QoL.

4.2. METHODOLOGY

The factors influencing family caregiver proxy ratings of QoL in dementia have been examined in the previous Chapter and discrepancies were found between the caregiver and people with dementia's QoL ratings. This Chapter intends to examine in more detail the factors influencing formal or paid caregiver proxy QoL ratings for people with dementia. Within this Chapter the design and methods undertaken for the second study forming part of this investigation will be described and this will be referred to as Study 2. Descriptions of the sample population, study procedure and instruments used are given. The aim of this Chapter is to compare the views of residents with dementia and staff within residential care homes about each resident's QoL and attempt to identify factors associated with QoL in dementia as rated by the staff and by the person with dementia.

4.3. STUDY DESIGN

This investigation was undertaken as part of a larger project examining the needs of older people with dementia living in residential homes (Hancock et al., 2006). The study design was a block randomised-control trial involving 238 people with dementia, who were recruited to the study from 24 residential homes in London, Wales and North East England. Purposive sampling was used and a current list of residential homes was obtained from the research areas. Randomisation was by residential home. For each region matched pairs of homes, based on size and registering body (local authority, private, voluntary) were selected. Residents were selected who were permanently placed and had lived in the home for at least one month with possible or definite memory problems. Following an initial screening interview to determine the presence of dementia, residents were recruited to the study. The screening included information collected and assessed by the researchers using case notes, discussion with staff or relevant others (e.g., family or GP etc). Data was then collected on resident's health status, needs, QoL and resource use. Fifty percent of the residential care homes were randomly allocated by computer (by someone external to the study) to the control group, while the other 50% of homes received the intervention. The main dependent variable was the amount of change on the CANE (pre and post, met and unmet needs) between the intervention and no-intervention/control groups. A follow up assessment was repeated after the planned interventions had been provided. A two tier selection process was designed to ensure that residents were not excluded due to the nature or severity of their condition, so a representative sample of people with dementia living in care homes could be entered into the study.

4.4. SAMPLE POPULATION

The selection of homes was made by contacting Social Services inspection units and requesting a current list of residential homes in the local research areas. Residential homes not offering specialist services (i.e., Elderly Mentally Infirm (EMI) units, or dementia specific homes) were highlighted. The largest homes with similar attributes, i.e., size, locality, registering body (government or private) and where possible, philosophy (e.g. religion) were noted. When two homes in an area could be matched an introductory letter was sent to the managers. The researcher then contacted the homes to gauge interest regarding participation in the study. If the home was interested the researcher arranged to visit and discuss the study further and to identify residents that met the inclusion criteria. All residents with existing identified memory problems were screened for possible/probable dementia. For each home between 8 and 12 residents with dementia (DSM-IV; American Psychiatric Association, 1994) who met the inclusion criteria were then randomly selected from the list of potential participants and recruited to the project (see Section 4.7). This over sampling was to account for possible attrition during the course of the study. If a participant dropped out during the initial assessment phase another eligible resident was randomly chosen from the list to take their place. If a family caregiver was available they were also invited to participate in the study, this was usually a family or friend that visited on at least a weekly basis. A staff member was also included; this was usually the resident's key worker. Twenty four homes participated in the study (10 London, 6 Manchester, 8 North Wales).

4.5. INCLUSION CRITERIA

- Participants were over 60 years old and living permanently in the residential home.

- Participants had to have lived in the home for the past month and were likely to be staying in the home for the following six months.

- A diagnosis of dementia according to DSM-IV revised interim version; American Psychiatric Association, (1994).

4.6. EXCLUSION CRITERIA

- Participants were excluded if their symptoms could be better accounted for by a delirium, other DSM-IV Axis I disorder (e.g., Major Depressive Disorder or Schizophrenia) or another medical condition.

4.7. PROCEDURE

When two homes could be matched i.e., size, locality, registering body (government or private), an introductory letter was sent to the manager of the homes, with an invitation to participate in the study. The interested homes were then visited by a researcher and all the residents were screened using the National Institute of Social Workers (NISW) Noticeable Problems checklist (Levin et al., 1983). This NISW checklist covers six items regarding the person's memory, orientation and level of dependency. The participants were required to show signs of dementia and those participants who scored 2 to 6 on the NISW were selected to go on to the second stage of the selection process. A score of 2 to 5 on the NISW indicates possible dementia and a score of 5 or 6 indicates probable dementia. Those residents who scored 0 or 1 on the NISW were excluded from participating in the study as they were not considered to show significant signs of dementia. The list of probable and possible residents with dementia were then further screened by the researcher using case notes and a brief assessment of the individual to ensure they could be regarded as having a diagnosis of dementia (DSM-IV; APA, 1994). All participants had evidence of significant memory impairment and one or more other cognitive problems (i.e., aphasia, apraxia, agnosia, or a disturbance of executive functioning). In addition, the disturbance in cognition and/or behaviour had to be a significant decline from the individual's previous level of functioning. Lastly, the symptoms of dementia had to have been present for the past six months. A number (minimum 8 - maximum 12) of eligible residents with possible or probable memory problems were then randomly selected for participation in the study. If a participant dropped out during the initial assessment stage another eligible resident was randomly chosen from the list to take their place. Residents were initially approached to gain their consent to participate in the study. Once obtained a review of the casenotes review and a diagnostic interview was undertaken to identify the presence of dementia

(DSM-IV; APA, 1994). Interviews were then undertaken separately with the resident and a staff member who was usually the resident's keyworker or the manager of the home. Where identified a family caregiver was also interviewed. Information was obtained through standardised interview, observation and a review of the care home documentation. Most of the interviews were undertaken within the residential homes, but some family caregivers chose to be interviewed in their own homes. The interviews were all conducted by trained experienced health professionals from nursing and clinical psychology. The interview time varied according to the ability of the resident. For those residents experiencing communication difficulties interviews tended to be shorter and were conducted in a conversational style using open ended questions rather than direct questions. Each interview took approximately 45 – 60 minutes to complete with the residents, 30 – 40 minutes with the staff member and 45 minutes with the family caregiver.

Data were collected on the person with dementia's demographic details, cognition, mental and physical health status, needs, activities of daily living, behaviour, QoL, medication and resource use (see Section 4.8). After all residents in the two homes had been assessed, clinical reports were devised based on the met and unmet needs identified. A multidisciplinary team meeting with medical, nursing and clinical psychology representation was then held to discuss the unmet needs of the residents. Each home was discussed in general and a list of interventions were then agreed upon to meet the resident's unmet needs identified, this included clinical interventions, management techniques, improvements to the environment, procedures within the home, or staff training. A home was then randomly selected on computer by an external person for feedback on the assessments and a period of intervention. The researcher visited the home for two hours every fortnight for a period of 20 weeks (plus or minus 2 weeks). During this time individual plans of care were agreed for those residents involved in the study. Modifications were also discussed regarding the home procedures and environment e.g. introducing an activity programme or reality orientation signs. When the need was identified for further education about the care of people with dementia teaching was also provided to the staff within the homes.

At follow up, both homes were visited by a different researcher who was blind to which homes had the interventions provided. The second researcher reassessed all the residents involved in the study following the procedure already outlined.

4.8. DATA COLLECTION

4.8.1. INSTRUMENTS

4.8.1.1. QUALITY OF LIFE IN ALZHEIMER'S DISEASE (LOGSDON ET AL., 1999)

As described in *Study 1 Instruments used for the person with dementia* see Chapter 2: Section 2.10.1.1., of this Thesis.

4.8.1.2. CAMBERWELL ASSESSMENT OF NEED FOR THE ELDERLY (REYNOLDS ET AL, 2000; ORRELL & HANCOCK, 2004).

The Camberwell Assessment of Need for the Elderly (CANE) offers a structured and comprehensive measurement of need in older people and identifies whether these are met or unmet (Reynolds et al, 2000). There are 24-items that cover domains relevant to mental and physical health, social and environmental needs. In addition, 2 further domains are included concerning the information and psychological needs of caregivers. Individual items are rated No Need (0), Met Need (1), Unmet Need

(2) or Unknown (9). For met or unmet needs the current level of help received from relatives and local services is then rated mild (1), moderate (2) or high (3) and whether the support received is adequate for the persons needs. The CANE is completed with the individual, a family caregiver (if available) and a staff member. An overall clinical rating is then applied by the researcher based on all the information obtained throughout the assessment. The CANE has good validity (correlating with the CAPE-BRS, r=0.66; and the Barthel r=-0.53) and reliability (ICC 0.99, 95% CI 0.90-1.00) as a needs assessment tool for older people and has been used in a variety of mental health settings (Orrell & Hancock, 2004). The CANE was included as it offers a structured, person-centred, and outcome orientated approach to measuring need in older people which can help identify areas of risk and priority for care planning (Orrell & Hancock, 2004).

4.8.1.3. MINI MENTAL STATE EXAMINATION (FOLSTEIN ET AL., 1975)

As described in *Study 1 Instruments used for the person with dementia* see Chapter 2: Section 2.10.1.3., of this Thesis.

4.8.1.4. THE CLINICAL DEMENTIA RATING SCALE (HUGHES ET AL., 1982)

The Clinical Dementia Rating scale (CDR) provides a global rating of severity of dementia (Hughes et al., 1982). This global scale assesses six cognitive domains, memory; orientation; judgement; problem-solving; community affairs; home and hobbies; personal care. Ratings on the CDR are staged in five levels: 0 = No impairment; 0.5 = Questionable impairment; 1 = Mild dementia; 2 = Moderate dementia; and 3 = Severe dementia. The CDR is a valid and reliable tool which is useful in providing a global assessment of cognitive function across all severities of dementia. The CDR showed highly significant correlations of .57 to .84 (p<0.0001) with other cognitive tests and accurately predicted ratings at 6 to 9 months follow up

(Hughes et al., 1982). The investigator applied the rating for the CDR. A popular and widely used assessment of dementia severity, the CDR was included as it is easily used and has proved useful in screening dementia (Juva et al., 1995).

4.8.1.5. CORNELL SCALE FOR DEPRESSION IN DEMENTIA (ALEXOPOLOUS ET AL., 1988b)

As described in *Study 1 Instruments used for the person with dementia* see Chapter 2: Section 2.10.1.4., of this Thesis.

4.8.1.6. RATING OF ANXIETY IN DEMENTIA (SHANKAR ET AL., 1999)

The Rating of Anxiety in Dementia (RAID) is a brief screening measure that identifies and measures anxiety in dementia (Shankar et al., 1999). The signs and symptoms of anxiety are included in 5 categories in the RAID: worry, apprehension and vigilance, motor tension, autonomic hyperactivity, phobias and panic attacks. There are 18 items rated on a four-point scale, absent (0), mild or intermittent (1), moderate (2) and severe (3). A total score of 11 and over indicates significant anxiety symptoms. The RAID has good validity (distinguishing between low and high anxiety states using modified DSM-IV criteria U=22.5, p=0.006; and clinical judgement U=31.5, p=0.03) and reliability (Cronbach's alpha was 0.83) and has been used to measure anxiety in people with dementia across a variety of psychiatric settings. Ratings were made on the level of anxiety symptoms after assessment of all relevant information (i.e. self and caregiver reports and through rater observation). The RAID was included as it provides a useful clinical instrument to study the prevalence of anxiety in dementia (Shankar et al., 1999).

4.8.1.7. CHALLENGING BEHAVIOUR SCALE (MONIZ-COOK ET AL., 2001)

The Challenging Behaviour Scale (CBS) is a 25-item checklist that measures and rates the incidence, frequency and severity of behavioural disturbance presented by older people with dementia. Behaviours include verbal and physical aggression, agitation, perseveration, wandering, non-compliance, apathy, self harm and neglect, disinhibition and dangerous activities. Presenting behaviours are scored on frequency 1 – 4 (occasionally – daily), severity 1 – 4 (minimal – extreme management difficulty). The 'level of challenge' is calculated by multiplying frequency and severity of the individual behaviours and a sum total score (0 – 400) determined. Higher scores indicate more difficult challenging behaviour. The CBS has good validity (correlating with CAPE-BRS subscales: social disturbance r=.69, p≤0.001 and apathy r=.36, p≤0.001) and reliability (in 6 separate studies Cronbach's alpha ranged from .57 to .99 for incidence; .5.7 to .97 for frequency; .27 to .98 for difficulty and .27 to .99 for challenge) and has been shown to be an effective measure to rate the incidence of challenging behaviour when used by trained staff in institutional settings (Moniz-Cook et al., 2001). The scale was completed with the staff member.

4.8.1.8. THE CLIFTON ASSESSMENT PROCEDURES FOR THE ELDERLY–BEHAVIOUR RATING SCALE (PATTIE & GILLEARD, 1979)

The Clifton Assessment Procedures for the Elderly–Behaviour Rating Scale (CAPE-BRS) measures behaviour and functional ability and can be used to rate levels of dependency (Pattie & Gilleard, 1979). It consists of 18 items which cover general behaviour, personal care, communication, socialisation, sleep and behaviour towards others. Items are rated 0 - 2, with 0 indicating no problems, 1 - mild to moderate problems and 2 - severe problems. Scores range from 0 to 36 with higher scores indicating increased functional dependency. The CAPE-BRS is useful because it assesses dependency. As a screening tool the CAPE BRS is reliable and valid in predicting criteria, such as service use and outcome (Little & Doherty, 1996). The CAPE BRS has been used to monitor and compare behaviour and dependency in older people with mental health needs in different settings (Philp et al., 1995; Clarke et al., 1996; Crawford et al., 1999; Simmons et al., 2001). This scale was completed with the staff member. The CAPE-BRS was included as it is quick and easy to administer and has been widely used by health professionals and care staff (Butler & Pitt, 1998).

4.8.1.9. BARTHEL SCALE OF ACTIVITIES OF DAILY LIVING (MAHONEY & BARTHEL, 1965)

The Barthel Scale of Activities of Daily Living (Barthel) provides a measure of an individual's ability to complete various activities of daily living (Mahoney & Barthel, 1965). There are 10 items which cover eating, mobility, personal hygiene and continence, which are graded 0, 5 or 10. The scale provides an indication of the dependency of the person and their need for assistance with individual tasks. ADL needs are ranked from 0 (very dependent) to 100 (independent), higher scores indicating better functional ability. The Barthel was designed as a simple index of level of independence which could be repeated over time to indicate changes in the person's functional ability. This scale was completed with the staff member. The Barthel is a well known, widely used and easily completed assessment of primary ADL scale and was included as it scores what the person actually does (Rodgers et al., 1993).

4.8.2. ADDITIONAL DATA COLLECTED

4.8.2.1. DEMOGRAPHIC DATA

Data were collected regarding the resident's age; gender; marital status; ethnicity; length of time in the residential home; previous employment and years of education.

4.9. ETHICAL APPROVAL

Ethical approval was granted by the London Multicentre Research Ethics Committee and all the appropriate Local Research Ethics Committees for Camden and Islington Community Health Services NHS Trust, North East London Mental Health Trust, Manchester Mental Health and Social care Trust, North West Wales NHS Trust (Appendix 2.b.).

4.10. CONSENT

The resident, family caregiver and staff member were all asked for their written informed consent (Appendix 3.b.). If the person with dementia was unable to give informed consent, they were asked for assent. The interview was stopped if the person with dementia asked to withdraw or showed distress. All participants were able to give some form of assent in line with their level of cognitive abilities (e.g. co-operating and showing no signs of distress when interviewed).

4.11. ANALYSIS

The data were analysed and descriptive data, relevant associations and correlations between QoL, clinical and demographic information are reported. The analysis was undertaken using SPSS 12.0. (SPSS, 2004). As in Study 1 (Chapter 3 of this Thesis) where one or two items were missing on the QOL-AD the mean QOL-AD scores were inserted, because person mean methods of imputation give better results for multi-dimensional data with respect to measures of discrepancy (Bernaards & Sijtsma, 2000). Descriptive data, relevant associations and correlations of clinical and demographic data with QoL ratings are reported. As the data was not normally distributed the Spearman's *rho* test was used for analyses and correlations of 0.4 and above were considered as being clinically significant (Dunn & Everitt (1995). A multivariate regression analysis was undertaken to determine predictors of QoL, as rated by the QOL-AD using individual and proxy ratings of residents QoL.

4.12. RESULTS

4.12.1. DEMOGRAPHIC CHARACTERISTICS

In total there were 238 residents with dementia included in the study. Demographic data were analysed and is reported (see Table 17 for all demographic characteristics). The mean age of residents was 86.5 years ranging from 60 – 104 years and they were predominantly female (80.7%) and white British (85.3%). Of the 238 residents 177 (74.4%) were widowed or divorced, 50 (21.0%) were single and 11 (4.6%) were married. The mean length of stay in the residential home was 33.5 months ranging from 1 - 180 months, and whilst most of the residents 142 (59.7%) had lived in a residential home for between 1 – 3 years, 42 (17.6) had lived within institutions for 5 years or more. The longest period of institutionalization was 10 years. For the 238 residents recruited the regional spread was London 104 (43.7%), Manchester 57 (23.9%) and Wales 77 (32.4%).

Table 17: Demographic characteristics of the sample population

Demographic	**Characteristic**	*(n)*	%
Gender	Male	46	19.3
	Female	192	80.7
Age	60 – 69	6	2.5
	70 – 79	29	12.2
	80 – 89	114	47.9
	90 – 99	84	35.3
	≥ 100	5	2.1
Ethnicity	White	203	85.3
	Other	3	1.3
	Not recorded	32	13.4
Marital Status	Widow	164	68.9
	Single	50	21.0
	Married	11	4.6
	Divorced	13	5.5
Length of time in home	1 – 12 months	62	26.1
	13 – 24 months	57	23.9
	25 – 36 months	38	16.0
	31 – 48 months	22	9.2
	43 – 60 months	17	7.1
	60+ months	42	17.6
Region	London	104	43.7
	Manchester	57	23.9
	Wales	77	32.4
Diagnosis recorded	Dementia	88	37.0
	Depression	4	1.7
	Dementia and depression	5	2.1
	No diagnosis	141	59.2

4.12.2. CLINICAL CHARACTERISTICS

The clinical characteristics of the 238 residents with dementia were analysed and are reported (see Table 18). For the clinical data, dementia severity was examined and the CDR ratings were completed for all residents, the mean score was 2.0. Only 186 (78.1%) residents had a completed MMSE (mean 8.7) as the rest were either too impaired or refused to complete the MMSE. Functional dependency was examined and the mean score on the Barthel was 63.8 and the mean score on the CAPE-BRS was 16.8. The presence of behavioural disturbance was indicated using the CBS with a mean score of 26.8. For the incidence of depressive symptoms the mean Cornell was 5.8 and for anxiety symptoms the mean RAID was 6.1. For the CANE ratings the residents had a mean of 12.1 met needs (S.D. 2.6) and 4.4 unmet needs (S.D. 2.6).

Table 18: Clinical characteristics of the sample population

Clinical Variable	**(n)**	**Mean**	**S.D.**	**Range**
MMSE	238	6.8	7.7	0 - 26
CDR	238	2.0	0.8	0.5 - 3
CORNELL	238	5.8	5.0	0 - 24
RAID	238	6.1	6.0	0 - 34
CBS	237	26.8	30.2	0 - 214
CAPE-BRS	238	16.8	5.2	2 - 32
BARTHEL	238	63.8	18.5	30 - 100
CANE - Met needs	238	12.1	2.6	5 - 12
CANE – Unmet needs	238	4.4	2.6	8 - 21
QOL-AD patient total	123	33.1	5.4	15 - 51
QOL-AD staff total	224	29.9	6.3	14 - 49
QOL-AD family caregiver total	65	29.0	5.4	17 - 45

4.12.3. QUALITY OF LIFE

There were 123/238 (51.7%) residents and 224 (94.1%) staff who were able to complete the QOL-AD (Table 19). The resident's (PQoL) mean QOL-AD score was 33.1 (n=123) and the staff (SQoL) QOL-AD ratings had a mean score of 29.9. (n=224). Where one or two items were missing mean QOL-AD scores were imputed, this was done for 54 (22.7%) of the resident completed QOL-AD scales and for 132 (55.5%) staff completed QOL-AD scales (Logsdon et al., 2002). A further 7 residents (2.9%) and 14 staff (5.9%) had 3 or more items missing and so these QOL-AD scales were excluded. Of the 108 (45.4%) residents who were unable to complete any of the QOL-AD scale, 3 residents scored >10 on the MMSE (2.8%) and 15 residents scored between 1 and 10 on the MMSE (13.9%). The remaining 90 residents either had an unrecorded score (n= 40, 37%) or scored 0 on the MMSE (n= 50, 46.3%). Difficulty in completing the QOL-AD has previously been observed in people with dementia scoring MMSE <3, see Chapter 2 of this Thesis.

Table 19: Resident and staff completion of the QOL-AD Scale

Participants interviewed	**PQoL**		**SQoL**	
	n	*(%)*	*n*	*(%)*
Completed QOL-AD scales	123	(51.7%)	224	(94.1%)
Incomplete QOL-AD scales >2 items missing	7	(2.9%)	14	(5.9%)
Number of non-completed QOL-AD scales	108	(45.4%)	0	
Matched resident and staff completed QOL-AD scales	119	(50%)	119	(50%)

4.12.4. FACTORS CORRELATED WITH INDIVIDUAL AND STAFF RATED QoL

The ratings of individual and staff proxies were correlated using the matched QOL-AD scales for those residents (119) and staff members (119) who had completed the QOL-AD scale and all the results are reported in Table 20. Correlations were initially undertaken with the resident's QoL ratings and the clinical variables. The resident's rating of higher PQoL was significantly correlated with less depressed mood and less anxiety, less unmet needs and more cognitive impairment. When the correlations were repeated using the staff, higher staff rated SQoL was significantly associated with lower physical disability, lower cognitive impairment, fewer behavioural symptoms, lower depression and anxiety symptoms, and fewer unmet needs.

An additional analysis was then undertaken which used all the available staff completed QOL-AD scales (224). This was to examine any difference in associations using all staff proxy SQoL ratings in comparison to the smaller number of matched staff and resident QoL ratings. Again there were highly significant correlations with the CAPE-BRS (-.47, p<0.001), Barthel (.36, p<0.001), CDR (-.32, p<0.001), Cornell (-.32, p<0.001), CBS (-.28, p<0.001), MMSE (.27, p<0.001), RAID (-.25, p<0.001) and unmet needs (-.30, p<0.001). This highlighted the strong association between staff perception of residents QoL and their level of dependency in contrast with resident's perceptions.

Table 20: Correlations with resident and staff member completed QOL-AD scores.

Variables	PQoL *(n = 119)*		SQoL *(n = 119)*	
	rho	*p<*	*rho*	*p<*
BARTHEL	-.10	0.30	.33	0.001
CAPE-BRS	.00	1.0	**-.53**	**0.001**
CDR	.20	0.03	-.22	0.02
CORNELL	**-.53**	**0.001**	-.36	0.001
CBS	-.15	0.10	**-.41**	**0.001**
MMSE	.02	0.82	.28	0.002
RAID	**-.50**	**0.001**	-.33	0.001
TOTAL MET NEED	.11	0.22	.14	0.13
TOTAL UNMET NEED	-.23	0.05	-.39	0.001

4.12.5. CORRELATIONS BETWEEN RESIDENT AND STAFF QoL RATINGS

The QoL scores for residents were further compared using only the matched resident and staff completed scales (119). The residents who completed the QOL-AD had a mean total score of 33.1 (S.D. 7.0), whereas the mean total for staff who completed the QOL-AD was 30.8 (S.D. 6.4) (see Table 21). The total QOL-AD score for individual and staff perceptions of the residents QoL was significantly correlated (rho .27 $p<0.005$). An item-item correlation was then carried out for the matched resident and staff completed QOL-AD scores to investigate the level of agreement between the two sets of ratings. Significant correlations were observed for the five items family, marriage, friends, ability to do things for fun and life as a whole (Table 21). Whilst there were similar means for both resident and staff QoL ratings, for all items the overall level of agreement between the QOL-AD ratings measured by the inter-item correlations was low (rho <0.4) and for kappa was low (≤0.2). This indicated that there was a clear discrepancy between staff and resident ratings for each item on the QOL-AD.

Table 21: QOL-AD item by item mean correlation and kappa coefficients

QOL-AD items	PQoL *(n=119)*		SQoL *(n=119)*		Correlations		Kappa coefficient
	Mean	*S.D.*	*Mean*	*S.D.*	*rho*	*p<*	*Values*
1. Physical health	2.7	.84	2.5	.81	-.02	NS	.04
2. Energy	2.4	.83	2.4	.83	.16	NS	.13.
3. Mood	2.6	.86	2.5	.72	-.01	NS	-.02
4. Living situation	2.8	.83	3.0	.59	.16	NS	.15
5. Memory	2.4	.87	1.9	.75	.15	NS	.06
6. Family	2.8	.90	2.6	1.1	.36	≤.001	.13
7. Marriage	2.9	.87	2.6	.92	.31	≤.001	.02
8. Friends	2.5	.98	2.2	1.0	.23	≤.012	.07
9. Self as a whole	2.6	.87	2.6	.73	.15	NS	.20
10. Ability to do chores	2.2	.95	1.7	.91	.11	NS	.11
11. Ability to do things for fun	2.2	.80	2.1	.95	.26	≤.005	.14
12. Money	2.3	.94	2.1	.99	.06	NS	.06
13. Life as a whole	2.6	.83	2.6	.71	.21	≤.020	.02
QOL-AD Total Score	**33.1**	**7.0**	**30.8**	**6.3**	**.27**	**≤.005**	**.29**

4.12.6. REGRESSION ANALYSIS

As multiple regression analysis allows for the relationship between several independent or predictor variables and a dependent variable to be determined a multiple linear regression analysis was undertaken to determine which scales were the best predictors of QoL (see Table 22). Completed resident and staff rated QOL-AD scores were each used as the dependent variables. The multiple independent variables included all the completed scales for the Barthel, CAPE-BRS, CBS, Cornell, MMSE, RAID, met need and unmet need. Any scales which had missing items were excluded. The people with dementia's QoL was significantly higher when the resident had less depressive and anxiety symptoms and ratings of their QoL were significantly predicted by the Cornell ($p<0.005$) and the RAID ($p<0.05$). No other predictors of QoL in the people were identified within the clinical variables used. This model accounted for 34% of the variance, which means 66% of QoL remained unexplained.

Staff gave lower ratings of QoL when the person with dementia had greater dependency. The staff ratings of QoL in people with dementia was significantly predicted by the CAPE-BRS ($p<0.001$). This model accounted for 43% of the variance.

Table 22: Predictors of resident and staff rated QoL using regression analysis

Variables	*PQoL* *(n) 191*		*SQoL* *(n) 167*	
	Beta	*p≤*	*Beta*	*p≤*
CORNELL	-.40	0.005		
RAID	-.32	0.05		
CAPE-BRS			-.59	.001
Model %	34		43	
F =	6.3		9.5	
p ≤	0.001		0.001	
Adjusted R^2	28		39	

4.13. DISCUSSION

4.13.1. SUMMARY OF FINDINGS

This study which examined the people with dementia and staff components of the QOL-AD separately has shown that in a sample of residential homes, the QOL-AD can be used to measure the QoL of many people with dementia and included nearly all severities of the disorder. The QOL-AD could be used to effectively measure the QoL of people with dementia in residential homes. Both individual and staff perceptions of resident's QoL were measured and in keeping with earlier studies the caregivers rated the person with dementia's QoL lower (Sands et al., 2004; Selai et al., 2001a; Logsdon et al., 1999). As found in Chapter 3 of this Thesis, the study showed disagreements between staff and residents ratings of QoL in dementia and it was possible to further investigate the factors associated with these discrepancies. Whereas mood was the main predictor of the resident's own assessment of their QoL, staff ratings of the resident's QoL were strongly linked to dependency.

4.13.2. QoL AND MOOD

The finding that the resident's ratings of their own QoL were most strongly influenced by their mood is consistent with other studies. Depression has been linked to QoL in dementia (Logsdon et al., 1999) and QoL ratings by people with dementia were shown to be most influenced by mood status (see Chapter 2 of this Thesis) and mood and environment (see Chapter 3 of this Thesis). In this investigation the residents mean QoL ratings were 33.1 (s.d. 6.9) which are similar to those shown for people living in institutions (see Chapter 3 of this Thesis). That investigation found the mean QoL rating was 34.2 (s.d. 7.0) for those people who lived in 24 hour care settings and lower QoL was found in this group compared to those people with dementia living at home. Environment may therefore be a factor contributing to either lower mood or lower QoL.

4.13.3. DISCREPANCIES BETWEEN PROXY AND SELF RATINGS IN DEMENTIA

In this study, assuming that only correlations of 0.4 and above can be considered clinically significant (Dunn & Everitt, 1995), only 5 out of the 13 QOL-AD items of the resident and staff QoL ratings were correlated and none were at the level of clinical significance. The Kappa coefficients also showed that none of the QOL-AD items were consistently rated the same way by both staff and residents. This suggests that staff ratings cannot be assumed to be a suitable proxy for QoL from the viewpoint of the person with dementia.

In studies that have investigated caregiver and individual perceptions of QoL, the ratings of the person with dementia's QoL were strongly influenced by the individual's mood and the caregiver's experience of caring (Karlawish et al., 2001; Logsdon et al., 2002; Sands et al., 2004). These studies used people with mild/moderate dementia living in the community and found that lower QoL ratings by the person with dementia were predicted by the presence of depressive symptoms, whilst lower ratings of their QoL by caregiver's were associated with caregiver depression and burden. A further study that investigated family caregiver, staff and individual perceptions of QoL for people with dementia in institutional care found poor agreement between patient and proxy ratings other than for observable measures of function such as physical health and disability (Novella et al., 2001b). The spouse and qualified nursing staff were found to have closer agreement with the patient's ratings of QoL than other family and staff members. The study used the Duke Health Profile which is a generic QoL measure (Novella et al., 2001a). Coucill et al., (2001) also investigated people with mild/moderate dementia rating their QoL using a modified version of the EQ-5D (EUROQOL, 1990) a generic QoL utility scale, and compared these with caregiver and physician ratings. The study found there were differences between the two proxy ratings and it was unclear who the most appropriate proxy was. Although Coucill concluded that the EQ-5D was suitable for use with this patient population concerns were raised about the validity of patient self-rating as 91% of self-rated responses accounted for all ceiling responses. Similarly Thorgrimsen et al., (2003) found most people did not report problems in the 5 domains of the EQ-5D and many found the visual analogue scale difficult to complete, she concluded that the QOL-AD was the preferred scale for this patient population.

4.13.4. PREDICTORS OF QoL

The resident's rating of their own QoL was highly associated with symptoms of both depression and anxiety. In contrast, ratings of the residents QoL by staff were clearly associated with level of dependency and behavioural problems. This suggests staff's perception of resident's QoL was most strongly influenced by observable levels of dependency. Perhaps staff are less likely to perceive the residents in terms of the resident's subjective experiences (eg mood, pleasant and unpleasant experiences), but are more likely to see them as people with disability. The multivariate analysis also showed that the Cornell and the RAID were the only predictors of QoL as rated by residents. In contrast, the CAPE-BRS was the only predictor for staff ratings of resident QoL. This further suggests that resident's perception of QoL is influenced by mood and staff perception of resident's QoL is influenced by functional ability.

4.13.5. FACTORS INFLUENCING QoL RATINGS

A number of other studies have investigated the potential predictors of QoL in people with dementia. Lower levels of depression and higher levels of functional ability, educational level, social contact and activity were found to be related to higher QoL in dementia (Burgener & Twigg's, 2002; Logsdon et al., 1999). Conversely low QoL was linked to poor physical health and memory, loss of role, increased boredom and loneliness (Thorgrimsen et al., 2003; Ready et al., 2002). More recent studies have suggested that QoL in dementia was influenced by mood and environmental factors independent of dementia severity (as discussed in Chapter 2 and Chapter 3 of this Thesis and Appendices 6.a. & 6.d.: Hoe et al., 2005, 2007). Studies that used only staff proxy ratings of QoL have compared those people with dementia living in the community and in long-term care institutions. The long-term care residents experienced lower QoL than community patients (Leon et al., 1998), and low ratings of QoL by staff were associated with orientation disturbances, physical dependence and anxiolytic treatment (Gonzalez-Salvador et al., 2000). Furthermore the need for privacy and enjoyment has proven difficult to measure reliably in the more cognitively impaired residents (Kane et al., 2003).

4.13.6. GENERALISABILITY OF THE FINDINGS

These residential homes were considered representative of the care homes available nationally as they covered different areas of the UK (London, northern England and Wales: inner-city, urban, suburban and rural), and therefore the results may be generalisable within the care home population. These findings are therefore particularly relevant as previous studies have indicated that many people in care homes have dementia (Hancock et al., 2006; Zimmerman et al., 2003; Macdonald et al., 2002).

4.13.7. LIMITATIONS

Limitations of the study were that staff perception of resident's QoL may have been influenced by; the nature of their relationship to the resident, their knowledge of the resident, their knowledge of and attitudes to dementia and factors about themselves such as hope, stress and job satisfaction (Spector & Orrell, 2006). Where possible the key worker was interviewed, and then if needed, information was further corroborated by asking a senior care worker or home manager. By using this method we attempted to obtain a staff rating of the resident's QoL from staff who knew the resident well. It is interesting to note that some staff felt unable to complete the QOL-AD, finding fewer problems with the other scales. Just over half of the residents in the total sample were able to complete the QOL-AD. Of those residents completing the QOL-AD many had severe dementia. Previous studies have shown that some people with dementia who have a MMSE score as low as 3 can rate the QOL-AD (Thorgrimsen et al., 2003; see Chapter 2 of this Thesis and Appendix 6.a.: Hoe et al., 2005). Where there were 2 or less items missing, mean scores were inserted for any missing items on the QOL-AD; these were predominantly for the items involving family relationships and money. This was usually due to the resident having no known spouse and family, or lack of knowledge about the resident's financial circumstances. Just under half of the residents included in the study could not complete the QOL-AD. Of these most had severe dementia and it may not be the case that these residents would feel the same as those residents who could complete the QOL-AD.

4.13.8. IMPLICATIONS

The QoL of approximately half the people with dementia in residential homes could be effectively measured using the QOL-AD. Whilst the staff provided ratings of QoL in dementia these did not reflect the resident's perceptions of their own QoL. The discrepancies between QoL ratings further suggest that paid caregivers are not a suitable proxy for the person with dementia's own rating of QoL and where possible self-ratings should be sought. The impact of mood as a factor influencing QoL suggests the need to treat anxiety and depressive symptoms more proactively in residents with dementia living in care homes. The importance of relationships with others, enjoyment and meaningful activities have been identified as significant factors influencing need and QoL in care homes (Martin et al., 2002, Kane et al., 2003). Further research should therefore consider the impact of the environment in which residents live on and examine how their individual needs influence QoL. Overall this study indicated that QoL in people with dementia living in residential homes may benefit from improved management of their anxiety and depressive symptoms.

4.13.9. CONCLUSION

In conclusion the QOL-AD was able to effectively measure QoL for many people with dementia in residential homes and was able to reflect perceptions of the individual and their wellbeing. Despite most having severe dementia, resident's views on their own QoL were strongly linked to their mood, suggesting that improving mood would increase QoL. In contrast, staff related QoL to dependency and behaviour problems suggesting that they considered disability to be the most important factor. Care staff and health professionals should be made aware that the QoL of people with dementia in residential homes might primarily relate to their mood in terms of both anxiety and depression. Maximising their enjoyment and enhancing wellbeing along with the identification and treatment of mood disorders should therefore be prioritised in care plans. The factors influencing self ratings of

QoL in people with dementia are suggested by the studies undertaken within this thesis. It would now be of interest to examine how QoL changes in people with dementia as the disease progresses. The next Chapter aims to measure change in QoL over time using the QOL-AD and will further investigate the factors that influence negative and positive perceptions of QoL in dementia over the course of time.

5.0. CHAPTER 5: CHANGES IN THE QUALITY OF LIFE OF PEOPLE WITH DEMENTIA LIVING IN RESIDENTIAL HOMES

5.1. AIMS AND HYPOTHESES:

Aim 3: To assess the sensitivity to change of the QOL-AD and to investigate which change in baseline clinical and demographic factors predict changes in QoL in dementia: namely cognition; mood; behaviour, function, environment and unmet need.

Hypothesis 4: There will be no significant relationship between change in QoL and change in any clinical or demographic factors.

5.2. METHOD

This Chapter examines the change in QoL over time in dementia and describes the aims and results of this study undertaken as part of Study 2. The sample population, study procedure and instruments used are as detailed in Chapter 4 (see Section 4.3.). The objective of this investigation was to follow up a sample of people with dementia living in residential homes over a period of 20 weeks to examine if their QoL had changed since baseline and if so what factors related with that change. Participants were followed up where possible even if they had moved out of the home. Although consent (see Chapter 4, Section 4.10.) had already been given, due to the nature of dementia and the majority of residents having significant memory problems their continued willingness to participate was checked by asking the resident if they still wished to participate in the study before commencing the follow up interviews.

5.3. STUDY DESIGN

Described in Chapter 4, see Section 4.3., Study Design, Page 144, of this Thesis.

5.4. SAMPLE POPULATION

Described in Chapter 4, see Section 4.4., Sample Population, Page 145, of this Thesis.

5.5. INCLUSION CRITERIA

Described in Chapter 4, see Section 4.5., Inclusion criteria, Page 146, of this Thesis.

5.6. EXCLUSION CRITERIA

Described in Chapter 4, see Section 4.6., Exclusion criteria, Page 146, of this Thesis.

5.7. PROCEDURE

Described in Chapter 4, see Section 4.7., Procedure, Page 147, of this Thesis.

5.8. DATA COLLECTION

5.8.1. INSTRUMENTS

- Quality of Life in Alzheimer's disease (Logsdon et al., 1999; see Chapter 2: Section 2.10.1.1., of this Thesis.

- Camberwell Assessment of Need for the Elderly (Reynolds et al, 2000; Orrell & Hancock, 2004), see Chapter 4: Section 4.8.1.2., of this Thesis.

- Mini Mental State Examination (Folstein et al., 1975), see Chapter 2: Section 2.10.1.3., of this Thesis.

- The Clinical Dementia Rating Scale (Hughes et al., 1982), see Chapter 4: Section 4.8.1.4., of this Thesis.

- Cornell Scale for Depression in Dementia (Alexopolous et al., 1988b), see Chapter 2: Section 2.10.1.4., of this Thesis.

- Rating of Anxiety in Dementia (Shankar et al., 1999), see Chapter 4: Section 4.8.1.6., of this Thesis.

- Challenging Behaviour Scale (Moniz-Cook et al., 2001), see Chapter 4: Section 4.8.1.7., of this Thesis.

- The Clifton Assessment Procedures for the Elderly–Behaviour Rating Scale (Pattie & Gilleard, 1979), see Chapter 4: Section 4.8.1.8., of this Thesis

- Barthel Scale of Activities of Daily Living (Mahoney & Barthel, 1965), see Chapter 4: Section 4.8.1.9., of this Thesis

5.8.2. ADDITIONAL DATA COLLECTED

Demographic data see Chapter 4: Section 4.8.2.1., of this Thesis.

5.9. ETHICAL APPROVAL

Described in Chapter 4 see Section 4.9., Ethical Approval, Page 154, of this Thesis.

5.10. CONSENT

Described in Chapter 4 see Section 4.10., Consent, Page 154, of this Thesis.

5.11. POWER CALCULATION

The sample size was estimated using the data from Selwood et al's (2005) study of QoL in dementia which found that change in QoL was predicted by QoL at baseline. We judged that a significant change would be equal to half a standard deviation and in Selwood's study (including only those in residential homes) this was 3 points. This value was taken as the expected and predicted increase or decrease of QoL. For an 80% (power) chance of finding a significant difference at the 1% level ($p<0.01$), the estimated sample size was 21 participants per quartile (approximately 84 people in the total study population).

5.12. ANALYSIS

The data were analysed using SPSS 12.0 (SPSS 2004) and descriptive data, relevant associations and correlations between QoL, clinical and demographic information are reported. As in the previous studies (Chapters 3 and 4 of this Thesis) where one or two items were missing on the QOL-AD the mean QOL-AD scores were inserted, because person mean methods of imputation give better results for multi-dimensional data with respect to measures of discrepancy (Bernaards & Sijtsma, 2000). ANOVA, *t* tests and Chi square were used to examine the mean difference between groups. As the data was normally distributed Pearson's *r* test was used for analyses. As there were multiple univariate analyses $p<0.01$ was used as the level for significance. Correlations of 0.4 and above were considered as being clinically significant (Dunn & Everitt, 1995). A stepwise linear regression analyses was undertaken to determine predictors of change in QoL, as rated by the QOL-AD using the resident's ratings of QoL. In step 1, the demographic data were entered to examine whether age, gender, and length of stay had an effect on the resident's QoL. In step 2, baseline and change scores for the clinical variables including cognition, mood, dependency and behavioural disturbance were entered to examine the effects of morbidity once demographics were considered. In step 3, those variables showing a significant association with changes in QoL score were entered to identify which clinical factors most strongly predicted change in QoL. Finally Wilcoxon matched-pairs signed-rank test was used to compare the difference in individual QOL-AD item scores between baseline and follow up.

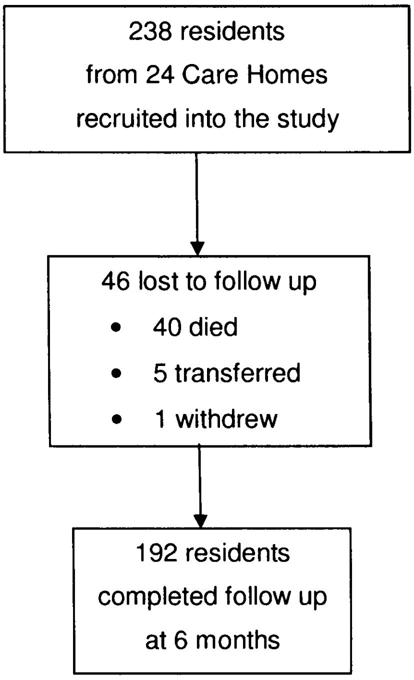
5.13. RESULTS

Of the original 238 residents included in study 2, there were 192 (80.7%) residents who were interviewed at follow up.

5.13.1. REASONS FOR NON-PARTICIPATION AT FOLLOW UP

There were 46 (19.3%) residents who did not participate at follow up. The reasons for non-inclusion were that 40 (16.8%) residents were deceased, 1 (0.4%) withdrew consent and 5 (2.1%) residents were unable to be contacted, usually because they had moved into alternative accommodation that was not within the study locality, for example one resident moved into a nursing home in Devon from London (see Figure 8).

Figure 8: Flow of participants through the study from baseline to follow up



5.13.2. DEMOGRAPHIC CHARACTERISTICS

The demographic data for those completing and not completing follow up is shown in Table 23. ANOVA was used to compare means for age, length of stay, dementia severity and dependency between the groups. Chi square was used to compare means for gender. The 46 (19.3%) residents not completing follow up were significantly older, mean age 89.3 years (s.d. 5.8, range 79 – 102) vs 85.8 years (s.d. 7.6, range 60 – 104) (F = 8.2, d.f. 1, p<0.005). There was no significant difference between the groups for length of stay, mean 35.3 months (s.d. 25.5, range 79 – 102), compared to 33.1 months (s.d. 31.0, range 1 - 180) for non completers vs completers. The group not completing follow up had significantly higher levels of dependency with a mean Barthel score of 54.7 (s.d. 15.9, range 30 – 95), compared to 66 (s.d. 18.4, range 30 – 100) for those completing follow up (F = 14.8, d.f. 1, p<0.001), and a mean CAPE-BRS score of 19.1 (s.d. 4.3, range 10 – 28), compared to 16.2 (s.d. 5.3, range 2 – 32) for those completing follow up (F = 11.4, d.f. 1, p<0.001). Those not completing follow up were also significantly more cognitively impaired, with a mean MMSE score of 4.2 (s.d. 6.0, range 0 – 23) compared to 7.4 (s.d. 8.0, range 0 – 26) for those completing follow up (F = 9.4, d.f. 1, p<0.003) and a mean CDR rating of 2.3 (s.d. 0.7, range 1 – 3) compared to 1.9 (s.d. 0.8, range 0.5 – 3), for those completing follow up (F = 9.9, d.f. 1, p<0.002). When gender was examined there was no significant difference between the groups.

Table 23: Demographic and clinical characteristics of the sample population

Demographic	**Characteristic**	**Completed Follow up** *(n=192)*		**Did not complete Follow up** *(n=46)*	
		(n)	%	*(n)*	%
Gender	Male	40	(20.8)	6	(13.0)
	Female	152	(79.2)	40	(87.0)
Age	60 – 69	6	(3.1)	0	
	70 – 79	26	(13.5)	3	(6.5)
	80 – 89	95	(49.5)	19	(41.3)
	90 – 99	61	(31.8)	23	(50)
	100 <	4	(2.1)	1	(2.2)
Ethnicity	White	166	(86.5)	37	(80.4)
	Other	3	(1.6)	0	
	Not recorded	23	(12.0)	9	(19.6)
Marital Status	Widow	127	(66.1)	37	(80.4)
	Single	43	(22.4)	7	(15.2)
	Married	11	(5.7)	0	
	Divorced	11	(5.7)	2	(4.3)
Length of time in home	1 – 12 months	54	(28.1)	8	(17.4)
	13 – 24 months	46	(24.0)	11	(23.9)
	25 – 36 months	27	(14.1)	11	(23.9)
	37 – 48 months	18	(9.4)	4	(8.7)
	49 – 60 months	14	(7.3)	4	(8.7)
	61+ months	31	(16.1)	8	(17.4)
	Not known	2	(1.0)	0	
Region	London	88	(45.8)	16	(34.8)
	Manchester	39	(20.3)	18	(39.1)
	Wales	65	(33.9)	12	(26.1)

5.13.3. CLINICAL CHARACTERISTICS

The clinical characteristics of the 192 residents seen at follow up were analysed and the mean scores were compared to those observed at baseline (see Table 24). The difference in means between baseline and follow up scores for the clinical variables were examined using *t* tests. Residents were observed to have increased dementia severity (CDR, p<0.001), greater dependency (Barthel, p<0.001), more met needs (CANE, p<0.001) and fewer unmet needs (CANE, p<0.001) at follow up. No significant difference in means were observed between baseline and follow up scores for cognition, depression and anxiety symptoms, dependency or challenging behaviour.

Table 24: Comparison of resident's clinical characteristics at baseline and follow up

Clinical Variable	**Baseline (n=192)**			**Follow up (n=192)**			**Mean Difference**		
	Mean	*(S.D.)*	*Range*	*Mean*	*(S.D.)*	*Range*	*+ / –*	*(S.D.)*	*p<*
MMSE	7.4	(8.0)	0 – 26	6.6	(7.8)	0 – 29	– 0.8	(8.1)	.156
CDR	1.9	(0.8)	0.5 – 3	2.2	(0.7)	0.5 – 3	+ 0.3	(0.6)	**.000**
CORNELL	5.6	(4.9)	0 – 24	5.9	(4.9)	0 – 26	+ 0.3	(6.6)	.464
RAID	5.8	(5.8)	0 – 34	5.8	(5.8)	0 – 36	– 0.03	(8.1)	.957
CBS	26.1	(29.6)	0 – 214	25.9	(29.9)	0 – 172	– 0.2	(31.2)	.934
CAPE-BRS	16.2	(5.3)	2 – 32	16.9	(4.8)	3 – 29	+ 0.6	(4.7)	.064
BARTHEL	66.0	(18.4)	30 – 100	60.5	(18.9)	15 – 100	– 5.6	(13.9)	**.000**
CANE - Met needs	12.0	(2.4)	5 – 17	12.8	(2.6)	6 – 19	+ 0.9	(3.1)	**.000**
CANE – unmet needs	4.4	(2.6)	0 – 13	3.1	(2.3)	0 – 10	– 1.3	(3.0)	**.000**

5.13.4. QUALITY OF LIFE

For the 192 residents seen at follow up the QOL-AD was completed by 50% of the residents and 99% of the staff (see Table 25). Where one or two items were missing mean QOL-AD scores were imputed (Logsdon et al., 2002). This was done for 35 (18.2%) of the resident completed QOL-AD scales and for 54 (28.1%) staff completed QOL-AD scales. There were 2 (1.0%) residents and 2 (1.0%) staff members who had 3 or more items missing and so these QOL-AD scales were excluded. As in previous studies a large number of residents had difficulty completing the QOL-AD and there were 94 residents (48.9%) who had an unrecorded score. There were 21 (10.9%) residents and 10 (10.9%) staff who completed the QOL-AD scale at follow up but not at baseline.

Table 25: Resident and staff completion of the QOL-AD Scale at follow up

Participants interviewed at follow up	**Residents**		**Staff**	
	(n)	*(%)*	*(n)*	*(%)*
Completed QOL-AD scales	96	(50)	190	(99)
Incomplete QOL-AD scales >2 items missing	2	(1.0)	2	(1.0)
Number of non-completed QOL-AD scales = all items missing	94	(48.9)	0	
QOL-AD scales completed at follow up but not at baseline	21	(10.9)	10	(10.9)
QOL-AD scales completed at follow up and at baseline	70	(36.5)	182	(94.8)

5.13.5. CHANGE IN QUALITY OF LIFE

Baseline and follow up ratings of residents QoL were examined using the QOL-AD scores. Analysis using *t* tests showed no significant difference in means between the mean QOL-AD total scores for the sample completing baseline and follow up (see Table 26) as rated by the person with dementia (PQoL), staff member (SQoL) or family caregiver (CQoL). There were 70 (36.5%) residents, 182 (94.8%) staff and 32 (80%) family caregivers who had completed the QOL-AD at both baseline and follow up.

Table 26: Baseline v Follow up QOL-AD scores

Clinical Variable	**Baseline QOL-AD score**				**Follow up QOL-AD score**			
	(n)	*Mean*	*(S.D.)*	*Range*	*(n)*	*Mean*	*(S.D.)*	*Range*
PQoL total sample	*(104)*	33.4	(6.8)	15 – 51	(96)	33.1	(6.2)	15 – 47
SQoL total sample	*(184)*	30.6	(6.0)	15 – 49	(190)	29.8	(5.9)	15 – 47
CQoL total sample	*(64)*	28.4	(5.9)	17 – 45	*(40)*	28.6	(6.4)	15 – 40
PQoL matched	*(70)*	32.6	(6.4)	15 – 46	*(70)*	32.4	(6.8)	15 – 47
SQoL matched	*(182)*	30.6	(6.0)	15 – 49	*(182)*	29.8	(5.9)	15 – 47
CQoL matched	*(32)*	29.0	(5.5)	20 – 45	*(32)*	28.7	(6.9)	15 – 40

5.13.6. CHANGE IN PQoL SCORES

Although the mean QoL did not change over time in this sample, changes in PQoL scores were evident on an individual basis. The direction and magnitude of individual change in PQoL was then examined in more detail for the QoL scores of the 70 people with dementia completing the QOL-AD at baseline and follow up. Individual changes in PQoL were calculated by deducting the baseline QOL-AD score from the follow-up QOL-AD score. The individual change and direction in scores were identified (see Table 27). Residents were considered to have no change in PQoL if their QOL-AD score change was <3. An improvement or deterioration in PQoL was considered if scores changed by 3 or more points. There was no change in PQoL for 19 (27.1%) residents in the sample, whereas an improvement in the PQoL was observed for 24 (34.3%) residents with 16 (22.9%) residents having an increase of 6 or more points on the QOL-AD. Similarly, 27 (38.6%) resident's PQoL had decreased with 16 (22.9%) residents showing a decrease of 6 or more points on the QOL-AD.

Table 27: Individual residents (n=70) score changes on the QOL-AD

Direction of PQoL change	**QOL-AD score change**	**(n)**	**%**
Increase in PQoL (n=24)	↑ 6 – 16	16	22.9
	↑ 3 – 5	8	11.4
No change in PQoL (n=19)	±0-2	19	27.1
Decrease in PQoL (n=17)	↓ 3 – 5	11	15.7
	↓ 6 – 17	16	22.9

5.13.7. DIFFERENCES BETWEEN GROUPED CHANGES OF PQoL

The PQoL scores for the 70 residents completing the QOL-AD at baseline and follow-up were then categorised into three groups of increase, no change and decrease in PQoL and the 3 groups were analysed separately. The group with an increase in PQoL (n=24) had a mean QOL-AD score of 29.8 (s.d. 4.7) at baseline and 36.8 (s.d. 4.8) at follow up, whilst the group with a decrease in PQoL (n=27) had a mean QOL-AD score of 36.0 (5.1) at baseline compared to 28.9 (s.d. 5.6) at follow up.

5.13.8. CHANGE IN QoL SCORES AND BASELINE VARIABLES

A separate analysis was undertaken first of the correlation of change in individual QoL scores and the baseline clinical variables scores and then the correlation of change in individual QoL scores and the individual changes in clinical variable scores. The analysis used only those residents (n=70) who had completed QOL-AD scores at baseline and follow up. This analysis was then repeated for those staff members (n=182) who had completed QOL-AD scores at baseline and follow up. Due to the low number of family caregivers their data were not included.

5.13.8.1. CHANGE AND RESIDENT RATED QoL

Individual increase in PQoL scores were strongly correlated with higher anxiety symptoms and lower QoL at baseline. When the changes in PQoL ratings were correlated with individual changes in the clinical variable scores, lower PQoL scores were associated with increased depression and cognitive impairment and higher rated QoL at baseline. Higher PQoL scores were associated with fewer anxiety symptoms and lower rated QoL at baseline. Clinically significant correlations of >0.4 for change in PQoL were observed with baseline QoL and change in the MMSE and RAID (Dunn & Everitt, 1995). Baseline QoL scores and improvement in anxiety symptoms had the strongest association with higher QoL ratings by residents over

20 weeks (see Table 28) whereas a decline in cognition had the strongest association with lower QoL.

Table 28: Change in PQoL v baseline and change in clinical variables

Clinical variables	**Baseline variable v PQoL change** *(n=70)*		**Variable change v PQoL change** *(n=70)*	
	r	*p<*	*r*	*p<*
BARTHEL	.055	.653	.144	.236
CAPE-BRS	-.010	.933	-.196	.104
CDR	.022	.857	-.078	.524
CORNELL	.138	.256	-.360	**.002**
CBS	.017	.888	-.240	.046
MMSE	-.122	.315	.421	**.000**
RAID	.341	**.004**	-.404	**.001**
TOTAL MET NEED	.131	.279	-.005	.965
TOTAL UNMET NEED	-.138	.256	-.030	.807
PQoL	-.492	**.000**		

5.13.8.2. FACTORS ASSOCIATED WITH CHANGE AND STAFF RATED QoL

There were 182 staff who had completed the QOL-AD at baseline and follow up. Individual decrease in SQoL ratings were strongly correlated with fewer depressive symptoms, less cognitive impairment and higher QoL at baseline. When the changes in SQoL were correlated with individual changes in the clinical variable scores, lower SQoL scores were associated with increased dependency, more depression, higher cognitive impairment and higher rated QoL at baseline; whereas higher SQoL scores were associated with fewer anxiety symptoms, fewer behavioural symptoms, fewer unmet needs and lower rated QoL at baseline. Clinically significant correlations of >0.4 for change in SQoL were observed with baseline QoL and change in the CAPE-BRS (Dunn & Everitt, 1995). Baseline QoL scores and an increase in functional dependency were the strongest associations with lower QoL ratings by staff at 20 weeks (see Table 29).

Table 29: Change in SQoL v baseline and change in clinical variables

Clinical variables	Baseline variable v SQoL change *(n=182)*		Variable change v SQoL change *(n=182)*	
	r	*p<*	*r*	*p<*
BARTHEL	-.007	.929	.078	.293
CAPE-BRS	.154	.039	**-.412**	**.000**
CDR	.056	.452	-.064	.389
CORNELL	.202	**.006**	-.350	**.000**
CBS	.057	.444	-.340	**.000**
MMSE	-.196	**.008**	.201	**.007**
RAID	.120	.107	-.245	**.001**
TOTAL MET NEED	-.103	.165	.154	.038
TOTAL UNMET NEED	.129	.082	-.204	**.006**
SQoL	-.544	**.000**		

5.13.9. FACTORS RELATED TO GROUPED CHANGES OF QoL

Initially oneway ANOVA was used to compare the difference in means between the clinical variable scores at baseline and follow up, for the 3 groups of increase, no change and decrease in QoL. Significant variance between the 3 groups was shown for the difference in mean individual ratings of the Cornell (F=5.2, d.f. 2, p<0.008), MMSE (F=6.4, d.f. 2, p<0.003), RAID (F=8.2, d.f. 2, p<0.001) and PQoL (F=129.1, d.f. 2, p<0.000). Correlations were then performed between the baseline and change in clinical variable scores with baseline QoL ratings for the 3 groups (see Table 30). Using p<0.01 as the level for significance, the residents experiencing a decrease in QoL from baseline to follow up was correlated with less depressive and anxiety symptoms at baseline. Both correlations were at a level of clinical significance >0.4 (Dunn & Everitt, 1995). When the grouped changes in QoL were correlated with individual changes in the clinical variable ratings, no significant associations were observed at the level p<0.01. A decline in individual QoL ratings for residents was therefore associated with worsening depression and anxiety symptoms.

Table 30: Correlations with baseline and change in clinical variable scores with baseline PQoL ratings for the 3 groups

Clinical variable	**PQoL change**	**Baseline score**	**Baseline variable v Baseline QoL**		**Change score**	**Variable change v Baseline QoL**	
	(n)	*Mean (s.d.)*	*r*	p<	*Mean (s.d.)*	*r*	p<
MMSE	↑ (24)	12.3 (7.5)	-.101	.637	2.3 (4.3)	.012	.954
	↔ (19)	10.7 (7.7)	.242	.318	-1.5 (4.9)	.117	.632
	↓ (27)	14.7 (6.5)	-.216	.311	-2.6 (5.6)	-.280	.157
CDR	↑ (24)	1.4 (0.6)	.184	.390	0.2 (0.7)	.120	.578
	↔ (19)	1.6 (0.7)	.127	.605	0.3 (0.6)	.091	.712
	↓ (27)	1.4 (0.5)	.246	.216	0.2 (0.5)	.071	.725
CAPE-BRS	↑ (24)	13.4 (5.0)	.185	.387	-0.3 (4.2)	-.265	.211
	↔ (19)	12.5 (5.1)	-.383	.105	1.2 (4.7)	.387	.102
	↓ (27)	13.5 (3.8)	-.263	.186	2.6 (5.0)	.408	.035
BARTHEL	↑ (24)	76.9 (15.1)	-.129	.548	-4.2 (11.8)	.353	.091
	↔ (19)	76.1 (16.7)	.052	.832	-3.7 (16.7)	-.218	.370
	↓ (27)	73.0 (12.9)	-.022	.913	-7.4 (13.2)	-.285	.150
CBS	↑ (24)	23.7 (30.3)	.014	.947	-10.1 (28.8)	-.068	.751
	↔ (19)	14.4 (12.6)	-.419	.074	2.8 (19.9)	.407	.083
	↓ (27)	19.5 (27.7)	-.452	.018	10.0 (37.1)	.446	.020
CORNELL	↑ (24)	6.8 (5.1)	-.416	.043	-3.2 (5.1)	.363	.081
	↔ (19)	5.8 (7.1)	-.803	.000	0.4 (7.5)	.506	.027
	↓ (27)	5.3 (5.1)	**-.579**	**.002**	2.9 (7.4)	.429	.025
RAID	↑ (24)	8.9 (6.6)	-.346	.097	-5.0 (7.1)	.265	.210
	↔ (19)	5.5 (2.2)	-.761	.000	1.2 (8.2)	.609	.006
	↓ (27)	4.0 (4.9)	**-.581**	**.001**	3.6 (7.8)	.459	.016
CANE – Met needs	↑ (24)	12.2 (2.6)	.037	.862	0.8 (2.8)	.179	.401
	↔ (19)	10.9 (2.0)	.040	.870	1.8 (3.3)	.297	.218
	↓ (27)	11.2 (2.4)	-.066	.745	1.0 (13.2)	-.252	.205
CANE – Unmet needs	↑ (24)	4.0 (2.4)	-.352	.092	-1.5 (2.6)	-.096	.654
	↔ (19)	4.6 (2.4)	-.450	.053	-1.1 (3.3)	.096	.696
	↓ (27)	4.9 (3.1)	-.112	.578	-1.4 (3.0)	-.024	.905

5.13.10. PREDICTORS OF CHANGE IN QUALITY OF LIFE BETWEEN BASELINE AND FOLLOW UP.

Further analysis was undertaken using stepwise linear regression analysis to determine which factors were independent predictors of change in resident's QoL. In step 1, the demographic variables of age, gender and length of stay were used as the independent variables. No predictors of change in PQoL were identified at this stage.

In step 2, the multiple independent variables were the baseline clinical rating scales and change in clinical ratings: Barthel, CAPE-BRS, CDR, Cornell, MMSE, RAID and PQoL. A decrease in PQoL was predicted by higher baseline QoL (PQoL, $p \leq 0.001$), and fewer depressive (Cornell, $p \leq 0.001$) and anxiety (RAID, $p \leq 0.01$) symptoms at baseline, and by a decline in cognition (MMSE, $p \leq 0.001$). This model accounted for 55% of the variance (F=4.3, adjusted R^2=42, $p<0.001$).

In step 3, just the baseline and change in clinical variables for the MMSE, Cornell, RAID and baseline PQoL were used as the multiple independent variables (see Table 31). A decrease in PQoL was predicted by higher baseline QoL, fewer depressive and anxiety symptoms at baseline. Lower PQoL was also predicted by worsening depression (Cornell, $p \leq 0.005$) and cognition (MMSE, $p \leq 0.001$). This model accounted for 52% of the variance (F=9.6, adjusted R^2=47, $p<0.001$).

Table 31: Final model of predictors of change of resident rated QoL using stepwise regression analysis

Variables	**Change in PQOL scores** *(n) = 70*	
	Beta	*p≤*
CORNELL (baseline)	-.870	.000
RAID (baseline)	.684	.001
PQoL (baseline)	-.433	.001
CORNELL (change)	-.541	.005
MMSE (change)	.356	.001
Model %	52	
F =	9.6	
p<	.000	
Adjusted R^2	47	

5.13.11. QOL-AD ITEM CHANGE

The mean change for each of the 13 items on the QOL-AD were examined for the 70 residents who completed ratings of QoL at both baseline and follow up and are shown in Table 32. An increase in the mean score was observed at follow up for living situation, self as a whole, money and life as a whole. There were no changes in the mean scores for the items energy, memory, marriage and ability to do things for fun at baseline and follow up. A decrease in mean score was observed for the items physical health; mood, family and ability to do chores.

Table 32: Change in QOL-AD items between baseline and follow up

QOL-AD item	**Baseline QoL** *n=70*		**Follow up QoL** *n=70*	
	Mean	*s.d.*	*Mean*	*s.d.*
Physical health	2.6	(0.7)	2.5	(0.8)
Energy	2.3	(0.8)	2.3	(0.9)
Mood	2.6	(0.8)	2.4	(0.8)
Living situation	2.7	(0.8)	2.8	(0.9)
Memory	2.4	(0.8)	2.4	(0.8)
Family	2.7	(0.9)	2.6	(1.0)
Marriage/Significant other	3.0	(0.9)	3.0	(1.0)
Friends	2.5	(1.0)	2.5	(0.9)
Self as a whole	2.5	(0.8)	2.7	(0.8)
Ability to do chores	2.1	(0.9)	2.0	(0.9)
Ability to do things for fun	2.3	(0.7)	2.3	(0.9)
Money	2.3	(0.9)	2.4	(0.9)
Life as a whole	2.5	(0.8)	2.6	(0.8)

5.13.12. COMPARISON OF INDIVIDUAL QOL-AD ITEM CHANGE

The difference in the individual QOL-AD items scored at baseline and follow up were then compared using Wilcoxon matched-pairs signed-rank test for the 3 groups of increase, no change and decrease in QoL (see Table 33). The Wilcoxon matched-pairs signed-rank test is a more sensitive test for measuring the difference in size between two samples (IFA, 2007). Several items on the QOL-AD are sensitive to change in QoL, which related to whether residents QoL showed an increase or decrease over time. Energy ($p<0.005$) and ability to do things for fun ($p<0.001$) all increased with improvement in overall life quality. Whilst mood ($p<0.005$) and family relationships ($p<0.01$) decreased with a reduction in overall life quality.

Table 33: Difference in means between individual QOL-AD Items and QOL change groups

QOL-AD item	Increase in QoL group (n = 24) Mean diff	(s.d.)	Z	p<	No change in QoL group (n = 19) Mean diff	(s.d.)	Z	p<	Decrease in QoL group (n = 27) Mean diff	(s.d.)	Z	p<
Physical health	0.3	(0.8)	-2.0	.046	-0.1	(0.7)	-.33	.739	-0.3	(1.0)	-1.7	.097
Energy	0.7	(1.0)	-2.9	.004	-0.1	(0.8)	-.83	.405	-0.4	(1.3)	-1.8	.072
Mood	0.3	(1.0)	-1.3	.210	0.1	(0.7)	-.33	.739	-0.6	(0.9)	-3.0	.002
Living situation	0.5	(0.9)	-2.3	.022	0.0	(0.8)	.00	1.000	-0.2	(0.9)	-1.3	.207
Memory	0.3	(1.0)	-1.1	.279	-0.1	(0.7)	-.71	.480	-0.3	(1.0)	-1.7	.090
Family	0.4	(1.1)	-1.5	.134	-0.2	(1.0)	-.58	.559	-0.6	(1.0)	-2.8	.006
Marriage/Significant other	0.7	(0.9)	-3.0	.003	0.1	(1.1)	-.31	.760	-0.5	(1.2)	-2.2	.030
Friends	0.9	(0.8)	-3.7	.000	0.3	(0.9)	-1.2	.248	-1.1	(0.8)	-4.1	.000
Self as a whole	0.7	(0.8)	-3.2	.001	0.5	(0.7)	-2.2	.030	-0.5	(0.9)	-2.6	.010
Ability to do chores	0.7	(1.0)	-2.9	.004	-0.2	(0.8)	-.88	.380	-0.9	(1.1)	-3.4	.001
Ability to do things for fun	0.7	(0.7)	-3.4	.001	-0.3	(0.7)	-1.7	.083	-0.3	(1.0)	-1.7	.095
Money	0.7	(1.0)	-2.8	.005	0.2	(0.9)	-1.1	.285	-0.7	(1.0)	-3.2	.001
Life as a whole	0.6	(0.8)	-3.0	.003	0.2	(0.6)	-1.1	.257	-0.4	(0.8)	-2.3	.022

5.14. DISCUSSION

5.14.1. SUMMARY OF FINDINGS

This study which examined the relationship between change in QoL and change in levels of cognition, mood, behaviour and functioning has shown that whilst there was no change in overall mean QoL for people with dementia, changes in QoL were very frequent for individual residents. This finding is similar to that found in previous studies that showed that QoL in a population of people with dementia does not necessarily decline over time (Selwood et al., 2005; Lyketsos et al., 2003). Moreover, this investigation reports associations with change in QoL for people with dementia and change in clinical variables as well as baseline QoL. The earlier studies cited found that change in QoL for people with dementia was only predicted by baseline QoL scores (Selwood et al., 2005; Lyketsos et al., 2003). In this investigation individual changes in QoL were apparent for nearly three quarters of the sample population, with just under half of the residents showing changes of 6 or more points on the QOL-AD scale. A decline in individually rated QoL was associated with increased depressive symptoms. The main findings are that there is evidence for the sensitivity to change of the QOL-AD in people with dementia, and that it was possible for most residents to rate their QoL using the QOL-AD. A reduction in residents QoL was predicted by lower baseline depression and anxiety symptoms, higher baseline QoL ratings and an increase in depressive symptoms and cognitive impairment at follow up. Previous studies examining change in QoL in dementia have shown no link to change in cognitive function (Selwood et al., 2005; Lyketsos et al., 2003). However, as with this study, the link between changes in QoL and cognition has previously been found by Woods et al., (2006); and in their study improvements in QoL scores were mediated by improved cognition. The QOL-AD could be used to effectively measure change in the QoL of people with dementia in residential homes.

5.14.2. RESPONSE RATE

5.14.2.1. NON RESPONSE AT FOLLOW UP

Of the original sample of 238 people with dementia living in residential homes, there were 192 residents who responded and 46 residents who were lost to follow up at 20 weeks. This showed a good overall response rate of 80.7% (Bowling, 1997) and a loss rate of 19.3%. Dementia is a degenerative and debilitating disorder that ultimately leads to death and as expected within a cohort of people with dementia most of those lost were deceased excluding them from follow up. A very small number of non-responders were unable to be contacted mainly because they had moved to nursing homes out of the catchment area or were hospitalised. The residential homes included within this sample were able to cater for most residents with a high level of dependency and care needs, as well as those displaying challenging behaviours and increasing dementia severity. However, it is not uncommon for the care of a person with dementia presenting with an altered physical or mental health status, such as a decline in their physical health or increased behavioural disturbances particularly physical and verbal aggression to be transferred to an alternative care setting such as a hospital or nursing home placement (Lee et al., 2001). Only one respondent refused to participate in the follow up study and overall the QOL-AD was well tolerated within this sample population. Those lost to follow up were generally older, had greater dementia severity and higher dependency needs than those residents participating in the follow up study. Death would therefore not be an unexpected outcome for a group of elderly, frail people experiencing poor physical health, disability and increasing cognitive decline.

5.14.2.2. RESPONSE AT FOLLOW UP

At follow up there was increased dementia severity and decreased activities of daily living; this is to be anticipated as dementia is known to worsen over time. The presence of dementia implies a global deterioration of a person's mental and physical abilities which is progressive and chronic in nature (Cooper, 1997; Royal College of Physicians, 1981). No significant changes in the other clinical variables were observed over time. At follow up the responders had more met needs and fewer unmet needs, which does indicate that residential homes are able to accommodate the changing needs of people with dementia. This investigation was however undertaken as part of a larger randomised controlled study which offered interventions for the unmet needs identified for individual residents and this may have impacted on the number of needs met at follow up (Orrell et al., 2007). Interventions were offered to the randomised intervention homes and included feedback on resident assessments and evaluations of their individual needs, both met and unmet. Individual plans of care were then outlined for each resident and the researchers visited the homes for two hours every fortnight to review changes in the care provided to residents. The needs for both groups improved, within the intervention and control homes and the intervention was unsuccessful as there was no significant difference at follow up. This may be due to a Hawthorne effect (Roethlisberger & Dickson, 1939), in that, staff within the homes may have become sensitised to the questions related to needs on the CANE (Orrell & Hancock, 2004) resulting in increased care being provided for their residents identified needs.

5.14.3. CHANGE IN QoL

Changes in QoL for people with dementia were associated with baseline and change in clinical factors such as mood and cognition and this is a new and important finding. Although Selwood et al., 2005 and Lyketsos et al., 2003 observed changes in individual QoL ratings for people with dementia, both found that change in QoL was only associated with baseline QoL ratings. Baseline QoL ratings were found to be associated with both an increase and decrease in QOL-AD scores at follow up in this study and support the findings of these earlier studies. Selwood et al., (2005) used the QOL-AD, DQOL and EQ-5D to measure change in QoL from baseline at one year for ratings based on self reports and compared baseline QoL ratings to those at follow up. Comparing total sample statistics at two points in time may be misleading when assessing change in case underlying changes go undetected; it is important therefore to assess changes using a change score calculated for each participant (Bowling, 1997). Lyketsos et al., (2003) used the ADRQL to measure change in QoL from baseline at two years for ratings based on proxy reports and compared baseline clinical variables with change in QoL ratings. To show validity of change, it is recommended the changes in one measure are compared with the changes in other measures (Bowling, 1997). A decline in individual QoL ratings was associated with an increase in depressive symptoms. Higher ratings of QoL are known to be associated with fewer depressive symptoms (Logsdon et al., 1999; and as discussed in Chapter 4 of this Thesis and Appendix 6.b.: Hoe et al., 2006). These findings suggest that by reducing depressive symptoms QoL in residents may be enhanced. When the changes in staff QoL ratings were examined, lower ratings of QoL were given to residents whose functional dependency had declined. It is interesting to note that staff ratings of resident's QoL are strongly influenced by levels of dependency (see Chapter 4 of this Thesis and Appendix 6.b.: Hoe et al., 2006).

5.14.4. PREDICTORS OF CHANGE IN QoL

The resident's rating of their own QoL continues to be highly associated with symptoms of both depression and anxiety (see Chapter 4 of this Thesis and Appendix 6.b.: Hoe et al., 2006). In the stepwise regression analysis the factors most likely to predict a reduction in QoL were higher baseline QoL and fewer depressive and anxiety symptoms at baseline, along with an increase in depressive symptoms and cognitive impairment. In a randomised controlled trial by Woods et al., (2006) who examined change in QoL for people with dementia participating in Cognitive Stimulation Therapy. Improvements in cognition were found to mediate improvements in QoL for the treatment group. Woods et al., (2006) found that whilst improvement in QoL was associated with a reduction in depressive symptoms which was mainly related to the control group, improvements in depression did not mediate change in QoL. Lower QoL ratings in people with dementia are associated with being institutionalised and having more depressive symptoms (see Chapter 3 of this Thesis and Appendix 6.d.: Hoe et al., 2007) and it is possible that in this investigation resident's mood may have continued to deteriorate in response to their living situation and their level of engagement with their environment.

5.14.5. SENSITIVITY TO CHANGE OF THE QOL-AD

Both the total QOL-AD score and the separate domains were sensitive to change in QoL over a 20 week period. The QOL-AD has good reliability (Logsdon et al., 1999; Thorgrimsen et al., 2003; and see Chapter 2 of this Thesis and Appendix 6.a.: Hoe et al., 2005) and the ability to detect change supports the use of the QOL-AD as a valid longitudinal measure of self rated QoL by people with dementia. Change in individual QoL was detected over a period of 20 weeks and this further confirms the possibility of using QoL as an outcome measure in studies providing interventions and treatment. Improvement in overall life quality was linked to improvements in the items energy and ability to do things for fun. This therefore suggests that QoL in dementia is enhanced by improvements in health status and increased stimulation and engagement with the environment. Furthermore, a decline in overall life quality was linked to the items mood and family relationships and suggests that QoL is diminished in response to lowered mood and the poor family relationships. Burgener & Twigg (2002) found people with dementia's social behaviour and activities were dependent on the involvement of family caregivers despite moving into care facilities. QoL in people with dementia could therefore be improved by providing increased activities to enhance wellbeing and through maintaining good relationships with family members.

5.14.6. GENERALISABILITY AND IMPORTANCE OF THE FINDINGS

The residential homes visited within the study covered different areas of the UK (London, northern England and Wales: inner-city, urban, suburban and rural), and therefore could be considered representative of the care homes nationally, therefore the results may be generalisable within the care home population. As previously mentioned in this thesis, many people in care homes have dementia (Hancock et al., 2006; Zimmerman et al., 2003; Macdonald et al., 2002). Improving QoL has now become a key area of focus alongside the health and welfare of residents, as well as the quality of care provided within residential homes (DOH, 2001).

Many of the residents had severe dementia and the ability for many of them to provide valid and meaningful responses regarding their QoL has been shown (Thorgrimsen et al., 2003; see Chapter 2 and 4 of this Thesis and Appendices 6.a. & 6.b.: Hoe et al., 2005; 2006). The QoL of residents in care homes may be influenced by different factors compared to those people with dementia living in their own homes or with relatives. Moreover, QoL has been shown to be higher for those people with dementia living in the community to those living in institutions (see Chapter 3 of this Thesis and Appendix 6.d.: Hoe et al., 2007). Perceptions of QoL may be different in those people unable to complete the QOL-AD and those lost to follow up as they tended to experience a more profound degree of dementia, some of whom were in the terminal stages of the disease.

5.14.7. LIMITATIONS

The study was a prospective, longitudinal cohort survey in design, which collected data at two points in time; nevertheless, it is difficult to suggest the cause and effect of relationships between variables. Dementia is a non-linear and complex disorder and has multiple causes and outcomes (Mack & Whitehouse, 2001); it is therefore difficult to encompass all factors influencing its progression and QoL experienced by individuals with the disease. The clinical factors incorporated within this study included mental and neuropsychiatric disorders such as anxiety, depression, and behavioural disturbances, which are known to commonly occur in dementia (Lyketsos et al., 2000). As is consistent with earlier studies in this thesis, half of the respondents in the follow up study could not complete the QOL-AD (see Chapter 2 and 4 of this Thesis and Appendices 6.a. & 6.b.: Hoe et al., 2005; 2006). Moreover, it is of note that in this study the QOL-AD was completed by 21 residents and 10 staff at follow up but not at baseline. This indicates that some of the QoL ratings may have been unnecessarily missed at baseline and that QOL-AD scores could have been provided for these residents and staff members. It is possible that these discrepancies were due to observer bias as rater competence and confidence may have been increased over the course of the study as the researchers became more familiar with the scales and is indicated by the increased response rate for staff members. The resident's ability to complete the QOL-AD may be as a result of fluctuations in cognition, particularly in attention and comprehension, which may have been influenced by underlying physical ill health or apathy and withdrawal. Alternatively, these discrepancies may be due to interviewer bias in that some researchers may have been able to affect a more thorough interview with these residents. All researchers were from nursing and psychology backgrounds and were experienced within the field of dementia care. Nonetheless, this variation in response rate may emphasise the need for adequate training prior to commencing a study and the provision of good and ongoing supervision of researchers collecting data throughout the course of a study.

5.14.8. IMPLICATIONS

The QOL-AD detected changes in individual QoL for residents with dementia and this study showed the scales sensitivity to measuring change in QoL. The QOL-AD is therefore suitable to use within longitudinal and intervention studies involving people with dementia. The QOL-AD could also be used as part of a package to assess the impact of interventions and treatment in clinical settings, as it was for example in the cognitive stimulation trial (Woods et al., 2006; Spector et al., 2003). The prescription of cholinesterase inhibitors is now subject to more stringent guidance (NICE, 2006) and the routine use of QoL measures within memory clinics may help to demonstrate the benefits of antidementia medication for people with dementia.

5.14.9. FUTURE RESEARCH

The need for further longitudinal studies to investigate naturalistic change in QoL should allow for QoL in people with dementia to be measured at regular intervals in time, thus allowing for the impact of dementia on QoL to be assessed throughout the course of the disease. QoL is an acceptable, valid and reliable outcome measure for use within research and most people with dementia are able to provide valid and reliable ratings of their own QoL. Future studies should therefore include QoL more consistently as a measure of outcome in research and be used to examine the impact of interventions for people with dementia. As changes in QoL were evident in people with dementia over a period of 20 weeks, QoL could be used as an outcome measure in clinical trials, particularly where the cost effectiveness of treatment is an issue such as the use of cholinesterase inhibitors and memantine (NICE, 2006). Although antidementia medication is not routinely prescribed for people with dementia in residential homes, memantine may be used in people experiencing severe dementia (Forstl, 2000), and may help reduce behavioural disturbances where the use of antipsychotic medication is contraindicated. (Smith & Beier, 2004; Brodaty et al., 2003b; Trinh et al., 2003; Clark & Karlawish, 2003; Katz et al., 1999).

5.14.10. CONCLUSION

In conclusion, changes in QoL were apparent for individual residents with dementia at follow up and were associated with changes in mood and cognition. QoL at 20 weeks was also strongly predicted by baseline QoL ratings. QoL does not necessarily diminish as dementia worsens but continues to be strongly influenced by the resident's mood and interaction with their environment. Improvement in cognition and mood may enhance QoL and the provision of stimulating activities for residents in care homes is important. In addition, care homes should encourage the involvement of family members where possible within activities.

The routine use of the QOL-AD as an outcome measure in people with dementia to show the benefits of clinical interventions and treatments as well as assess the impact of the disease process on individuals through the course of the illness is indicated. Further studies investigating change in QoL in people with dementia should examine the individual scores for participants QoL and clinical ratings and not just the sample mean, as this may be misleading.

6.0 CHAPTER 6: DISCUSSION

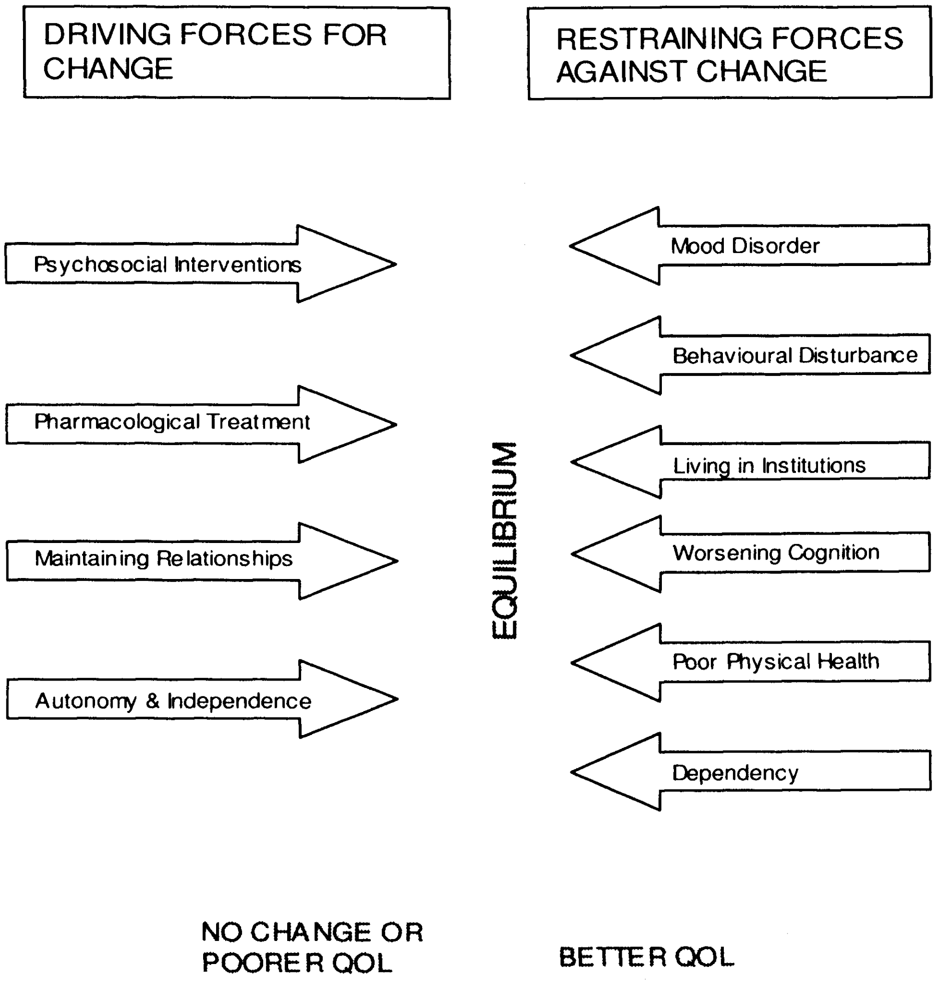
6.1. OVERVIEW

The results from four separate investigations have been presented in this thesis. Firstly, I examined the validity and reliability of the ratings of people with severe dementia of their QoL using the QOL-AD and factors associated with QoL in this population. This investigation confirmed the ability of people with a MMSE scores ≥3 to provide valid and reliable ratings of their own QoL. Moreover, the findings suggested that mood, functional ability and psychosocial factors such as family relationships and involvement in activities were associated with QoL in this population group. This finding of their validity and reliability provided a basis for my further research as it allowed QoL to be explored in a wider population of people with dementia. In my second study, I examined factors influencing individual and family caregiver perceptions of the person with dementia's QoL and explored reasons for the disparity in ratings in both family and paid caregivers across community and institutional settings. This investigation was done in an attempt to add to the current debate as to whether proxy perceptions of QoL provide an accurate account which reflects the perceptions of QoL for people with dementia. The people with dementia's ratings of QoL were found to be significantly related to current mood, treatment with cholinesterase inhibitors and living environment, whereas family caregiver ratings were related to the person with dementia's mood status and neuropsychiatric symptoms. In my third study, factors influencing individual and paid caregiver perceptions of the person with dementia's QoL were explored in both residents and staff in 24 separate residential homes. Differences were again found between the residents and staff ratings of their QoL, confirming the importance of seeking self ratings of QoL in people with dementia. Mood was again found to be the strongest predictor of the person with dementia's perception of their own QoL but staff ratings of resident's QoL was predicted by levels of dependency. Lastly, the change of QoL over time (20 weeks) in people with dementia in care homes and their caregivers was examined. This enabled the factors influencing such changes specifically cognition; mood; functional ability and behavioural disturbance to be investigated. These factors along with living situation and treatment were suggested as elements contributing to change in QoL in dementia in the conceptual model proposed in Chapter 1 (see figure 6: Section 1.7.1 of this Thesis). These factors were investigated both at baseline and follow-up and the relationship between QoL and change in levels of cognition, mood, behaviour and functioning was determined. A decline in QoL was most strongly predicted by better mood and QoL at baseline and by an increase in depressive symptoms and cognitive impairment over the 20 week period. Furthermore, the ability of the QOL-AD (Logsdon et al., 1999) to show change was established. This Chapter will discuss and critically evaluate the results from these investigations within the context of the current literature.

6.2. CONCEPTUALISING CHANGE IN QUALITY OF LIFE IN DEMENTIA

Calman (1984) described QoL as measuring the gap between the individual's present experience and their expectations for the future and that by narrowing this gap through improving experience or by lowering expectations, QoL could be improved. Individuals do change with time and the basis on which they perceive their QoL may change, a phenomenon known as response shift. That QoL does not necessarily decline over time has been shown both by comparing populations of people with dementia at different stages of the disease and individuals as they change. Instead, low QoL in dementia is contributed to by several key factors that can impact directly or indirectly on overall QoL in this population. Most notably is mood, but the other prominent factors are functional ability, behavioural disturbance and change in level of cognition. Living environment and physical health are also important elements influencing QoL in dementia. It is possible that QoL in dementia may be improved through enhancing mood and cognition, increased engagement, maintaining relationships, and preserving independence and autonomy in the person with dementia. QoL is a multidimensional evaluation (Lawton, 1991) and it is highly plausible that these factors also have a significant influence on each other as well as a bearing on perceptions of QoL. QoL is also dynamic in nature (Lawton, 1983) and the negative and positive influence of factors such as mood, functional ability, behaviour; cognition, living environment, relationships, psychosocial interventions and pharmacological treatment on QoL are shown in Figure 6 as a dynamic balance or equilibrium of forces working in opposite directions.

Figure 6: Model conceptualising the relationship between the factors influencing change in QoL in dementia (Hoe, 2007)



6.3. QUALITY OF LIFE AND MOOD

The predominant predictors of QoL in dementia are affective symptomatology, namely depression and anxiety symptoms and this was found in each study undertaken in this thesis. This finding is consistent with other studies as all have identified depression as a predictor of lower QoL in dementia (Fuh & Wang, 2006; Ready et al., 2004; Thorgrimsen et al., 2003; Karlawish et al., 2001 Selai et al., 2001a; Logsdon et al., 1999). That change in QoL is predicted by change in depressive symptoms is also important, although it is not known if this relationship is causal. Furthermore anxiety which is associated with depression in dementia is often more prevalent in the milder stages and is associated with agitated behaviour, which increases in severe dementia (Shankar & Orrell, 2000; Goudeman & Thomas, 1994; Forsell et al, 1993; Yesavage & Taylor, 1991). That change in depressive symptoms is linked to change in QoL is of interest as depression can be treated and QoL may be improved for people with dementia. The primary hypothesis proposed was that lower QoL as rated by the person with dementia will significantly correlate with higher levels of depression and anxiety symptoms.

Depressive symptoms were predominantly measured using the Cornell scale which provides an objective rather than a subjective assessment of depression in dementia, obtained from self and caregiver reports and through rater observation. The Cornell is able to rate depressive symptoms across all dementia severities and includes cognitive, somatic, affective and behavioural domains (Alexopolous et al., 1988b). Other studies that have examined change in QoL for people with dementia have also used the Cornell to measure depressive symptoms. The Cornell was not a predictor of change on the ADRQL which is rated by proxies and not the person with dementia (Lyketsos et al., 2003). Whereas Burgener & Twigg, (2002) found significant improvements in Cornell rated depression over 18 months, they did not identify changes in depression as a predictor of QoL. Although increased QoL was associated with improvements in caregiver-care recipient relationships. Improvements in QoL were however associated with the depression aspect of the Psychological Well-Being in Cognitively Impaired Persons (PWB-CIP: Burgener & Chiverton, 1992) but only for participation in pleasant events. Selwood et al., (2005) found highly significant associations between the Cornell and the QOL-AD and the DQOL, but change in depression did not predict change in QoL at 12 months. These differences may be due to the difference in analysis as discussed in Chapter 5 of this Thesis as Selwood's study compared mean baseline QoL ratings to those at follow up which may be misleading. Woods et al., (2006) included all the change in variables in his analysis and found that improvements in QOL-AD scores were associated with fewer symptoms of depression. Mean depression scores as measured by the Cornell were similar in all four investigations in this thesis and all were below the cut point of 8 which would indicate significant depressive symptoms. This suggests levels of depression were consistent across the different dementia severities and care settings.

Causality cannot be shown in a cross sectional cohort study; nonetheless the finding that depression is linked to poor QoL suggests the improvement of depression in dementia may result in an improvement of wellbeing in people with dementia. Hence, the assessment and treatment of mood disorders in dementia needs to become routine including those people with severe dementia. Increased levels of engagement through participation in social activities and interaction may also be particularly important in sustaining mood and promoting wellbeing in dementia.

6.4. QUALITY OF LIFE AND COGNITION

Cognition was not found to be associated significantly with QoL when it was measured at a single point in time. This is consistent with many other studies which found cognition was not a predictor of QoL (Banerjee et al., 2006; Logsdon et al., 1999). Decreased QoL was however predicted by an increase in cognitive impairment over the 20 week period. QoL may therefore decline as cognition deteriorates and this is of interest.

Many people with severe dementia still rated their QoL as good or high. The link between highly rated QoL and increased dementia severity has been previously discussed and an association with a reduction in insight and anosognosia suggested (Vogel et al., 2006; Selai et al., 1999, Brod et al., 1999; Whitehouse et al., 1997). However this thesis has shown that people with severe dementia are able to provide meaningful perceptions of their QoL. A decline in cognition was observed both in some people whose QoL decreased or did not change over time. Brod et al., (1999) argued that awareness of cognitive impairment may be distinct from awareness of their own feeling states and that this may be preserved despite impaired cognitive function. The person with dementia can therefore often provide an accurate perception of their QoL. It was apparent that QoL ratings in dementia were influenced by mood and psychosocial factors such as relationships and environment and as such this supports the conceptualised model of change in QoL in dementia. It is encouraging to observe that even in the more severe stages of the disease people with dementia could express likes and dislikes and state whether their needs were met.

6.5. QUALITY OF LIFE AND BEHAVIOURAL DISTURBANCE

Behavioural disturbances occur as a manifestation of dementia and are associated with neurological deficits and psychological distress through impaired judgement, increased impulsivity, frustration and mood lability that interfere with interactions with others (Tariot et al., 2002; Lyketsos et al., 1999). Despite the high prevalence of behavioural disturbances, occurring in 90% of people with dementia (Tariot, 1999), little is understood about their impact on the individual and their QoL. Fewer behavioural disturbances were correlated with better family caregiver rated QoL in my study but were not a predictor of QoL for the person with dementia. Previous studies have observed links between increased neuropsychiatric symptoms (as measured by the NPI) and poorer QoL (Shin et al., 2005; Ready et al., 2004). Ready et al., (2004) found that increased neuropsychiatric symptoms predicted lower QoL, as rated by the DQOL, analysing the NPI total scores rather than the individual elements. Whereas Shin et al., (2005) examined associations between the individual NPI items and patient rated QOL-AD and found QoL scores for people with mild to moderate dementia were correlated with NPI depression. Studies of the impact of behavioural disturbances on the caregiver have identified behavioural disturbances as the most consistent predictor of carer burden (Coen et al., 1999; Donaldson et al., 1997). Shin et al., (2005) found that NPI rated agitation/aggression, disinhibition and irritability were most strongly correlated with caregiver rated QOL-AD scores, whilst Banerjee et al., (2006) found that NPI total scores predicted lower caregiver rated QoL for the person with dementia. In this thesis, the NPI total score and apathy had the strongest correlations with family caregiver rated QoL and the NPI items apathy and irritability were identified as predictors of family caregiver ratings for the person with dementia's QoL. This is not unexpected as the family caregiver witnesses the distress experienced by the person with dementia and perceives it as impacting on their relatives QoL.

Interventions are available to manage neuropsychiatric symptoms in dementia and behavioural symptoms are considered more amenable to treatment than other dementia-related symptoms (Finkel et al., 1996). Moreover, interventions which improve neuropsychiatric symptoms may enhance the person with dementia's QoL and general day to day life. Improved QoL and wellbeing may be achieved through the person with dementia experiencing better mood, a better sleep pattern, less agitation, less distressing hallucinations and fewer paranoid beliefs.

6.6. QUALITY OF LIFE AND FUNCTIONAL DEPENDENCY

Dependency was a predictor of caregiver perceptions of lower QoL in dementia. Dependency was also found to have an association with paid caregiver ratings of residents QoL at both baseline and follow up. This confirms that staff perceptions of people with dementia's QoL are determined by disability. Gessert et al., (2005) found that staff in long-term care facilities rated elements impacting on QoL for physically impaired residents as being more significant than for those with cognitive impairment. It is possible that staff may have difficulty understanding the resident's subjective experiences (eg mood, pleasant and unpleasant experiences) or feel unable to change them.

An association with higher functional dependency and lower QoL was not a predictor of QoL for the person with dementia. Andersen et al., (2004) however, found that the main factor contributing to QoL in dementia was dependency on others to perform activities of daily living. In Andersen's study, QoL was assessed using the EQ-5D (a generic QoL measure) and difficulties have previously been reported for people with dementia completing the EQ-5D (Thorgrimsen et al., 2003). The authors overcame this by devising proxy questions which were mapped to questions on the EQ-5D scale, but caution that this may give rise to quotation bias and goodness of fit (Andersen et al., 2004), which means that answers are thereby influenced to fit the responses expected. Within this thesis, people with dementia who were unable to complete the QOL-AD and those who were lost to follow up were more dependent. It is possible that QoL was poorer for these people and was linked to their reduced functional status. Perceptions of QoL remain difficult to measure in people experiencing the most profound dementia severity. For people experiencing less severe dementia severity, it is possible that they retain less insight into their physical impairments due to anosognosia. Within dementia, anosognosia is manifested through underestimation of ADL deficits and poor awareness of behavioural changes which is apparent in all stages of the disease (Starkstein et al., 2006).

6.7. QUALITY OF LIFE AND LIVING SITUATION

QoL was higher for those people with dementia living in the community compared to those in institutions, although it is not known if this relationship is causal. This finding may suggest that QoL is better for those people with dementia who live alone or with relatives and should be supported in the community for as long as possible. For this to be achieved resources would need to be available to support both the person with dementia and the caregiver and at present a package of care will not usually be financed beyond the cost of institutional care. Both the individual and the family caregiver rated QoL lower when the person with dementia lived within a 24 hour care setting. Conversely, Selwood et al., (2005) reported higher QOL-AD scores for people with dementia living alone and in residential care compared to those living with relatives, but this did not correspond to the DQOL scores and QoL was not predicted by care settings. Other studies that have examined QoL for residents of long term care facilities found QoL to be lower for people with dementia living in skilled nursing facilities in comparison to those in assisted living accommodation (Edelman et al., 2005; Burgener & Twigg, 2002; Gonzalez-Salvador et al., 2000). Which suggests that QoL worsens in people with dementia as their care needs increase through advancing dementia severity and greater functional dependency. Or it may be that people with dementia prefer to live in their own homes and their QoL worsens when living in a care home.

6.8. QUALITY OF LIFE AND TREATMENT

QoL was rated higher by both the individual and the caregiver when the person with dementia was taking AChEIs. This is an important finding as QoL in dementia and the use of AChEIs has not previously been investigated using a validated QoL measure. AChEIs were not included in the follow up study in residential care in this thesis. While causality cannot be shown in a cross sectional cohort study, this finding underlines the necessity for future randomised controlled trials to be designed with a valid disease specific QoL measure and shows that it is practical. The current NICE (2006) guidance for the prescribing of AChEI recommend that antidementia medication is only given to those people with moderate Alzheimer's Disease, despite benefits of AChEIs being shown across other stages and diagnoses of dementia (Overshott & Burns, 2005; Simpson et al., 2005). The first analysis of cost effectiveness for AChEIs and memantine were based on utility measures described by Neumann et al., (1999) and is considered by some to be flawed (RCPsych, 2006). QoL ratings in dementia were obtained using caregiver proxy ratings using the Health Utilities Index Mark II (HUI:2) and single-attribute utility scores declined considerably across the different stages of dementia, with those in the more advanced stages of AD having lower HRQoL scores (Neumann et al., 1999). The HUI:2 has not been validated for use in AD or with proxy ratings. In addition, QALYs may be considered ageist as they focus on cure rather than care (Bowling, 1997).

The sensitivity of the QOL-AD to measuring change in QoL in dementia means it can be used within future clinical trials and settings, such as Memory Clinics, where AChEIs are prescribed. Taking AChEIs can improve cognition, function and behaviour all of which may benefit QoL as discussed earlier in this Chapter.

6.9. PERCEPTIONS OF QUALITY OF LIFE FOR PEOPLE WITH DEMENTIA

QoL was measured using both caregiver and patient ratings. For the person with dementia it was their experience rather than their disability that most influenced their QoL, so that mood was the main determinant of QoL at every stage of dementia severity. Whilst all aspects of health are important in assessing the impact of the disease process, it is the individual's subjective interpretation of the objective experience that truly defines QoL (Brod & Stewart et al., 1999; Testa & Simonson, 1996). Mood relates to psychological well-being, happiness, self-esteem and judgements of overall life satisfaction which are all determinants of QoL (Bowling, 2005; Lawton, 1991). An important feature of psychological well-being is the capacity of individuals to adapt to losses and maintain a positive self-belief and increased frailty does not necessarily diminish the strength of self (Lawton, 1991). This supports the concept of personhood, in that individuality is maintained throughout the dementia process. An individual's sense of control is also core to QoL and this incorporates feelings of self-efficacy, perceived control and learned helplessness which relate to people's personal beliefs and expectations (Abeles, 1991). Within dementia a person's sense of control may be considered to be diminished through the degenerative and debilitating nature of the disease process. Nonetheless, aspects of QoL such as relationships, independence, concept of self, having fun, financial security and overall life quality were all important to people with dementia and this is no different to society in general. Relationships were a key element in sustaining QoL in dementia and this can be linked to the 'four global sentient states' outlined by Kitwood & Bredin (1992) in that they reinforce a sense of personal worth, a sense of agency, social confidence and hope. Maintaining relationships between people with dementia, their families and friends are important as this demonstrates acceptance and are central to fulfilling the psychosocial needs outlined in Figure 1: comfort; attachment; inclusion; occupation and identity (see Section 1.3.6.1. of this Thesis). Moreover, relationships remained important even in the more severe stages of dementia and were very much influenced by their environment. The significance of maintaining relationships and establishing new ones should be recognised when people with dementia are placed in residential care and every effort should be made to promote integration for new residents and their families.

Caregivers complete the QOL-AD as a questionnaire and the person with dementia completes it in interview format about their own QoL (Logsdon et al., 1999). Whilst the people with dementia were able to select the response of *poor, fair, good* or *excellent,* they frequently justified their answers with supplementary evidence. What was evident during the completion of the QOL-AD was that some of the people with dementia used downward comparisons to rate their own QoL. This was particularly evident in the care homes where residents contrasted their own wellbeing to that of residents less fortunate than themselves, in particular those residents with increased physical and mental frailty and those receiving none or few visitors. Comments were made with regard to their own mobility, ability to feed themselves, orientation to surroundings and references to family and friends visiting. This evidence is however anecdotal, as although the QOL-AD does have an area for additional comments at the end of the scale and this data was documented, it was not analysed.

6.10. CAREGIVER PERCEPTIONS OF QUALITY OF LIFE FOR PEOPLE WITH DEMENTIA

Differences are apparent between individual and caregiver ratings of QoL in people with dementia. Caregiver perceptions of the person with dementia's QoL were predominantly influenced by observable factors including disability. This implies that staff may view resident's QoL according to their level of abilities and the tasks that need to be undertaken for them. Paid caregivers do not necessarily understand the experience of dementia for the individual but are able to observe the disabling aspects of the dementia process on the individual. QoL ratings may also be affected by how the caregiver is feeling. Winzelberg et al., (2005) used a modified version of the QOL-AD to examine factors associated with nursing assistant perceptions of residents QoL in long term care facilities and found nursing assistant's reporting more work stress provided lower QoL ratings. Those nursing assistants, who valued resident QoL more by providing a higher level of person centred care, were better able to meet residents QoL needs. Macdonald & Wood (2005) also examined the attitudes to dementia and dementia care of nursing staff in non-EMI care homes and observed that better recognition of dementia was associated with person-centred attitudes unrelated to experience or training. Novella et al., (2001b) found qualified nursing and spousal ratings of QoL were closest to those of people with dementia, however, only moderate agreement was shown for the domains of physical health and disability. Other health professionals and the patient's children showed less agreement, with care assistants having the worst agreement with patient ratings. What is apparent is that paid caregivers place more emphasis on the observed components of QoL and these are important, but an empathic understanding of the person with dementia's subjective experience can be lacking.

Family caregiver ratings of the person with dementia's QoL were more insightful into subjective experiences. Functional dependency, the NPI total score and NPI item apathy were correlated at the level of clinical significance (≥0.4). In multivariate analysis however, mood status, behaviour and the person with dementia's living situation were significant predictors of family caregiver rated QoL. Logsdon et al., (2002) suggested differences between patient and caregiver reports were due to varying perceptions of the patient's QoL rather than the reliability of the QOL-AD scale and family member's ratings were associated with family caregiver depression and burden. Sands et al., (2004) found differences in QoL ratings were not associated with the type of relationship between the person with dementia and their family caregiver, or with the patient's level of dependency, but were predicted by carer burden and depression in the person with dementia. In this thesis, the caregiver QoL ratings were not influenced by caregiver depression or anxiety symptoms, but were associated with the person with dementia's mood status and behavioural disturbances which are known to be predictors of caregiver burden (Waite et al., 2004).

6.11. MEASURING CHANGE IN QUALITY OF LIFE IN DEMENTIA

Although the sample mean QoL did not change over time, there was individual change in QoL for people with dementia. Decreased QoL was most strongly predicted by baseline mood and QoL and by an increase in depressive symptoms and cognitive impairment over the 20 week period. Whilst causality is not established, this finding suggests that QoL is not fixed in dementia and the experience of the individual does change as factors influencing QoL such as mood and cognition alter, and that it may be possible to measure the benefits of interventions and treatments on QoL in dementia. Improvement in overall QoL was associated with increased scores for energy and ability to do things for fun, which suggests that QoL improves with better health and stimulation. In contrast, a decline in overall QoL was associated with lower mood and family relationships indicating lower levels of engagement. Integration and inclusion through the provision of stimulating activities and engagement with the environment may be a way of improving QoL in people with dementia.

The QOL-AD which was used to rate QoL is a simple and straightforward scale to use as response choices are consistent across all questions and all items are rated according to the person with dementia's current QoL (Logsdon et al., 2002). People with dementia prefer multiple rating scale points to categorical dichotomy responses and Likert categorical scales are considered easier to administer, analyse and interpret (Brod & Stewart, 1994; Jaeschke et al., 1990). Items on the QOL-AD were rated on a four point scale of *poor, fair, good* and *excellent* and this construct allows for variance in QoL to be more easily measured at two different points in time and there was no evidence of 'floor or ceiling effects'. A shift of item scores were apparent for nearly three quarters of the sample population followed up, with just under half of the residents showing changes of 6 or more points on the QOL-AD scale. The change in QoL scores may therefore show evidence of response shift and demonstrate that people with dementia are able to re-evaluate their situation. Response shift is where the individual's experiences constantly change their expectations and people constantly move towards an ever changing point of equilibrium (Schwartz et al., 2007). Response shift is not necessarily a conscious process and may differ across individuals (Sprangers & Schwartz, 1999). That change in QoL was influenced by baseline mood and QoL scores, and changes in mood and depression, would suggest that the point of equilibrium as conceptualised in figure 6 can be altered and thus supports the model of change in QoL proposed.

So as conceptualised in Figure 6, mood, cognition, function and behaviour are the key components impacting on change in QoL. Mood and cognition both impact on behaviour and a decline in cognition is linked to a decline in function and possibly on mood. Conversely, improvements in these factors may result in improvements to all, which is consistent with the findings of Woods et al., (2006), where improvements to cognition (and mood) appear to lead to improved QoL as rated by the person with dementia. In terms of intervention studies often there is little impact on ADL (i.e. function) but there may be an impact on cognition, mood or behaviour e.g. reduced agitation, wandering, which may result in improved QoL. Functional ability and behaviour influence the person with dementia's living situation, which in turn can influence the person's mood and behaviour further, usually negatively. Whereas, providing treatment through medication and appropriate psychosocial interventions may improve function and behaviour which may possibly enhance mood and subsequently impact on QoL. This is a simple and straightforward model of change in QoL in dementia and the dynamic and continuous nature of the relationships between these factors and QoL can be observed.

6.12. LIMITATIONS

A number of limitations have been outlined relevant to the individual studies and there were limitations that were consistent across all investigations. Data were collected from two different main studies, Study 1 was longitudinal in design and Study 2 was a randomized controlled trial. One intention of the thesis was to investigate change in QoL through combining the data from both studies as is evident in the initial aims stated within the research proposal (see appendix 1 of this thesis). However, differences in methodology and research design did not allow the sample data to be combined and the serendipitous nature of the thesis is acknowledged. What became apparent was that the ongoing studies offered the opportunity for four separate investigations to be undertaken that allowed relevant issues related to QoL in dementia to be explored. As the data collected within the studies included a good number of people experiencing more severe levels of dementia it was relevant that their ability to rate their own QoL using the QOL-AD was examined. Furthermore, the person with dementia's self-rating of QoL and proxy ratings have been shown to be different and are not completely representative of the person with dementia's own perceptions of their QoL (Sands et al., 2004; Novella et al., 2001b), and further investigation of the validity of these ratings was justified. The data collected allowed for comparisons of the person with dementia's ratings of QoL with both family and staff proxy ratings of their QoL to be examined separately. There was no crossover of participants and the samples in both main studies were relatively large and the results are representative of the populations studied. Change in QoL could have been examined in both studies, but was hindered by the constraints of thesis size that did not allow for the changes in QoL for both study samples to be investigated, or allow further time points to be measured. Change in QoL was only analysed in those participants living in residential homes and these findings are limited to this population.

Limitations due to the lack of an accepted 'gold standard' rating of QoL in dementia meant that the QOL-AD scale does not have criterion validity. Where no established gold standard criterion exists then 'known group validity' can be assessed (Prince, 1998a), and the use of proxy measures is recommended (Bowling, 1997). As discussed in other studies of QoL in dementia, individual subjective ratings can be used as the gold standard for measuring QoL in dementia (Brod et al., 1999; Whitehouse, 1998; Whitehouse, 1999; Novella et al., 2001a; Kane et al., 2003). Difficulties with insight in dementia have been raised, but the QoL ratings were found to be meaningful across all dementia severities, except in the more advanced stages of the disease. The QOL-AD has also previously been used with a small number of people with severe dementia MMSE ≥3 (Thorgrimsen et al., 2003, Logsdon et al., 2002). Difficulties in completing the QOL-AD scale were consistently found for approximately half of the participants in each study who had a more profound degree of dementia (MMSE <3), where severe deficits with communication and comprehension were evident. This finding may be as a result of non response bias in that some of the study population were unable or refused to complete the QOL-AD. The findings in this thesis may not therefore be applicable to those people with the most advanced and terminal stages of dementia as they did not complete the study. In addition, those people scoring 3-11 on the MMSE who were unable to complete the QOL-AD may be subject to misclassification bias and the use of a global rating may have deemed them to have a more profound degree of dementia, and conversely those few people able to complete the QOL-AD with a MMSE below 3 may have less severe dementia severity. Non-completion of the QOL-AD scale may also be explained through interviewer factors (eg experience, bias) or by fluctuations in participant's ability or willingness to co-operate as some scales could not be completed at baseline but were able to be completed at follow up. For the investigations outlined in Chapters 3, 4 and 5 where there were two or less items missing on the QOL-AD, the mean person score was calculated and substituted for any missing items on the QOL-AD as described in Logsdon et al's., (2002) paper. Those QOL-AD scales with 3 or more items missing were excluded. Other studies have imputed mean values of between 20 – 49% (3 - 6 points) for missing QOL-AD scores (Smith et al., 2006b, Edelman et al., 2005). Had this approach been adopted in this thesis and the missing QOL-AD values imputed in the first investigation, I would have had scores of QoL for more people with dementia. Nonetheless, a number of participants could not complete any of the items on the QOL-AD. Although there is no 'gold standard' to establish criterion validity the QOL-AD is arguably the best scale available and is recommended by the European Interdem collaboration (Moniz-Cook et al., 2008). The QOL-AD seems the preferred scale for measuring QoL in dementia and was already selected as a standard QoL measure for the two studies prior to commencing this thesis.

The face validity of the QOL-AD was established through its development in the USA, which included a review of the literature and consultation with people with dementia, family caregivers and experts in dementia (Logsdon et al., 1999; 2002) and has also been shown to be an acceptable instrument for use in the UK (Thorgrimsen et al., 2003: Selai et al., 2001b). A small number of staff and some of the people with dementia were found to have difficulty completing the QOL-AD scale fully. For the people in residential homes the missing values were predominantly for the items involving family relationships and money. This was because the staff member interviewed was not aware of the resident's family and financial circumstances or did not rate the item if the resident was widowed. The face validity of the QOL-AD could be called into question with regard to the items family, marriage and finances, when used with this population of people living in residential homes. Edelman et al., (2005) modified the QOL-AD for use in residential homes and dropped the items money and marriage which they then replaced with four additional items related to staff, self care, living with others and ability to make choices in life. However this thesis showed that many people living in institutional settings were able to rate the QOL-AD in its standardised form and no items were considered irrelevant, the face validity of the QOL-AD is therefore maintained across the different stages of dementia severity.

Precision validity was shown in that the QOL-AD was able to detect small changes in mood and cognition and the QOL-AD was responsive to actual changes in the QoL score. However, had the hypothesis specified more clearly the changes expected over time, e.g. changes in MMSE or Cornell scores, or used additional time points, the thesis may have been more successful in determining the sensitivity to change of the QOL-AD. A change in QoL scores, both positive and negative, was evident for nearly three quarters of the sample population and the QOL-AD was sensitive to detecting change in QoL for people with dementia. The QOL-AD has shown sensitivity to change in QoL over a one year period (Selwood et al., 2005). Indeed, living with disability is a process of constant change and constant adjustment, that is difficult to measure and categorise, furthermore response shift can affect standard psychometric indices such as reliability and validity (Schwartz et al., 2007). The QOL-AD was designed to reflect the domains identified as important to QoL in people with dementia (Logsdon et al., 1999; 2002) and incorporates the four dimensions of QoL in older people, behavioural competence, perceived QoL, objective environment, and psychological well-being (see figure 2: Lawton, 1983). These domains remained relevant across the severity of dementia and the content validity of the QOL-AD was demonstrated within this thesis in that QoL was shown to be influenced by the factors namely cognition; mood; functional ability, behavioural disturbance, living situation and treatment. Construct validity of the

QOL-AD was indicated by correlations with measures of cognition, function, mood and behaviour. It therefore successfully integrates information about mental, physical and environmental dimensions and their effects on health as is desirable from a QoL instrument. Evidence of convergent validity is indicated as the QOL-AD correlated with related variables such as the mood, behaviour, function and cognition. Evidence of discriminant validity is indicated as the QOL-AD did not correlate with age, gender or education probably because these are not measures of emotional state. Whilst cognition and QoL were measured subjectively using the person with dementia's own ratings, the other clinical variables measuring mood, dementia severity, function and behaviour were assessed using a combination of participant interview and proxy measures including caregiver reports and researcher observation. Differences are known to occur between individual perceptions and proxy ratings of function and disability in people with dementia (Yasuda et al., 2004; Kiyak, et al., 1994). There is therefore a risk of bias through a halo effect as the raters overall impression of the person with dementia may influence their rating of other characteristics either positively or negatively (Polit & Hungler, 1995). Furthermore, as differences were observed between individual and proxy ratings it is no longer appropriate to combine the QOL-AD scores to create a composite score.

The reliability analysis was undertaken to examine internal consistency of the QOL-AD using the model alpha (SPSS, 2004). Measures of internal consistency estimate how consistently individuals respond to the items within a scale and are often called measures of "internal consistency reliability" or even "reliability," but this is thought to merge the distinct concepts of internal consistency and reliability, which do not necessarily go together and alpha makes no assumptions about what measures would be obtained at a different time (Miller, 1995). Cronbach's alpha also known as the reliability coefficient is the most common estimate of internal consistency of items in a scale and measures the extent to which item responses obtained at the same time correlate with each other. Cronbach's Alpha thus provides an estimate of reliability based on all possible correlations between all items within the scale (Bowling, 1997). Alpha estimates internal consistency from the average correlation, and also takes into account the number of items so, when the number of items in a scale is higher, alpha will be higher (Garson, 2007). An alpha of 0.70 or higher is widely accepted as the cut off for a set of items and to judge them to be reliable (Garson, 2007), although Bowling (1997) argues that good internal consistency and test-retest reliability are indicated at levels of 0.50 and above. The reliability analysis for the QOL-AD showed a Cronbach's alpha of 0.78. Not all correlations were highly correlated in the reliability analysis and Bowling (1997) cautions that questions that deliberately tap different dimensions within a scale will not necessarily have high item-item or item-total correlations. Nonetheless, those items with the highest item-item correlations indicating that they 'belong to each other' were between the items where participants rated relationships and overall QoL.

Sampling bias was avoided by using a stratified sample for gender, dementia severity and living situation in study 1, and the results of this thesis have external validity in that they are generalisable to the wider dementia population. Internal validity was not however demonstrated as the analysis did not establish causality. Cross sectional surveys tend to be descriptive and exploratory, but the analysis should be related to the stated research objectives (Prince, 1998b). Regression analysis was used to identify predictors of QoL in dementia and whilst these are true at this time, this analysis does not offer future predictors. Regression analysis was used in three of the investigations. The objective of the regression analysis is to select the best combination of predictor variables that together provide a linear prediction of the QoL score. R square (R^2) or the coefficient of multiple determination can establish that a set of independent variables explains a proportion of the variance in a dependent variable at a significant level and can establish the relative predictive importance of the independent variables (Garson, 2007). Put simply, R^2 measures how well a regression line approximates real data points; and an R-squared of 1.0 (100%) indicates a perfect fit. The use of R^2 is limited in that it does not tell whether independent variables are a true cause of the change in the dependent variable or whether the most appropriate set of independent variables has been chosen. In multiple regression analysis adjusted R^2 is used when the number of independent variables is high relative to the number of cases, or when comparing models with different numbers of independents. If a high number of independent variables are used R^2 may become artificially high as some 'chance variations' may be explained by small parts of the variance in the dependent variable (Garson, 2007). Adjusted R^2 is described as the percent of variance after the contribution of chance has been subtracted and its use is recommended. If few independent variables are used R^2 and adjusted R^2 will be close. Alternatively when many independent variables are used, the adjusted R^2 may be noticeably lower. The use of multiple variables also increases the risk of type 1 error and this was accounted for in the analyses as $p<0.01$ was used as the level for significance. Furthermore, only correlations of 0.4 and above were considered as being clinically significant (Dunn & Everitt, 1995). Irrespective of whether the R^2 or adjusted R^2 is used to explain the model some of the factors influencing QoL remain unexplained and alternative methods of analysis may have been preferred.

As there were multiple variables used, the data could be amenable to logistic regression to look at predictors of QoL scores as logistic regression can be used when the dependent is dichotomous and the independents are of any type. Logistic regression can be used to predict a dependent variable on the basis of continuous and/or categorical independents and estimates the probability of a certain event occurring (Garson, 2007). It could therefore be possible to look at predictors of QoL scores by dividing the QOL-AD rating scale into two variables of poor/fair and good/excellent and consider these as the dependent predictor. Logistic regression assesses the modifying or confounding effects and ranks the relative importance of the independent variables, although it should be noted that logistic regression calculates changes in the 'log odds' of the dependent, not changes in the dependent itself (Garson, 2007; Daly & Bourke, 2000). Structural equation modeling (SEM) is similar to multiple regression, but is a more powerful alternative in that SEM is a largely confirmatory, rather than exploratory technique (Rigdon, 2004). SEM is used to determine whether a certain model is valid, rather than to find a suitable model and there are three possible approaches: strictly confirmatory, alternative models and model development, the latter being the most common approach (Garson, 2007). The strictly confirmatory approach uses SEM goodness-of-fit tests to determine if the pattern of variances and covariances in the data is consistent with a structural model specified by the researcher. The alternative models approach tests two or more causal models to determine which has the best fit. Whereas the model development approach tests a model using SEM procedures, which if found to be deficient, an alternative model is then tested based on changes suggested by SEM modification indexes. Garson (2007) states that SEM offers more flexible assumptions when compared to multiple regression, but regardless of approach, SEM cannot establish causal direction and relies on the theoretical insight and judgment by the researcher. Whilst SEM cannot give causal answers it can indicate the direction of the paths.

Caregiver burden was not measured as part of the studies and this may have been of interest as caregiver burden was found to be associated with family caregiver perceptions of the person with dementia's QoL in other studies (Sands et al., 2004; Logsdon et al., 2002).

Lastly, the sample populations recruited to the studies were predominantly white British and only a small minority was from other ethnic groups. One of the reasons was that there were no interpreting services available for the research interviews and so those people unable to speak English were excluded. This therefore limits the generalisability of the findings to English speaking people.

6.13. IMPLICATIONS FOR PRACTICE

The findings of this thesis have several implications for practice and offer both opportunities and challenges for improvements within dementia care. Firstly, mood was the main determinant of QoL and change in mood influenced the direction of change in QoL. Whilst causality has not been determined this finding does suggests that wider treatment of mood disorders may be of benefit to this population. Both the provision of interventions that stimulate mood and the prescribing of antidepressant therapy may enhance QoL. Relatively few people with dementia experienced depression at the level of caseness, although symptoms of depressive and anxiety disorders impacted on QoL and ongoing assessment of mood is indicated within this population. Secondly, people with dementia taking AChEIs had better QoL and this may have implications for the use of these medications in people with dementia. AChEIs can help to improve cognition and behaviour and are often a preferred treatment for behavioural disturbances in contrast to the use of antipsychotic medication.

The use of routine QoL measurement may be helpful within clinical practice to show the benefits of interventions undertaken in dementia. Within Memory clinics where AChEIs are most commonly prescribed and monitored the routine recording of QoL measures would help establish an evidence base for the benefits to QoL of using this medication for dementia. Moreover people across all severities of dementia, mild, moderate and severe were able to provide meaningful self-ratings of their QoL, and this means that the impact of interventions on QoL can be assessed across the disease process, except for the most profound stages of the illness. Clinicians should be aware that proxy ratings do not necessarily replicate the person with dementia's views of QoL and should not be substituted for self-ratings, it is important to ask both the caregiver and the patient about the person with dementia's QoL.

6.14. IMPLICATIONS FOR RESEARCH

The findings of this thesis equally have several implications for research and again offer both opportunities and challenges for research into dementia. Firstly, the ability of many people with severe dementia (MMSE ≥3) to self-rate their own QoL indicates that studies can further investigate QoL in this population. Most studies examining self ratings of QoL in dementia have focused on people in the mild to moderate stages of the disease (e.g. MMSE >10). Moreover studies that have examined QoL in more cognitively impaired people have tended to use observational tools which use proxy ratings. This thesis however confirms that the person with dementia's self-rating of QoL and that of the proxy ratings are distinct. Separate analysis of the self-ratings and the proxy ratings are preferred as differences do exist between the two groups and as stated earlier, proxy ratings are not completely representative of the person with dementia's own perceptions of their QoL.

Change in individual QoL could be detected over a period of 20 weeks, suggesting that the benefits of interventions can be measured and evaluated within a reasonable time span. The inclusion of QoL as a measure of outcome within clinical trials is important if the benefits of interventions for dementia are to be shown on QoL. The QOL-AD is a valid and reliable measure of QoL in dementia and is responsive to individual changes in this population; it is practical and uncomplicated and was acceptable for use with both people with dementia and their caregiver, its use is therefore strongly recommended in future intervention research studies. Nevertheless, the ability to examine change in QoL in sufficient detail when it is measured across two time points may be questioned and future studies should consider the use of additional time points. This may be available within the first study which is longitudinal in design and has continued to follow people up over time. Measuring change in QoL at an additional time point would help to find out if the QOL-AD is sensitive to change over a longer time period.

6.15. FUTURE RESEARCH

Research related to QoL in dementia is still within the early stages and further studies are needed to advance knowledge and increase understanding of the factors affecting QoL in dementia. The findings of this thesis contribute to this knowledge and can be used as a basis to develop future research protocols. Future research in dementia using self rated measures of QoL can be investigated across the severity of dementia, except for the most profound stages of the illness. It would be of interest to further investigate the ability of people with severe dementia to rate their own QoL and to confirm the findings of this thesis in a larger sample. Future studies investigating QoL in dementia should however consider using the cutpoint of ≥3 MMSE when completing the QOL-AD.

The findings of this thesis are limited to a UK population, so studies investigating the ability of people with dementia to provide self ratings of QoL and examining what factors are influencing their perceptions should be carried out across different study populations and cultures. Moreover, intervention studies are needed to identify treatments and psychosocial interventions that may improve QoL for people with dementia. In particular, RCTs are needed to further investigate and establish the causal links between those factors observed to be linked with QoL in people with dementia within this thesis, namely mood, changing mood and cognition, living situation and treatment with AChEIs. The finding that QoL is higher when the person with dementia is taking AChEI medication is significant although this may not be causal. This indicates the need for RCTs to establish whether there is a causal relationship between AChEIs and QoL. Future trials providing interventions for depression in dementia should also measure QoL to further assess the impact of mood on QoL and establish whether there is a causal relationship between them. The importance of living situation should be further explored by comparing the QoL of people with dementia across different settings and its determinants. The results of which may be used to influence policy as to where care can be best provided for this population. Change in QoL has been measured in a residential population with dementia and investigating change for those people with dementia living in community settings would also be of interest and is worth considering in future studies. In addition, change in QoL has been linked to changes in cognition and mood, RCTs are therefore needed to further explore the effectiveness of interventions that improve cognition and mood and establish whether there is a causal relationship with QoL. Longitudinal studies that examine change in QoL over different time points are needed to establish how QoL in dementia may change over the course of the disease.

Lastly, the QoL of family caregivers is an additional area of importance for future research. Examining the relationship between the person with dementia's QoL and the caregiver's QoL would be of interest, as would exploring the impact of caregiver burden on the caregiver's QoL. Moreover, further studies are needed to identify appropriate instruments for measuring the QoL of caregivers for people with dementia.

6.16. CONCLUSIONS

The main finding of this thesis is that the strongest association with individual perceptions and QoL in dementia is the person's mood, although this relationship may not be causal. A model of change in QoL is proposed that conceptualises the relationships between the factors influencing change in QoL in dementia which can be used to assist future thinking when planning strategies for care and research in dementia. The hypothesis that lower QoL as rated by the person with dementia will significantly correlate with higher levels of depression and anxiety symptoms was shown at baseline and follow up. This was despite the fact overall that changes in depressive and anxiety symptoms were relatively small and it meant that more subtle changes could be detected. Therefore even a small impact of therapeutic interventions for mood disorders may enhance QoL in dementia.

The hypothesis that the majority (two thirds) of people with severe dementia will not be able to provide valid and reliable assessments of their QoL was not shown as the studies included many people with severe dementia and many could provide ratings of their QoL. Indeed, a reduction in QoL was also predicted by increased cognitive impairment and challenges the common assumption that change in cognition does not impact on QoL. Furthermore, residents whose QoL improved had better cognitive function at follow up. This is a significant finding as interventions (psychosocial and pharmaceutical) may be able to boost cognition and QoL in dementia and is promising as many people with increasing cognitive impairment can provide valid and reliable ratings of their QoL.

An objective of the thesis was to investigate the association between clinical and demographic factors and QoL in dementia including cognition; mood; behaviour, function, environment. I hypothesised that QoL as rated by the person with dementia will not significantly correlate with clinical factors, namely cognition, behavioural disturbances or activities of daily living. Overall, for the person with dementia lower QoL ratings were linked to increased depression and anxiety, living in 24 hour care settings and not taking cholinesterase inhibitors. Similarly, family caregivers rated their relatives QoL lower if the person with dementia was living in 24 hour care, was depressed, or not taking cholinesterase inhibitors; as well as being influenced by level of dependency and behavioural disturbance. Whereas, dependency was the key factor influencing paid caregiver ratings of the person with dementia's QoL. Low mood and behavioural disturbances are features of dementia that may improve in response to treatment and appropriate interventions should be offered and these may promote better QoL. Furthermore recognition of these factors may help caregivers understand the experience of dementia on the individual and its influence on QoL. This reinforces the concept of personhood and need for person centred care in dementia. Autonomy and independence are highly valued features of everyday living even in dementia and higher QoL was observed for those people with dementia living in the community when compared to those living in institutions. I can not establish the direction of causality but it supports the policy of caring for people at home.

In chronic and disabling disorders such as dementia where symptomatic and functional recovery is unrealistic, improving quality of life is a very worthwhile outcome. This study has shown that QoL can be measured even in severe dementia, highlighted key factors (e.g. mood) associated with QoL and identified that improving mood and cognition may also improve QoL. This has important clinical implications for research and practice in dementia care.

To conclude, the aims of this thesis have been achieved and several important findings contribute to the existing knowledge about QoL in dementia.

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Quality of Life in Dementia - Research Proposal for PhD.

Background

The meaning of Quality of Life

The debate around the theoretical concepts of quality of life (QoL) have emerged over the previous 3 decades (Oliver et al, 1996; Muldoon et al, 1998; Orley et al, 1998; Sarvimaki & Stenbock-Hult, 2000). Dilemmas exist as to the true definition and meaning of QoL, particularly with regard to whether ratings are objective or subjective, the criteria used and what is actually being measured 'the quality of an individual's life, state of life or the meaning of life in general' (Oliver et al, 1996). Quality of life has been described as being a generalised, broad based and multidimensional concept, that includes individual perceptions of wellbeing, happiness, goodness and satisfaction with various aspects of their lives and environment (Dalkey & Rourke, 1972. cited in Oliver et al, 1996; Lehman, 1983; Franklin et al, 1986). However, Oliver et al (1996) caution that the concept of QoL 'may be disunified, an ad hoc collection of ideas... incapable of valid definition'. The expression QoL may also overlap with the terms health status and functional status and have been considered interchangeable (Guyatt et al, 1993). However this overlap to may be misleading (Farquhar, 1995) since the context for measuring QoL should be made specific i.e. health related or research specific QoL. Further concerns have been that perceptions of wellbeing may also be influenced by psychological factors unrelated to health and differing criteria (Muldoon et al, 1998).

Health related Quality of Life

Despite the consensus of opinion in definition and value that exists, the agreed methods for rating and recording QoL remain unclear (Gill & Feinstein, 1994; Farquhar, 1995; Muldoon et al, 1998; Mack & Whitehouse, 2001). Within the context of health, Gill & Feinstein (1994) defined QoL as a 'reflection of patients perception and response to their health status and to other non-medical aspects of their lives', thus allowing for an overall rating of wellbeing. A more formal definition is used by the World Health Organisation Quality of Life Group (WHOQOL), this being "the individuals' 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, expectations, standards and concerns" (WHO, 1991). This offered a broad description that encompassed the complex nature of the persons physical, psychological and social wellbeing in relation to their environment. Alternatively, Farquhar (1995) offers a framework for classifying definitions of QoL, either by origin i.e. expert, professional or lay, which may be global, component, focused or a combination and argued that 'influencing factors' need to be controlled to achieve a consensus definition.

One area of consensus is that QoL measurements are multidimensional and cover several domains. Lawton's (1991) definition includes objective environment, behavioural competence, perceived QoL and psychological wellbeing. This definition is supported by Bowling (1997), who outlined the need for several domains within QoL including emotional, psychological, physical and social wellbeing, social and support networks, community integration and role function. The value and importance of using health related QoL measures which are reliable and valid has been established (Guyatt et al, 1993; Mack & Whitehouse, 2001; Orley et al, 1998). Nonetheless, both Gill &

Feinstein (1994) and Farquhar (1995) have expressed concern that conceptual definitions of what is meant by QoL are not always given.

There is also disagreement in the use of disease specific versus generic rating scales to measure quality of life. Guyatt et al (1998) stated that specific measures may be of little use in surveys measuring the range of disability. This belief is supported in Mack & Whitehouse (2001) who warned that using disease specific scales may disadvantage arguments for additional resources. Alternatively, Orley et al (1998) reasoned that disease specific instruments are needed to reflect the particular issues contributing to that disease.

Quality of Life and Dementia

Within recent government publications there appears to be a reluctance to use the term quality of life in favour of the concept quality of care when discussing improved care of older people (Audit Commission, 2002). This may be in recognition of service requirements and provision rather than the actual experience of the individual. Despite its emphasis on improving and providing person centred care, the National Service Framework for Older People (NSF) only mentions the need to improve quality of life within two chapters of the document (DOH, 2001). One of these is the area of mental health in older people, achieved through improving general wellbeing and providing treatment for 'coexisting physical illnesses' in older people with possible depression. The other area is the promotion of health and active life in old age. Quality of life scales should be essential in helping to measure health status or provision, particularly due to the complex nature of older persons health and with factors such as comorbidity, reduced finances, limited access to resources and increased vulnerability, all of which may have an impact. Use of the concept quality of life is however more apparent in documentation regarding institutionalised care. The new national standards for residential and nursing home care are designed to provide robust measurable and maintainable standards, offering protection for residents and 'safeguarding and promoting health, welfare and QoL.', with the document stating that all standards must focus on 'the key areas that affect the quality of life experienced by service users' (DOH, 1999).

Issues regarding QoL and Dementia

Quality of life (QoL) measures are becoming a focus within dementia care and have increasing political, moral and ethical significance as an outcome measure for treatment and interventions and as a determinant of future care needs (Mack & Whitehouse, 2001. Jonnson et al, 2000). The nature of dementia implies a reduced scope for improvement in the disease and means that the care provided must be deemed of benefit to the patient and assist their caregivers. Outcome measures such as QoL scales should be able to reflect improvements in symptoms and other domains, if not in the overall illness. These may include efficacy of medication, physical and mental wellbeing, maintenance of activities and ongoing social networks. Overall the increased vulnerability of the elderly population and threats to safety, means that QoL ratings may be crucial for measuring and translating the experience of the individual and helping to assess risk. This may include influencing decisions on where a person is to receive care i.e. community or institution. Ratings of QoL can therefore be viewed as having significance for clinical settings in defining the benefits of treatment and statutory services in determining the effectiveness of care provision. Carers may also find the QoL ratings useful for assisting with making choices and decisions to benefit their relatives, particularly where patient perceptions are incorporated within the measure.

Are specific scales for QoL needed in dementia?

In devising the Cornell-Brown Quality of Life in Dementia scale, Ready et al (2002) did not include measures of cognitive or functional ability, to avoid contamination of QoL with other disease features. However, Jonnson et al (2000) recommend the use of disease specific scales, questioning the validity of generic instruments as they do not feature cognitive domains. Gill & Feinstein (1994) also recommended the use of disease specific scales to ensure good face validity, which should include specific domains of measurement that reflect QoL rather than purely health status. Additional recommendations in the paper were for the use of global ratings, including rates of severity and importance, allowing for supplemental items and the need for aggregate scores as a summary was also advised. Bowling (1997) also argued the need for disease specific QoL scales to ensure greater sensitivity to changes in health status and disease severity. A model of QoL and related factors in old age was used in a study in Finland that focused on measuring overall health, functional capacity and coping mechanisms incorporating both internal and external factors to measure the individuals sense of wellbeing, meaning and value (Sarvimaki & Stenbock-Hult, 2000). Positive views were held by respondents that life was meaningful, intelligible and manageable, including strong beliefs regarding self-esteem and personal value.

Measuring QoL in Dementia

i Use of generic scales

Due to the subjective nature of measuring QoL, several studies have examined the use of proxy ratings for measuring QoL in Alzheimer's Disease (Karlewish et al, 2000; Burgener & Twigg, 2002; Neumann et al, 1999). A tendency in caregivers to rate disability higher than patients rated it was found in a study measuring health utilities in

Alzheimer's Disease, these included 'sensation, mobility, emotion, cognition, self-care and pain' (Neumann et al, 1999). Use of the Euroqol (EQ-5D) and Quality of Life Alzheimer Scale showed 'large differences' in patient and proxy rating within the 'usual activities' domain (Jonnson et al, 2000). Orley et al (1998) questioned the legitimacy of psychiatric patient's judgement in determining QoL due to the nature of their illness, but argued that the patient's perception was valid. Ready et al (2002) used the Cornell-Brown scale for Quality of Life in Dementia to measure both patient and caregiver perceptions and found reduced QoL scores were 'moderately associated' with increased disease severity. However patients with a Mini Mental State Examination (MMSE) score below 9 were not included in the study and the interviews were held jointly with the patient and caregiver. In a community based study Pettit et al (2001) used the 12 item Health Service Questionnaire (HSQ-12) and 12 item Short Form Health survey (SF-12) to provide a broad measure of health and well being in older people. There were higher completion rates in subjects with dementia still living at home and it was found that people with mild to moderate dementia did provide valid assessments of their own QoL. Interestingly, the SF12 was unable to distinguish between people with or without dementia, whilst the HSQ-12 was found to be more sensitive to the wellbeing of the caregiver rather than the person with dementia.

ii Use of dementia specific scales

Logsdon et al, (1999) devised a scale to measure QoL in Alzheimer's disease (QOL-AD) that could be completed by both patient and caregivers and included assessment of domains relevant to physical and mental health, plus relationships with family and friends, finances and overall life quality. Lower incidence of depression and functional dependency, plus continued education were determined as predictors of higher QOL-AD scores. The QOL-AD instrument was found to have good reliability in rating patient and caregiver responses, but had limited usefulness as a self-rating assessment in patients with a MMSE below 10. These findings were repeated in an additional paper Logsdon et al (2002), although differences in agreement between patient and caregiver reports was considered to be due to varying perceptions of the patients QoL rather than the reliability of the scale. Thorgrimsen et al (2003) carried out a further study that examined the validity and reliability of the QOL-AD, the study used focus groups involving people with dementia and carers and individual QoL measures with 261 subjects were undertaken. The QOL-AD ratings were compared to ratings from the Dementia Quality of Life Scale (DQoL; Brod et al., 1999) and the EQ-5D scale (EuroQoL Group, 1990). Thorgrimsen concluded the scale was a reliable and valid tool, which could be satisfactorily used to rate QoL in patients with dementia, some of whom had MMSE scores as low as 3.

Predictors of QoL and their importance for older people with dementia have also been determined through examining the perceptions of caregivers. A study that examined caregiver preferences for the treatment of patients with Alzheimer's Disease indicated the importance of patient QoL, preserved cognition and function to caregivers. Delay in nursing home placement was identified as a QoL indicator (Karlawish et al., 2000). Initial findings within an ongoing longitudinal, prospective study (Burgener & Twigg, 2002) of the caregiver relationship factors and QoL in patients with dementia, found ongoing social contact and activity were factors influencing care recipients QoL. Other studies have focused on wellbeing and personhood as determinants of QoL and have used Kitwood and Bredin's (1994) Dementia Care Mapping to measure the quality of care for older people with dementia. Dementia Care Mapping was found to be of use in highlighting areas for change and improvement (Williams & Rees, 1997), and assisting with care-planning (Younger & Martin, 2000).

Planned study and definition of QoL

It is apparent from the literature that the measurement of QoL in older people with dementia and the ability of patients and caregivers to provide accurate ratings has been thoroughly investigated. Nonetheless, it is not apparent how QoL may be affected over time in relation to changes in health status. Further investigation is therefore required to examine the use of repeat QOL measures over a period of time to reflect changes in cognition, mood and functional ability. In addition, it is also important to determine the benefits and relevance of using QoL ratings within clinical and research settings. It is therefore intended to undertake an investigation that will examine the QoL of people with dementia of varying severity. This will be achieved, through exploring the effects of changing cognition and changing QoL in both community and institutional settings. The study will focus on measuring health related quality of life (HRQOL) and the main tool of assessment will be the QOL-AD (Logsdon et al, 1999).

Logsdon structured the QOL-AD based on the domains recommended by Lawton (1983. Cited in Logsdon et al, 1999), this conceptual framework identified four important domains, these being 'behavioural competence, the objective environment, psychological well-being and perceived QoL'. Lawton defined subjective wellbeing as 'perceived QoL' and 'psychological wellbeing' and concluded 'Psychological well-being is a subjective sense of overall satisfaction and positive mental health that is commonly thought to be the best indicator of unobservable constructs such as self-esteem and ego strength' (Lawton, 1984:69. Cited in Oliver et al, 1996). A definition of QoL is required for the study to clarify the basis on which QoL will be judged. Lawton's definition for QoL will therefore be used within the study.

The QOL-AD is reported to have successfully measured QoL in older people with MMSE scores above 10, indicating a moderate level of dementia (Logsdon, 1999). Thorgrimsen et al (2003) indicated the QOL-AD was used with people experiencing more severe levels of dementia, some scoring as low as 3 on the MMSE. As the project is anticipated to include older people with a range of severity levels for dementia, the study will also examine how useful the QOL-AD scale is in rating QoL in people with severe dementia, focusing on those scoring below 10 on the MMSE.

Aims of the project

Overall aim

To investigate how QoL changes over time in people with dementia and to identify factors which are associated with such changes including cognition, mood, daily living skills, unmet needs, living situation and service use.

Hypotheses

Primary

Quality of life measures will be able to differentiate between older people who have increased depressive symptoms and those without. When recorded at baseline interview and at 6 months follow up.

Secondary

i There is no relationship between QoL and cognition, either at baseline or in terms of change over time.

ii Low QoL in older people with dementia will be associated with additional psychiatric problems specifically clinical depression or challenging behaviour.

iii Lower QoL scores for older people with dementia will be associated with living in institutional care compared with community settings.

The overall aim will be achieved by specifically targeting the following objectives:

1. Examining the relationship between changing QoL (as rated by the QOL-AD) and changing symptoms of depression (as rated with the Cornell) for people with dementia.
2. Examining the relationship between dementia (as rated by the MMSE) and QoL through measuring changing cognition and changing QoL.
3. Examining the relationship between QoL and use of resources for people with dementia. To determine where QoL influences or is changed by resource allocation.
4. Selecting outcome indicators appropriate for this population and assessing the validity and sensitivity to change of the QOL-AD.
5. Comparing ratings and influences of QoL for older people with dementia between community and institutional settings.

Experimental design and methods to be used in the project

The overall objective of the present study is to examine QoL in relation to changes in mood, cognition, daily living skills and resource utilisation for the person with dementia. The overall project will be carried out as two separate studies, although data relating to quality of life from both investigations will be collated for the main investigation. This will be achieved through undertaking a longitudinal study and include a cross-sectional survey to examine the relationship between changing cognition and changing QoL. An additional randomised controlled study will also be undertaken within the main investigation to examine unmet needs (as assessed using the CANE) and QoL of older people with dementia in residential care.

Baseline assessments will be undertaken with follow-up assessments of all participants six months later. At baseline an examination of the QoL ratings will be undertaken to determine the usefulness of the QOL-AD measures in people with a MMSE score below 10.

Study 1

Study 1 specific aims

Examining the relationship between QoL and functional ability for people with dementia within a community setting.

Hypothesis

Low QoL in older people with dementia will be associated with poor activities of daily living skills and lower levels of independent functioning.

Study design

The study design is an epidemiological study with a 6 months following of a cohort of 220 patients with dementia. Patients will be selected to be representative of the community in terms of gender, severity and living settings. There will be stratification on severity of dementia in order to balance the sample for mild, moderate and severe patients, gender and living status. Participants will be known to the clinical teams (Essex, Camden and Islington and Barnet, Haringey & Enfield) or will be volunteers (through the local Alzheimer's Society). There will be a first assessment (baseline) with data collection on the disease, the patient's status, QoL and resource use. A second assessment at 6 months is planned.

Rationale for design

The current design allows collection of clinical data at a given point of time in a given population. This is appropriate for the overall objective and for assessing the relationships between scales and the ability to discriminate between clinical populations. Having a second assessment 6 months later is necessary to obtain data for:

- the sensitivity to change of the QOL-AD scale and other rating instruments
- mapping of the determinant(s) of outcomes and resource utilisation

Study Population

Patients will have dementia (DSM-IV; American Psychiatric Association, 1994), whatever the age of onset and their treatment status. There is no upper limit set for Mini Mental State Examination (MMSE) scores. Patient recruitment will be balanced regarding the disease severity on MMSE score. Patients will be considered mild when MMSE > 20, moderate when MMSE < 20 and >10, and severe when MMSE < 10. In addition 60-70% of the included patients will be female. This gender proportion will have to be applied for the three groups of severity level. On the other hand, patients will be balanced regarding their living settings: 65% will have to be community-based and 35% institutionalised. The stratification on living status will be independent of severity and gender, i.e. this proportion of 65%/35% will not be applied to the three groups of severity. This is because people with severe dementia are more likely to live in institutions. Caregivers are defined by the mean time per week they spend (minimum of 4 hours/week contact) in close contact with the patient. There is no condition on the nature of the relationship they have with the patient (spouse/husband, relatives, neighbour). One person only will be considered the caregiver and this person will be the same throughout the whole study.

Inclusion criteria

- Age more than or equal to 50 years old at inclusion.
- Diagnosis of dementia according to DSM-IV revised interim version.
- MMSE score that indicates the presence of cognitive impairment.
- Patient has to have a knowledgeable, co-operative and reliable caregiver/informant.
- Caregiver/informant has to spend at least 4 hours a week with the patient to be able to observe the patient's ability to cope with the dementia.
- Signed Consent of the patient and the caregiver.

Exclusion criteria

- Vascular dementia, as defined by Hachinski Ischemic Score (HIS) criteria (Rosen *et al*, 1980).
- Other significant neurological disease (e.g. Dementia with Lewy body, Parkinson´s disease, Huntington´s disease, Normal Pressure Hydrocephalus, brain trauma).
- History of other severe and enduring mental illness.
- Endocrine or metabolic disorders possibly causing dementia (e.g. hypothyroidism,).
- Psychotic episodes requiring hospitalisation or neuroleptic treatment for more than 2 weeks during the last 10 years not associated with Alzheimer's disease.
- Alcohol/drug abuse during the last 10 years.
- Patient unable to comply with the study assessment, either due to another disease or inability to understand the national language that would interfere with, or prevent their participation.

Study 2

Study 2 specific aims

Examining the relationship between unmet need and QoL for people with dementia in residential settings.

Hypothesis

Low QoL in older people with dementia will be associated with higher levels of unmet needs.

Study design

This study will be a block randomised-control trial. Two independent variables will be used. Fifty percent of residential care homes will be randomly chosen to be the control group, while the other 50% of homes will receive the intervention. The main dependent variable will be the amount of change on the CANE (pre and post, met and unmet needs) between the intervention and no-intervention/control groups.

Study Population

Approximately 260 individuals over 65 years of age will be recruited to the study.

Selection of Homes:

Social Services inspection units will be contacted and asked to mail out a current list of residential homes in the local research areas for which local NHS trust and ethical approval has been obtained (i.e. North East London, Camden/Islington, North Wales, Cheshire, and North Manchester). Residential homes not offering specialist services (i.e., Elderly Mentally Infirm (EMI) units, or dementia specific homes) will be highlighted. The largest homes with similar attributes, i.e., size, locality, registering body (government or private) and where possible, philosophy (e.g. religion) were noted. When two homes can be matched on these types of variables an introductory letter will be sent to the manager of the homes. The introductory pack includes examples of the information and consent forms and the National Institute for Social Work (NISW) questionnaire and an invitation to contact the researcher.

The researcher will contact the two homes one week after the introduction pack has been posted to see if the manager had had the opportunity to read through the material and to gauge their interest in participating in the study. If the home are interested the researcher will visit the home to discuss the study further and to identify residents that meet the inclusion criteria. The Home Manager using National Institute for Social Work (NISW) guidelines, will make the initial decision as to whether an individual is considered to have dementia. This checklist covers six items regarding the person's ability to; remember events, work out basic everyday tasks, know the time, know where he/she was, correctly name person he/she sees regularly, or whether he/she could keep touch with a conversation. Residents will have noticeable problems on the six items of the NISW Noticeable Problems checklist.

Inclusion criteria

Inclusion of participants into the study will be completed in two phases:

- All participants will be over 65 years old and reside permanently in the residential facilities.
- Participants have lived in the home for the past two months and have intentions of staying in the home for the following six months.
- All participants will be able to give some form of assent in line with their level of cognitive abilities (e.g. co-operating and showing no signs of distress when interviewed).
- In addition, participants are required to show signs of dementia. Participants who score 5 or 6 on the NISW will be regarded as having probable dementia.
- Those residents who score 2 to 5 on the NISW noticeable problems checklist will be considered to have possible dementia and go on to phase 2 of the selection process.
- Those who score 0 or 1 on the NISW will be excluded from participating as they will not be considered to show significant signs of dementia.
- The list of probable and possible residents with dementia will then be further screened by the researcher using case notes and a brief assessment of the individual to ensure they can be regarded as having a diagnosis of dementia (DSM-IV; APA, 1994). All participants will have evidence of a significant memory impairment and one or more other cognitive problems (i.e., aphasia, apraxia, agnosia, or a disturbance of executive functioning).

- Participants will be excluded if these symptoms can be better accounted for by a delirium, other DSM-IV Axis I disorder (e.g., Major Depressive Disorder or Schizophrenia) or another medical condition.
- Additionally, the disturbance in cognition and/or behaviour has to present a significant decline from the individual's previous functioning.
- Lastly, the symptoms of dementia must have been present for the past six months.
- This information will be collected and assessed by the researchers using, case notes, discussion with staff or relevant others (e.g., family or GP etc). If a person is identified as having probable dementia they will be entered into the randomisation procedure.

This two tier selection process will be designed to ensure that certain individuals are not excluded due to the nature or severity of their condition, so a representative sample of people with dementia can be entered into the study. From this list between ten and twelve participants will be selected at random from each home to participate in the study.

Exclusion Criteria

- Residents selected for inclusion for the study who are unable to meet the criteria specified or are intending to move from the home soon, will be excluded.

Instruments

Instruments to be used in study 1 and 2

- Quality of Life in Alzheimer's Disease (QOL-AD)

The QoL-AD is a specific scale suitable for measuring quality of life in patients with mild-moderate Alzheimer's Disease. The QOL-AD is a 13 item scale that measures the quality of life in people with Alzheimer's Disease, through recording ratings from both patients and caregivers. (Logsdon et al, 1999).

- Mini Mental State Examination (MMSE)

A brief test of cognitive function, which measures orientation, memory and attention. Validity and reliability studies have demonstrated that the MMSE is sensitive to measuring changes in cognition (Folstein et al, 1975).

- Cornell Scale for Depression in Dementia

The Cornell Scale provides a brief screening tool of depression in people with dementia, achieved through assessment from patients, caregivers and an overall observer rating. The Cornell Scale is sensitive to measuring the severity of depression in differing levels of cognitive impairment in institutional settings (Alexopolous et al, 1988).

- Client Service Receipt Inventory (CSRI)

The CSRI collects general data (sociodemographics, educational level, living status, marital status etc.) on the patient as well as accommodation, medication, hospitalisation, use of statutory and voluntary resources and costs of residential and nursing care (Beecham & Knapp, 1992).

Additional instruments - Study 1 only

- Alzheimer's Disease Co-operative Study – Activities of Daily Living Inventory (ADCS-ADL).

The functional domain will be assessed by the ADCS-ADL inventory. The ADCS-ADL inventory is a 42-item scale corresponding to the Modified Alzheimers Disease Co-operative Study–Activities of Daily Living and will be used to determine levels of functional ability (Galasko et al, 1997).

- Health Status Questionnaire (HSQ-12)

Patients will be assessed through two distinct Quality-of-life scales: a generic scale and a specific scale. The HSQ-12 is a generic scale derived from the short form 36 (SF-36), adapted to older subjects (Bowling and Windsor, 1997). It has been shown to be suitable for monitoring QoL in with patients experiencing mild-moderate dementia (Radosevich & Pruitt, 1996).

Additional instruments - Study 2 only

- Camberwell Assessment of Need for the Elderly (CANE)

A tool which offers a structured and comprehensive measurement of need in older people and was shown to have high levels of reliability and validity (Reynolds et al, 2000). The CANE assessed a range of mental and physical health, social and environmental needs and identified whether these were met or unmet, with information being collated from patients, carers and professionals.

- Challenging behaviour scale (CBS)

A 25 item checklist that measures and rates the frequency and severity of challenging behaviour presented by older people living in residential homes. The CBS rating scale has been shown to be an effective measure to rate the incidence of challenging behaviour when used by trained staff (Moniz-Cook et al, 2001).

Procedure

The overall project will be carried out as two separate studies, although data relating to quality of life from both investigations will be collated for the main investigation. Patients in study 1 will be assessed through two distinct quality-of-life scales: a generic scale and a specific scale. Patients in study 2 will be assessed using a dementia-specific scale only.

The study will recruit 480 older people with dementia from both community and institutional settings - which will include inpatient wards, residential and nursing homes. All subjects will have a caregiver who has regular contact with the individual and is able to provide information about the patient. Participants will be over 65 and have a diagnosis of dementia that meets the criteria specified in DSM IV.

All subjects and a caregiver (formal or informal) will be interviewed using the instruments stated. The interviews will then be repeated after a period of 5/6 months. The instruments in both studies will be administered by experienced and trained investigators.

Interviews will be arranged by individual members of the research team. In study 1, the same researchers will undertake the follow up interviews. In study 2, an additional researcher will provide the follow up assessments once the intervention period has been completed. It is anticipated that all of the interviews and interventions will be completed after a period of 18 months. The data will be inputted onto an SPSS database and statistical analysis undertaken. The results will then be written up and the findings disseminated.

Power Calculation

It is anticipated that at follow up interview, a group of subjects QoL scores will have increased and a group whose QoL scores will have decreased from those measures taken at baseline. A power calculation was undertaken focusing on change in measures for depressive symptoms, at follow up interview. The estimated rise in depressive symptoms was 3 points on the Cornell Scale for Depression in Dementia. The value was taken as the expected and predicted increase in depressive symptoms as there are no previous studies to compare with, that use changes in QoL as an outcome measure in older people with dementia. With a 90% (power) chance of finding a significant difference at the 1% level ($P<0.01$), the estimated sample size was 20% of the group (approximately 96 subjects out of 480 people in the total study population).

Ethical approval

Ethical approval has been obtained from the relevant Ethics Committees for both studies to proceed, this includes the areas of Camden & Islington Mental Health Services; North East London Mental Health Services; Essex Mental Health Services and Barnet; Haringey & Enfield Mental Health Services

Data analysis

Analysis will be undertaken using relevant statistical tests from the SPSS software package. The analyses of the data will be used to look at the relationship between changing quality of life, changing cognition and dementia severity. Comparisons will be made between scores for the MMSE, the Cornell and QoL, along with calculating the correlation between QoL scores and resource use. Analyses will be dependent on whether the data is parametric or non-parametric, using cross tabulation for the categorical data and with a comparison of means and analysis of variance for the continuous data. Specific tests will probably include use of t-test, Anova, Chi-square test and the Mann U Whitney test. The data from both samples groups will be initially examined independently and then combined together, regression analysis will be used to explore and measure common themes related to QoL.

Project management and role of the applicants

The project will be undertaken by Juanita Hoe, Clinical Research Nurse, UCL; who will co-ordinate the collection and analysis of the data for this specific investigation. The principal investigator is currently working alongside two teams of researchers within the main studies, these additional researchers will be involved in the collection of data for this study. Supervision will be provided by Dr Martin Orrell, Reader in Psychiatry, UCL and Dr Gill Livingston, Reader in Psychiatry, UCL. Using the quality of life data for this purpose is an original idea developed through having a keen personal interest in this issue and realising the opportunity existed within these two investigations.

The investigation of QoL in older people with dementia offers a challenging and interesting subject for a PhD, that will provide an opportunity to explore the existing theories and concepts of QoL and examine how these relate to this client group. A broad scale study of QoL in this population group has not currently been undertaken. It is hoped that by exploring QoL in older people with dementia, a stimulating debate will be established, that will influence people's perceptions of QoL judgements for this client group and recognise the value of improving QoL where possible.

Implications of the results

This project will assist in establishing the feasibility of using a QoL rating scale for people with dementia in both the field of research and clinical practice. This will be achieved through undertaking widescale ratings of QoL in older people with dementia and correlating these measures with clinical data and information regarding resource use. It is hoped the results will assist in understanding the impact of clinical symptoms such as changing cognition and depression on QoL and the effect of accessing resources. Overall the aim will be to influence increased understanding of the value in promoting good QoL in this population group, through providing effective treatment and adequate care provision. It is also anticipated that the study will demonstrate the usefulness of QoL tools as an outcome measure, within both research and clinical settings.

The plan for dissemination of the results

The project will be undertaken as a project for a PhD thesis at UCL. Following submission the work will be written up as several papers focusing on key themes and submitted for publication.

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YOUNGER, D. & MARTIN, G.W. (2000) 'Dementia care mapping: an approach to quality audit of services for people with dementia in two health districts'. *Journal of Advanced Nursing* Vol 32 (No5) pp1206-1212.

Study Brief and Contact

Title: A longitudinal study in patients with memory difficulties

Background:

Alzheimer's disease is a neurodegenerative disorder with a frequency which increases with age. The initial clinical picture is usually of memory loss. As Alzheimer's disease progresses, patients become increasingly impaired in different cognitive functions (orientation, language, reasoning, integration of information...) in such a way that they progressively lose their autonomy. In the later stages most sufferers can no longer be cared for in their own homes and require transfer to specialised institutions. The emergence of behavioural problems increases the likelihood of transfer to such residential care.

Alzheimer's disease is a growing concern to health and social care providers because of the increasing number of affected persons, the cost of caring for them and the emergence of specific and effective but costly pharmacological therapies (acetylcholinesterase inhibitors- AChEIs) that may produce increased expenditure.

Rationale:

People with Alzheimer's disease and their caregivers may have an impaired quality of life due to the progressive decline of cognitive functions and the associated behavioural disorders. Although many factors are known to be associated with such impairment, it is not easy to rank them in importance in terms of their impact on patients and caregivers' lives. The difficulty arises partly from the lack of validation of the Quality-of-life scales used in Alzheimer's disease, and more particularly from lack of information concerning their sensitivity to changes in ADL skills. It is also difficult to predict what the consequences of a treatment-related improvement in cognition will be, in terms of patients' global functioning, on patients' and caregiver's daily lives and on disease cost. Despite the recent availability of drugs with significant positive effects on cognitive functioning in Alzheimer's disease, no published study to date tackles these issues adequately.

Purpose of the study:

This is a longitudinal study of an epidemiologically representative sample of patients with Alzheimer's Disease. The overall objective of the present study is examine quality-of-life, resource utilisation and caregiver burden (time spent, economic burden, physical burden and psychological burden) as well as cognition, behaviour, psychosis, mood and daily living skills of the patient with Alzheimer's disease.

The overall aim will be achieved by:

1. Correlating clinical data and Quality-of-life and thereby translating clinical efficacy as traditionally assessed in clinical trials into patient's benefit.

2. Collecting health economic data and determining which factors will influence the costs of illness.

3. Selecting outcome indicators appropriate for this population:

   (a) Identifying clinically meaningful discriminative determinant(s) of Quality-of-life in patients with Alzheimer's disease

   (b) Assessing the suitability and sensitivity to change of some Quality-of-life instruments

   (c) Examining correlations between clinical instruments, Quality-of-life instruments and resource utilisation

4. Having a second assessment 6 months later is necessary to obtain data for:

   - the sensitivity to changes of the Quality-of-life scales and other rating instruments

   - mapping of the determinant(s) of outcomes and resource utilisation

Study design:

The study design is an epidemiological study with a 6-months following of a cohort of patients with Alzheimer's disease. Patients will be selected to be representative of the community in terms of gender, severity and living settings. There will be stratification on severity of dementia in order to balance the sample for mild, moderate and severe patients, gender and living status. Participants will be known to the clinical teams) or will be volunteers (through the local Alzheimer's Society). There will be a first assessment (baseline) with data collection on the disease, the patient's and caregiver's status, quality-of-life and resource use followed by a second assessment at 6 months.

Contact:

Juanita Hoe
Clinical Research Nurse
UCL, Dept of Psychiatry & Behavioural Sciences
Holborn Union Building - Archway Campus
Highgate Hill, London N19 5LW

Direct Line: 020 7288 5931

E-mail: j.hoe@ucl.ac.uk

Study Brief and Contact

Title: A single-blind randomised study to identify and address the needs of older people with dementia in residential care.

Aims:

1) To compare the met and unmet needs of dementia sufferers in residential care from a range of areas.

2) To investigate the relationship between costs of care, quality of life and met & unmet needs.

3) To determine and cost appropriate interventions to meet unmet needs and provide systematic feedback on the needs and suggested interventions to the care staff for a 50% sample.

4) To follow up all dementia sufferers six months later and examine whether systematic feedback of needs resulted in needs being met, interventions being carried out, the actual cost of the individual interventions and the costs of other outcomes (e.g. hospital admission).

Scientific Background:

The House of Commons Health Select Committee (1996) has commented that there was no national information on the characteristics of people living in residential and nursing homes. The needs of residents in continuing care settings have increased in recent years (Darton, 1998; Crawford et al., 1999). There is also growing concern that geographic variations in service provisions are increasing not as a result of differences in local needs but because of historical accidents of funding and a blurring of the distinction between health and social care (BMA, 1996). Many studies in residential care have looked at disability or mental health status but not needs. The MRC topic review on the health of the UK's elderly people (MRC, 1994) recommends that in future *'research in community care should be focused on areas of particular relevance to the changes in care within the community notably, needs based approaches'.* Older people with dementia in residential care frequently have complex needs because mental health problems often coexist with disability, physical illness and social problems. Chronic problems may also be overlooked unless needs are systematically assessed. Pilot studies in continuing care have shown that dementia sufferers have multiple needs many of which are unmet (Martin, 1998). A pilot study of day hospital attenders also indicated that the Camberwell Assessment of Need for the Elderly can be used to identify needs and generate feasible interventions in at least 70% of instances.

Brief outline of present study:

The present study proposes to evaluate met and unmet needs by using a comprehensive, valid and reliable instrument (Camberwell Assessment of Need for the Elderly, Reynolds et al., 1998; 2000) which covers 24 areas of need (e.g. memory, psychological distress, daytime activity). Needs are rated as no need/met need unmet need for each area. It has 2 items on carer's needs as well as separate ratings for staff, user's and carer's views of needs to be recorded). The study will include 260 older people who have dementia and live in residential homes in three areas of the UK (London (Camden/Islington MHT and North East London MHT), Manchester, and North Wales). 50% of the homes will be randomised to an intervention group whereby their needs will be systematically reported back to the care staff and a clinical psychologist or community psychiatric nurse will work with the staff and residents to address the unmet needs. The costs of care and of additional interventions for each individual will be evaluated using the Client Service Receipt Inventory. Six months after the initial assessment all subjects will be followed up by a rater blind to the original data to assess their needs, use of services, and any costs associated with other outcomes (e.g. hospital admission). Costs to carers where relevant will also be assessed.

Contact:

Juanita Hoe
Clinical Research Nurse
UCL, Dept of Psychiatry & Behavioural Sciences
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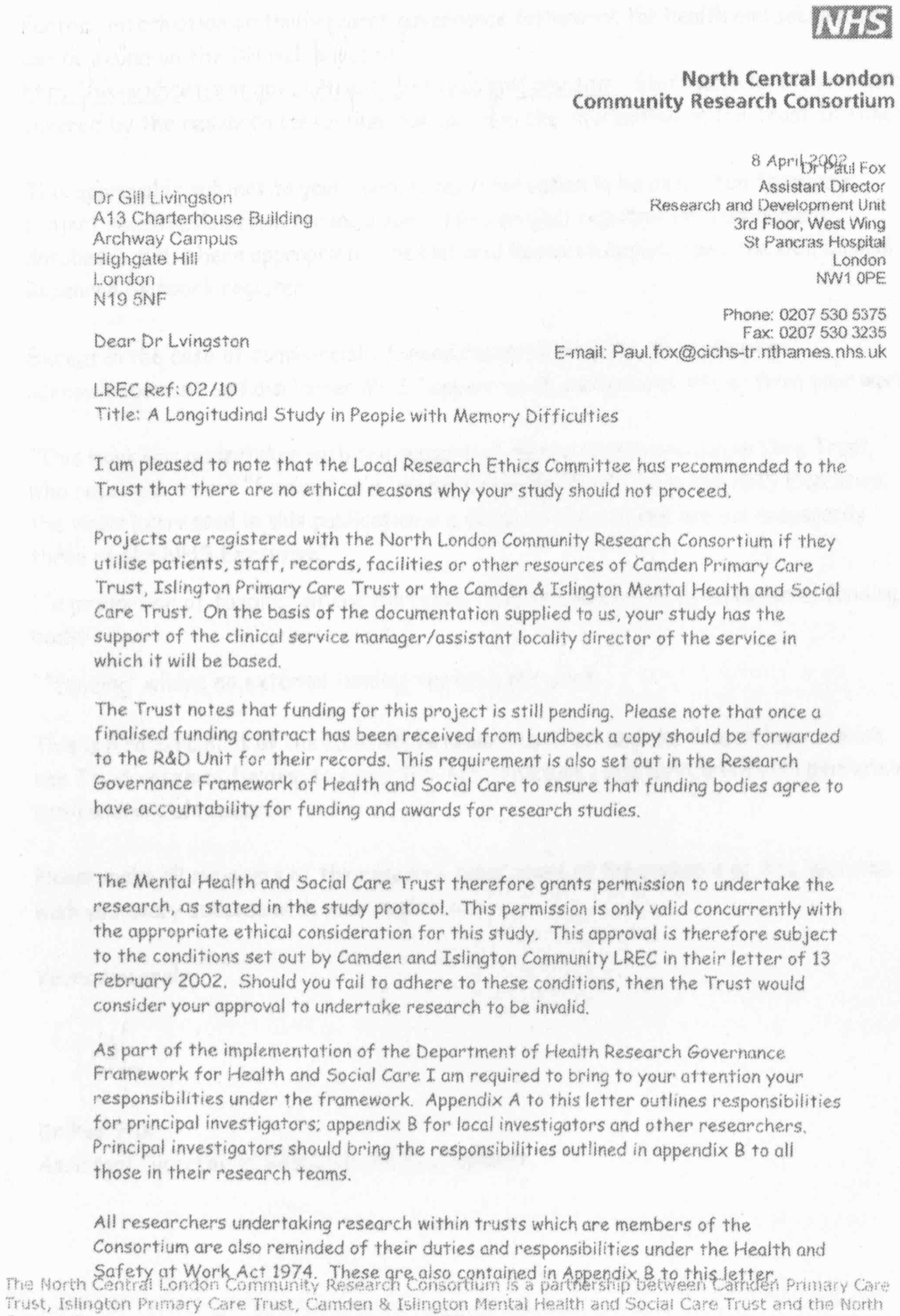
LONDON, W1N 8AA
Tel: +44 (0) 20 7679 9420 Fax: +44 (0) 20 7679 9426
E-mail: j.hoe@ucl.ac.uk



NHS

North Central London
Community Research Consortium

8 April 2002
Dr Paul Fox
Assistant Director
Research and Development Unit
3rd Floor, West Wing
St Pancras Hospital
London
NW1 0PE

Phone: 0207 530 5375
Fax: 0207 530 3235
E-mail: Paul.fox@cichs-tr.nthames.nhs.uk

Dr Gill Livingston
A13 Charterhouse Building
Archway Campus
Highgate Hill
London
N19 5NF

Dear Dr Lvingston

LREC Ref: 02/10
Title: A Longitudinal Study in People with Memory Difficulties

I am pleased to note that the Local Research Ethics Committee has recommended to the Trust that there are no ethical reasons why your study should not proceed.

Projects are registered with the North London Community Research Consortium if they utilise patients, staff, records, facilities or other resources of Camden Primary Care Trust, Islington Primary Care Trust or the Camden & Islington Mental Health and Social Care Trust. On the basis of the documentation supplied to us, your study has the support of the clinical service manager/assistant locality director of the service in which it will be based.

The Trust notes that funding for this project is still pending. Please note that once a finalised funding contract has been received from Lundbeck a copy should be forwarded to the R&D Unit for their records. This requirement is also set out in the Research Governance Framework of Health and Social Care to ensure that funding bodies agree to have accountability for funding and awards for research studies.

The Mental Health and Social Care Trust therefore grants permission to undertake the research, as stated in the study protocol. This permission is only valid concurrently with the appropriate ethical consideration for this study. This approval is therefore subject to the conditions set out by Camden and Islington Community LREC in their letter of 13 February 2002. Should you fail to adhere to these conditions, then the Trust would consider your approval to undertake research to be invalid.

As part of the implementation of the Department of Health Research Governance Framework for Health and Social Care I am required to bring to your attention your responsibilities under the framework. Appendix A to this letter outlines responsibilities for principal investigators; appendix B for local investigators and other researchers. Principal investigators should bring the responsibilities outlined in appendix B to all those in their research teams.

All researchers undertaking research within trusts which are members of the Consortium are also reminded of their duties and responsibilities under the Health and Safety at Work Act 1974. These are also contained in Appendix B to this letter.

Further information on the research governance framework for health and social care can be found on the DH web pages at http://www.nhsetrent.gov.uk/trentrd/resgov/govhome.htm. Staff working within trusts covered by the research consortium can also find the information on the Trust Intranet.

This approval is subject to your consent for information to be extracted from your project registration form for inclusion in NHS project registration/management databases and, where appropriate, the National Research Register and the UCL Clinical Research Network register.

Except in the case of commercially funded research projects, the following acknowledgement and disclaimer MUST appear on all publications arising from your work.

"This work was undertaken with the support of Mental Health and Social Care Trust, who received [insert "funding" or a "proportion of funding"]* from the NHS Executive; the views expressed in this publication are those of the authors and not necessarily those of the NHS Executive".

* "a proportion of funding" where the research is also supported by an external funding body;

* "funding" where no external funding has been obtained

This is a requirement of the contract between the Trust and the Consortium in which the Trust receives funding to cover the infrastructure costs associated with performing non-commercial research.

Please make all members of the research team aware of the contents of this approval. I wish you every success with your research.

Yours sincerely,

Dr Paul Fox
Assistant Director of Research and Development

Camden and Islington Community Health Service
LOCAL RESEARCH ETHICS COMMITTEE
Research & Development Unit, 3rd Floor, West Wing, St. Pancras Conference Centre
St Pancras Hospital, London NWI OPE
tel 020 7530 3376 fax: 020 7530 3236
e-mail: ayse.ali@cicha-tr.nthames.nhs.uk
Chair: Stephanie Ellis Administrator: Ayse Ali

13 February 2002

Dr Gill Livingston
A13 Charterhouse Building
Archway Campus
Highgate Hill
London
N19 5NF

Dear Dr Livingston

LREC Ref: 02/10 (please quote in all further correspondence)
Title: A Longitudinal Study in People with Memory Difficulties

Thank you for your letter dated 4 March 2002 addressing the concerns raised by the committee. I am pleased to inform you that after careful consideration the Local Research Ethics Committee has no ethical objections to your project proceeding. This opinion has also been communicated to the Research and Development Unit of Camden & Islington Mental Health NHS Trust.

PLEASE NOTE THAT THIS OPINION ALONE DOES NOT ENTITLE YOU TO BEGIN RESEARCH.

Camden and Islington Community Health Service LREC considers the ethics of proposed research projects and provides advice to NHS bodies under the auspices of which the research is intended to take place. It is that NHS body which has the responsibility to decide whether or not the project should go ahead, taking into account the ethical advice of the LREC[1]. Where these procedures take place on NHS premises or using NHS patients, the researcher must obtain the agreement of local NHS management, who will need to be assured that the researcher holds an appropriate NHS contract, and that indemnity issues have been adequately addressed.

N.B. Camden and Islington Community Health Service LREC is an independent body providing advice to the North Central London Community Research Consortium. A favourable opinion from the LREC and approval from the Trust to commence research on Trust premises or patients are **NOT** one and the same. Trust approval is notified through the Research & Development Unit.

The following conditions apply to this project:

- You must write and inform the Committee of the start date of your project. The Committee (via the Local Research Ethics Committee Administrator or the Chair at the above address) must also receive notification:

    a) when the study commences
    b) when the study is complete;
    c) if it fails to start or is abandoned;
    d) if the investigator/s change and
    e) if any amendments to the study are made.

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

---

[1] Governance Arrangements for NHS Research Ethics Committees, *July 2001 (known as GAfREC)*

Page 1 of 2

- It is the responsibility of the investigators to ensure that all associated staff, including nursing staff, are informed of research projects and are told that they have the approval of the Ethics Committee and management approval from the body hosting the research.

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

- If data is 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 1998. Please consult your department data protection officer for advice.

- Failure to adhere to these conditions set out above will result in the invalidation of this letter of no objection.

Please forward any additional information/amendments regarding your study to the Local Research Ethics Committee Administrator or the Chair at the above address.

Yours sincerely

Stephanie Ellis
Chair, LREC

**OPERATING THROUGH THE
WEST ESSEX LOCAL RESEARCH
ETHICS COMMITTEE**
**Westgate House, c/o The Princess Alexandra Hospital NHS Trust
Hamstel Road, Harlow, Essex CM20 1QX
Tel: 01279 641884 Answerphone/Fax: 01279 641883
Internal: (69)4917**

North Essex NHS
Health Authority

HAYMEADS DAY HOSPITAL
15 APR 2002

10th April 2002

Professor C Katona
Professor Psychiatry of the Elderly
UCL and Hon Consultant Psychiatrist
Haymeads Day Hospital
Herts & Essex Hospital
Bishops Stortford

Dear Professor Katona

1436-0202
A LONGITUDINAL STUDY IN PATIENTS WITH MEMORY DIFFICULTIES

The Research Ethics Committee considered your project at its meeting on 14th March 2002, and requested certain additional information and amendments to your submission and protocol.

Following consideration of the additional information provided in your undated letter, received here on 2nd April, by the Chairman under delegated powers, he has given ethical approval for your project to proceed.

The following documents were considered by the Committee and/or Chairman:

- Protocol dated 8th January 2002
- LREC Application Form dated 29th January 2002
- Indemnity Certificate
- Patient Information Sheet version 1 dated 10 December 2001
- Patient Consent Form undated
- GP Information Sheet version 1 dated 10th December 2001
- Carer Information Sheet version 1 dated 10th December 2001
- Caregiver Consent Form undated
- CV for Professor Katona and Gillian Livingston
- Professor Katona's undated letter received here on 11th March 2002
- Professor Katona's undated letter received here on 2nd April 2002

The Committee specifically confirms that it would expect you to approach both Dr Walker and any other local old age psychiatry consultants necessary in identifying and making the initial approach to suitable patients under their care.

Chairman: Alex Sexton
Chief Executive: Nigel Beverley

PL7274

Whilst giving approval to this project, the Committee is still interested in exactly how the sum of nearly £369,000 is being utilised in this piece of research. They felt that this is important in view of your statement that the refurbishment of the room at St Margaret's hospital appears to have been undertaken from the existing UCL research trust funds. Perhaps you could give us, in due course, further detail and clarification of the proposed budget for this research project.

Whilst this letter gives approval to the ethical aspects of your application, it is the researcher's responsibility to ensure that all other approvals necessary or required are received prior to commencing work on the research.

It is the researcher's responsibility to ensure that the research is carried out in strict accordance with the protocol submitted and that no changes to the protocol are undertaken without the prior approval of this Committee (other than matters of urgency for the safety of the participants).

Should any serious unexpected events occur in connection with your research, these should be reported immediately to the Committee, together with your recommendations as to any changes to the protocol or other action that might be necessary. These reports should be received within 7 days of the incident concerned.

The Committee retains the right to inspect or review your project at any time during the currency of the research.

You should submit a progress report not less than annually (where appropriate). A brief report or Abstract on the final results of the research should be submitted within 3 months of its completion.

It is confirmed that this Committee operates under ICH-GCP guidelines and in accordance with the Declaration of Helsinki 2000. A list of members in attendance at the meeting in March when your project was considered is attached.

May I wish you every success with your research.

Yours sincerely

Administrator

North Central London
Strategic Health Authority

Victory House
170 Tottenham Court Road
London W1T 7HA
Tel: 020 7756 2500
Fax. 020 7756 2510

Chair Marcia Saunders
Chief Executive Christine Outram

29th November 2002

Ginnette Kitchen
Team Manager & Research Nurse
Department of Psychiatry and Behavioural Sciences
Holborn Union Building, Archway Campus
Whittington Hospital, Highgate Hill
London N19 5LW

Dear Ms Kitchen

147/02 – (C&I LREC 02/10) A Longitudinal Study in Patients with Memory Difficulties

Acting under delegated authority I write to inform you that the Barnet, Enfield & Haringey LREC sub group considered in full the locality issues relating to the above application at the meeting held on 12th November 2002. The issues reviewed were as follows:

- The suitability of the local researcher
- The appropriateness of the local research environment and facilities
- Any specific issues that may relate to this local community

The LREC members on behalf of the LREC consider the locality issues have been adequately addressed and the proposed research can be conducted within the boundary of this Health Authority on the understanding that you will follow the conditions set out below:

- You do not undertake this research in an NHS organisation until the relevant NHS management approval has been granted as set out in the framework for Research Governance in Health and Social Care.
- You do not deviate from, or make changes to, the protocol without prior written approval of the lead LREC (C&I) and notifying this LREC of this approval, except where this is necessary to eliminate immediate hazards to research participants, or when the change involves only logistical or administrative aspects of the research.
- You notify this LREC when you have completed your research, or if you decide to terminate it prematurely.

- You advise your sponsor of any unusual or unexpected results that raise questions about the safety of patients taking part in the research.

It was noted that the patient Information sheet has two addresses at the top and it was suggested that you remove one to avoid confusion.

Please quote LREC number 147/02 on any future correspondence.

Yours sincerely

Christine Hamilton
Barnet, Enfield & Haringey, LREC Co-ordinator

The LONDON MULTICENTRE
RESEARCH ETHICS COMMITTEE

CENTRAL MIDDLESEX HOSPITAL
THE OLD REFECTORY
ACTON LANE
PARK ROYAL
LONDON NW10 7NS
Tel: 020 8453 2336
Fax: 020 8961 0012

1st November 2000
hd/lc/00-2-77

Dr Martin Orrell
Reader in Psychiatry of Ageing
Department of Psychiatry & Behavioural Sciences
University College of London
Wolfson Building
48 Riding House Street
London
W1N 8AA

Dear Dr Orrell

Application reference number **MREC/00/2/77**
Title A single-blind randomised study to identify and address the needs of older people with dementia in residential care

The Chairman of the London Multicentre Research Ethics Committee has considered the amendments submitted in response to the Committee's earlier review of your application on 27th September 2000 as set out in our letter dated 5th October 2000. The documents considered were as follows:

MREC Application Form	*(dated 23rd August 2000)*
Protocol (Wellcome Trust Application)	*(dated 24th February 2000)*
Patient Information Sheet	*(Version 2, dated 12th October 2000)*
Patient Consent Form	*(Version 2, dated 12th October 2000)*
Carers Information Sheet	*(Version 2, dated 12th October 2000)*
Consent Form for Carers	*(Version 2, dated 12th October 2000)*
Principal Researcher's Curriculum Vitae	

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. I am, therefore, happy to give you our approval on the understanding that you will follow the conditions of the approval set out below. A full record of the review undertaken by the MREC is contained in the attached MREC Response Form. The project must be started within three years of the date on which MREC approval is given.

Conditions of approval

- No research subject is to be admitted into the trial until agreement has been obtained from the appropriate local research ethics committees.

Chairman: Dr Hugh Davies Administrator: Miss Louise Cox

- You must follow the protocol agreed and any changes to the protocol will require prior MREC approval.
- If projects are approved before funding is received, the MREC must see, and approve, any major changes made by the funding body. The MREC would expect to see a copy of the final questionnaire before it is used.
- You must promptly inform the MREC and appropriate LRECs of:
    - (i) deviations from or changes to the protocol which are made to eliminate immediate hazards to the research subjects;
    - (ii) any changes that increase the risk to subjects and / or affect significantly the conduct of the research;
    - (iii) all adverse drug reactions that are both serious and unexpected.
    - (iv) New information that may affect adversely the safety of the subjects or the conduct of the trial.
- You must complete and return the standard progress report form to the MREC one year from the date on this letter and thereafter on an annual basis. This form should also be used to notify the MREC when your research is completed.

While 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 / Has) in which the work will be done.

Local Submissions

It is 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
- Annex D of the Application Form
- **One** copy of the protocol
- The final approved version of the Patient Information Sheet and Consent Form

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. In addition, you should submit to LRECs only the revised paperwork reflecting the requirements of the MREC as referenced in the Response Form.

Local Sites

Whist 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 details of local sites as soon as a researcher has been recruited. This is essential to enable the MREC to monitor the research it approves.

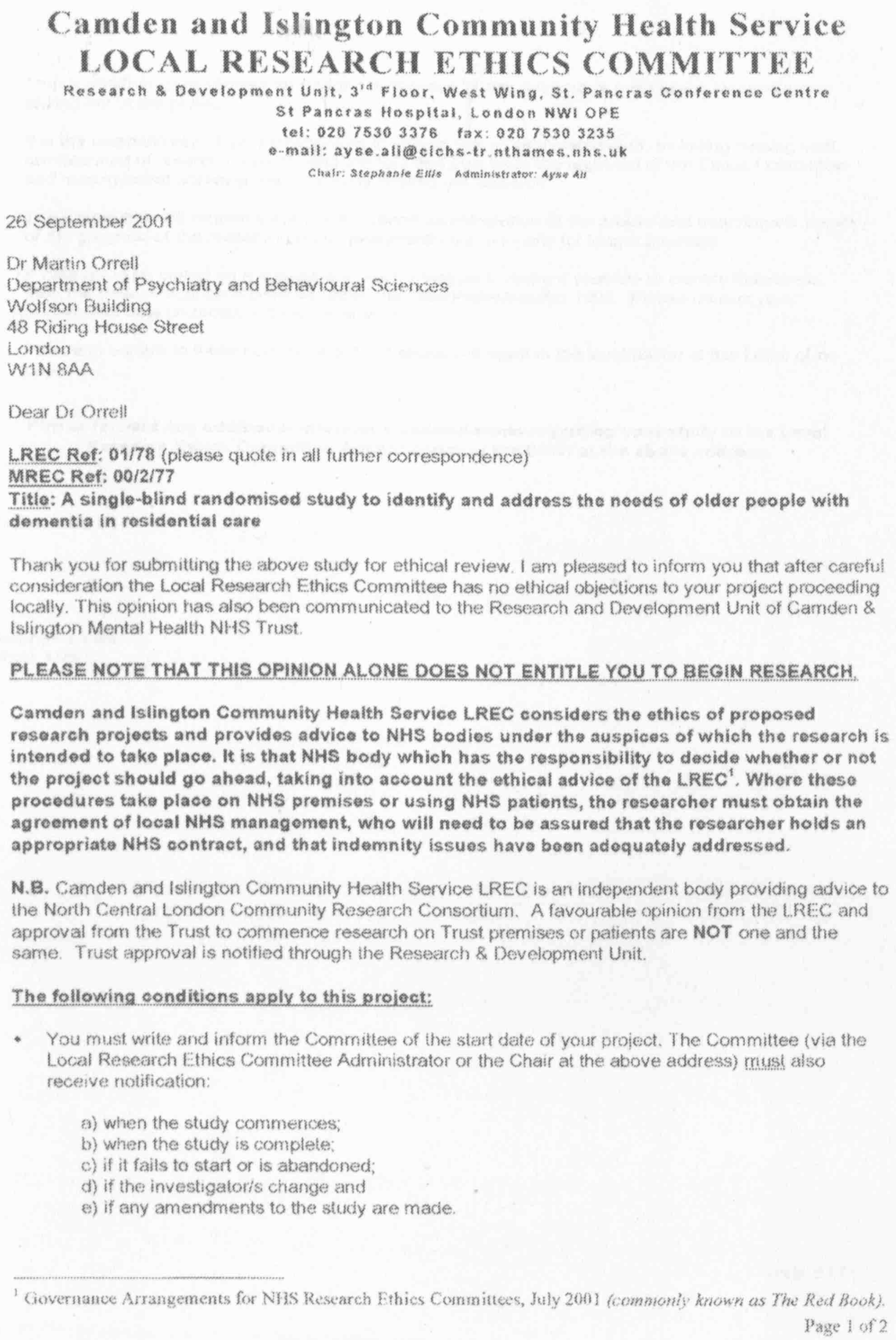
ICH GCP Compliance

The MRECs are fully compliant with the International Conference on Harmonisation / Good Clinical Practice (ICH GCP) 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

Louise Cox
Administrator
the London Multicentre Research Ethics Committee

Enc



Camden and Islington Community Health Service
LOCAL RESEARCH ETHICS COMMITTEE
Research & Development Unit, 3rd Floor, West Wing, St. Pancras Conference Centre
St Pancras Hospital, London NWI OPE
tel: 020 7530 3376 fax: 020 7530 3235
e-mail: ayse.ali@cichs-tr.nthames.nhs.uk
Chair: *Stephanie Ellis* Administrator: *Ayse Ali*

26 September 2001

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

Dear Dr Orrell

LREC Ref: 01/78 (please quote in all further correspondence)
MREC Ref: 00/2/77
Title: A single-blind randomised study to identify and address the needs of older people with dementia in residential care

Thank you for submitting the above study for ethical review. I am pleased to inform you that after careful consideration the Local Research Ethics Committee has no ethical objections to your project proceeding locally. This opinion has also been communicated to the Research and Development Unit of Camden & Islington Mental Health NHS Trust.

PLEASE NOTE THAT THIS OPINION ALONE DOES NOT ENTITLE YOU TO BEGIN RESEARCH.

Camden and Islington Community Health Service LREC considers the ethics of proposed research projects and provides advice to NHS bodies under the auspices of which the research is intended to take place. It is that NHS body which has the responsibility to decide whether or not the project should go ahead, taking into account the ethical advice of the LREC[1]. Where these procedures take place on NHS premises or using NHS patients, the researcher must obtain the agreement of local NHS management, who will need to be assured that the researcher holds an appropriate NHS contract, and that indemnity issues have been adequately addressed.

N.B. Camden and Islington Community Health Service LREC is an independent body providing advice to the North Central London Community Research Consortium. A favourable opinion from the LREC and approval from the Trust to commence research on Trust premises or patients are **NOT** one and the same. Trust approval is notified through the Research & Development Unit.

The following conditions apply to this project:

- You must write and inform the Committee of the start date of your project. The Committee (via the Local Research Ethics Committee Administrator or the Chair at the above address) must also receive notification:

    a) when the study commences;
    b) when the study is complete;
    c) if it fails to start or is abandoned;
    d) if the investigator/s change and
    e) if any amendments to the study are made.

---

[1] Governance Arrangements for NHS Research Ethics Committees, July 2001 *(commonly known as The Red Book).*

- The Committee must receive immediate notification of any adverse or unforeseen circumstances arising out of the project
- It is the responsibility of the investigators to ensure that all associated staff, including nursing staff, are informed of research projects and are told that they have the approval of the Ethics Committee and management approval from the body hosting the research
- The Committee will require a copy of the report on completion of the project and may request details of the progress of the research project periodically (i.e. annually for longer projects).
- If data is? 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 1998. Please consult your department data protection officer for advice.
- Failure to adhere to these conditions set out above will result in the invalidation of this Letter of no objection.

Please forward any additional information/amendments regarding your study to the Local Research Ethics Committee Administrator or the Chair at the above address.

Yours sincerely

Stephanie Ellis
Chair, LREC

Barking and Havering NHS
Health Authority

The Clock House
East Street
Barking
IG11 8EY

Tel: 020 8591 9595
Fax: 020 8532 6201
Minicom: 020 8532 6230
DX 121410 Barking 4

Dr. Martin Orrell
Reader in Psychiatry of Ageing
North East London Mental Health Trust
Warley Hospital
Brentwood
ESSEX

19th October 2001

Dear Dr. Orrell

Re: LREC (B&H) 170 (SC)
A single blind randomised study to identify and address the needs of older people with dementia in residential care

I am pleased to advise you that the above multi centre research application was considered by the Barking & Havering Local Research Ethics Committee on the 17th October 2001.

The Committee noted that paragraph 2 of the Carer Consent Form referred to "my" participation and "I" am free to withdraw. These should be amended to "their".

Subject to this amendment the Committee was able to approve the ethical aspects of this study.

The Committee looks forward to receiving a final report of your research findings in due course.

Yours sincerely

Mrs. J Irwin-Hunt pp
Chair LREC

Royal Free & University College Medical School
UNIVERSITY COLLEGE LONDON

DEPARTMENT OF MENTAL HEALTH SCIENCES

Juanita Hoe, Research Nurse
Royal Free & University College London Medical School
UCL - Department of Mental Health Sciences
Holborn Union Building - Archway Campus
Highgate Hill, London N19 5LW

Direct Line: 020 7288 5931

Insert Date

PATIENT INFORMATION SHEET

Dear *Insert Name*

You have been invited to take part in a research study. Before you decide whether to take part it is important for you to understand why the research is being done and what it will involve. Please take time to read the following 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.

Dr Gill Livingston and Professor Katona run this project from the Whittington hospital.

This study aims to describe the characteristics and difficulties of people with memory problems and how these change over six months. This is in order to know which aspects matter most in people's lives. This information may also help in designing and developing new medicines for these problems.

We are asking for you to participate in this study because we understand that you may have memory problems. If you agree to participate in the study we intend to see you and make a full assessment to see if we think that you might have a medical diagnosis. We are particularly interested in studying people who may have Alzheimer's Disease. This will involve asking you questions about yourself and your symptoms, examining you and taking blood tests if these have not been done already. We would also want to see you again after six months to ask some of the same questions again.

The interviews will be about:

- Personal details (age, education, etc.)
- Memory, feeling, thinking and any difficulties in looking after yourself
- Quality-of-life
- Use of services

The study does not involve any new treatments or affect your current or future treatment.

The time taken for this study will vary but we estimate that the first interview is likely to take about an hour and the second interview about one hour. If you find this tiring the person seeing you can stop and come back again. We will come and visit you at home.

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. If you decide to take part you are still free to withdraw at any time and without giving a reason. A decision to withdraw at any time, or a decision not to take part, will not affect the standard of care you receive.

The results of this study are expected to be published in relevant conferences and publications. All interviews are confidential and your name will not be disclosed to anyone else. The information collected in the study will be anonymised but may be seen by Lundbeck Pharmaceuticals, the funders of the study. You will not be identified in any report/publication.

All proposals for research using human subjects are reviewed by an Ethics Committee before they can proceed. This proposal was reviewed by Camden and Islington NHS Research Ethics Committee.

Thank you for reading this letter. Please contact a member of the research team at the above address or number if you would like further information.

Yours Sincerely

Juanita Hoe
Clinical Research Nurse

Study Number:

CRF No.____________ **Centre No.**________________

Patient Identification Number for this trial: _______________

PATIENT CONSENT FORM

Title: A longitudinal study in people with memory difficulties

Name of Researcher: ________________

Please initial box

1. I confirm that I have read and understand the information sheet dated...................... 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 caregiver	Date	Signature
Name of Person taking consent (if different from researcher)	Date	Signature
Researcher	Date	Signature

Royal Free & University College Medical School
UNIVERSITY COLLEGE LONDON

DEPARTMENT OF MENTAL HEALTH SCIENCES

Juanita Hoe, Research Nurse
Royal Free & University College London Medical School
UCL – Department of Mental Health Sciences
Holborn Union Building - Archway Campus
Highgate Hill, London N19 5LW

Direct Line: 020 7288 5931

Insert Date

CARER INFORMATION SHEET

DEAR *Insert Name*

We would like to invite you and *insert name* to take part in a research project. Before you decide whether to take part, it is important that you understand why the research is being done and what the study will involve. Please take time to read the following 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.

Dr Gill Livingston and Professor Katona run this project from the Whittington Hospital.

This study aims to describe the characteristics and difficulties of people with memory problems, any change in these problems over six months, and the effects of any changes. This is in order to understand which aspects matter most in people's lives. This information may also help in designing and developing new medications for these problems.

We are asking you to participate in this study because we understand that *insert name* to whom you provide care, may have memory problems. If you agree to participate in the study we intend to see you and make an assessment of the consequences providing care has on your life. We are particularly interested in studying people who may have Alzheimer's Disease.

The interview will involve asking you questions about *insert name* and yourself. We would also want to see you again after six months to ask some of the same questions again.

The interviews will be about:

- Demographic details such as your dates of birth and schooling.
- How you feel about you and *insert name* health and lifestyle.
- Current contact with care services.
- Your impression of the care that *insert name* requires.

The study does not involve any new treatments or affect *insert name* current or future treatment.

The time taken for the interview will vary but we estimate that each interview is likely to take approximately an hour. We will come and visit you at home. If either of you find this tiring the person seeing you will be happy to stop and come back at a later date which is convenient to you.

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 will be asked to sign a consent form. If you decide to take part you are free to withdraw at any time, without giving a reason.

The results of this study are expected to be published in relevant conferences and journals. All interviews are confidential and your name will not be disclosed to anyone else. The information collected will be anonymised but may be seen by Lundbeck Pharmaceuticals, who are funding the study. You will not be identified in any report/publication.

All proposals for research using human subjects are reviewed by and ethics committee before they can proceed. This proposal was reviewed by Camden and Islington NHS Research Ethics Committee.

Thank you for reading this information sheet. Please contact the research team at the above address or number if you would like any further information. (Please mark written correspondence for the attention of the research team).

Yours Sincerely

Juanita Hoe
Clinical Research Nurse

Study Number:

CRF No.____________ **Centre No.**_______________

Patient Identification Number for this trial: _______________

CARER/RELATIVE CONSENT FORM

Title: A longitudinal study in people with memory difficulties

Name of Researcher: ________________

	Please initial box
4. I confirm that I have read and understand the information sheet dated.................. for the above study and have had the opportunity to ask questions.	☐
5. 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.	☐
6. I agree to take part in the above study	☐

Name of Carer:	Date	Signature
Name of Person taking consent (if different from researcher)	Date	Signature
Researcher	Date	Signature

Royal Free & University College Medical School
UNIVERSITY COLLEGE LONDON

DEPARTMENT OF MENTAL HEALTH SCIENCES

Juanita Hoe, Research Nurse
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UCL – Department of Mental Health Sciences
Holborn Union Building - Archway Campus
Highgate Hill, London N19 5LW

Email j.hoe@ucl.ac.uk

Direct Line: 020 7288 5931

Insert Date

GENERAL PRACTITIONER INFORMATION SHEET

Title: A longitudinal study in people with memory difficulties

Dear Dr *Insert Name*

Insert Name (Dob *insert*) has been invited and consented to take part in a research study. Please let us know if there is anything that is not clear or if you would like more information.

Prof Katona and Juanita Hoe run this project from North Essex Mental Health Partnership Trust .

This study aims to describe the characteristics and difficulties of people with memory problems any change over six months and the effects of any changes. This is in order to know which aspects matter most in people's lives. This information may also help in designing and developing new medicines for these problems.

We are particularly interested in studying people who may have Alzheimer's Disease. We would also want to see your patient again after six months to ask some of the same questions again.

The interviews will be about:

- Personal details (age, relationship, educational level, etc.)
- quality-of-life
- Use of services
- Difficulties your patient's caregiver may experience

The study does **not** involve any new treatments or affect your patient's current or future treatment.

The results of this study are expected to be published in relevant conferences and journals. All interviews are confidential and will not be disclosed to anyone else. The information collected in the study will be anonymised but may be seen by Lundbeck Pharmaceuticals, the funders of the study. Patients will not be identified in any report/publication.

All proposals for research using human subjects are reviewed by the local Ethics Committee before they can proceed

Thank you for reading this. Please contact Prof Katona at the above address or number if you would like further information.

Yours Sincerely

Juanita Hoe
Clinical Research Nurse

Camden and Islington NHS
Mental Health and Social Care Trust

THE NEEDS OF OLDER PEOPLE WITH MEMORY PROBLEMS, LIVING IN RESIDENTIAL CARE

Information Sheet

This project looks at the needs of older people with memory problems. It takes place in a number of residential homes in London, Essex, Manchester and North Wales. We are hoping to find how best to meet the needs of older people 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 asking about your needs, problems and quality of life. In stage one, all the people in the study will have their needs carefully assessed. In stage two, the residential homes will be randomly divided into two groups, the intervention group and the no intervention group. For the homes in the intervention group we will produce a written description of your needs and help for those needs. The no intervention group of homes will not receive any extra help or feedback about your needs unless it is very urgent that they be told. You will have a 1 in 2 chance of being in a home in the intervention group. All residents in the home will continue to receive their normal health care. After six months we will come back to check your needs again and see how you are.

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 Dr. Martin Orrell or Juanita Hoe.

Contact:
Martin Orrell Tel:
Juanita Hoe, Clinical Research Nurse
Department of Psychiatry and Behavioural Sciences
University College London, Wolfson Building, 48 Riding House Street
London, W1N 8AA
Phone:
Email:

Camden and Islington NHS
Mental Health and Social Care Trust

Centre Number:
Study Number:
Patient Identification Number for this trial:

CONSENT FORM

Title of Project: **THE NEEDS OF OLDER PEOPLE WITH MEMORY PROBLEMS LIVING IN RESIDENTIAL CARE.**

Name of Researcher: **JUANITA HOE**

Please initial

1. I confirm that I have read and understand the information sheet 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 understand that sections of any of my medical notes may be looked at by responsible individuals from Camden and Islington NHS Trust or from regulatory authorities where it is relevant to my taking part in research. I give permission for these individuals to have access to my records.

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

------------------------	--------------------	----------------------------
Name of Patient	*Date*	*Signature*
------------------------	--------------------	----------------------------
Name of Person taking consent (if different from researcher)	*Date*	*Signature*
------------------------	--------------------	----------------------------
Researcher	*Date*	*Signature*

1 for patient; 1 for researcher; 1 to be kept with home notes

Camden and Islington NHS
Mental Health and Social Care Trust

THE NEEDS OF OLDER PEOPLE WITH MEMORY PROBLEMS, LIVING IN RESIDENTIAL CARE

Carers Information Sheet

This project looks at the needs of older people with memory problems. It takes place in a number of residential homes in London, Essex, Manchester and North Wales. We are hoping to find how best to meet the needs of older people with memory problems. We would like to invite you to participate in our project.

We would like to interview you for about 30 minutes, using standard forms. We will ask you about any difficulties you may have had coping, your quality of life, your needs and the needs of your relative. In stage one, all the people in the study will have their needs carefully assessed. In stage two, the residential homes will be randomly divided into two groups, the intervention group and the no intervention group. For the homes in the intervention group we will produce a written description of your needs and help for those needs. The no intervention group of homes will not receive any extra help or feedback about your needs unless it is very urgent that they be told. You will have a 1 in 2 chance of being in a home in the intervention group. All residents in the home will continue to receive their normal health care. After six months we will come back to check your relative's needs again and see how you are.

Taking part is your choice, and if you do not it will not affect your relative's treatment in any way. You or your relative can leave the project at any time, without having to explain why. You cannot give consent on behalf of your relative but can express an opinion as to whether or not you feel they would have wanted to take part in this research. 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 Dr. Martin Orrell or Juanita Hoe.

Contact: **Martin Orrell**
Juanita Hoe, Clinical Research Nurse
Department of Psychiatry and Behavioural Sciences
University College London, Wolfson Building,
48 Riding House Street
London. W1N 8AA
Phone:
email:

Camden and Islington NHS
Mental Health and Social Care Trust

Centre Number:
Study Number:
Patient Identification Number for this trial:

CARER CONSENT FORM

Title of Project: **THE NEEDS OF OLDER PEOPLE WITH MEMORY PROBLEMS LIVING IN RESIDENTIAL CARE.**

Name of Researcher: **JUANITA HOE**

Please initial

1. I confirm that I have read and understand the information sheet 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.

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

------------------------	--------------------	----------------------------
Name of Carer	*Date*	*Signature*
------------------------	--------------------	----------------------------
Name of Person taking consent *(if different from researcher)*	*Date*	*Signature*
------------------------	--------------------	----------------------------
Researcher	*Date*	*Signature*

1 for carer; 1 for researcher; 1 to be kept with home notes

Royal Free & University College Medical School
UNIVERSITY COLLEGE LONDON

DEPARTMENT OF MENTAL HEALTH SCIENCES

Juanita Hoe, Research Nurse
Royal Free & University College London Medical School
UCL – Department of Mental Health Sciences
Wolfson Building - Bloomsbury Campus
48 Riding House Street,
London W1N 8AA

Email j.hoe@ucl.ac.uk

Direct Line: 020 7679 9420

Insert Date

THE NEEDS OF OLDER PEOPLE WITH MEMORY PROBLEMS, LIVING IN RESIDENTIAL CARE

Information Sheet for Primary Care Teams

This project looks at the needs of older people with memory problems. It takes place in a number of residential homes in London, Essex, Manchester and North Wales. We are hoping to find how best to meet the needs of older people with memory problems. *insert names from insert name Residential Home* are patients in your primary care practice and have agreed to participate in this research.

Taking part involves being interviewed for about 45 minutes, using standard forms asking about this person's needs, problems and quality of life. In stage one, all the people in the study will have their needs carefully assessed. In stage two, the residential homes will be randomly divided into two groups, the intervention group and the no intervention group. For the homes in the intervention group we will produce a written description of this individual's needs and help for those needs. The no intervention group of homes will not receive any extra help or feedback about residents' needs unless it is very urgent that they be told. Participants will have a 1 in 2 chance of being in an intervention group home. All residents in the no intervention homes will continue to receive their normal health care. After three months we will come back to check on the individual's needs again. At this stage, all participants will receive feedback regarding their needs.

Taking part is each person's choice, and if they do not it will not affect their treatment in any way. They can leave the project at any time, without having to explain why. Information obtained from interviews is confidential. If you have any concerns or questions about this research, please contact Juanita Hoe or Dr. Geraldine Hancock at the address above.

Quality of Life – Alzheimer Disease (QOL-AD)

Instruction: Please Circle the relevant 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:

MINI-MENTAL STATE EXAMINATION (MMSE)

Total score: _______ **/30**

Orientation:

What is the – **year** **season** **date** **day** **month** ? 5 __
Where are we now? – **country** **city/county** **town/borough** **road/street** **number/name of facility** 5 __

Registration:

Ask the patient to repeat and then remember the following three objects:
APPLE TABLE PENNY (allocate one second to say each word and then ask the patient to name all three objects after you have said them.) Give one point for each correct answer given. Make sure that you have repeated them until the patient has clearly heard. Do not prompt any answers. Count the trials and record number of attempts. 3__

Attention and calculation:
Ask the patient to begin with 100 hundred and count backwards removing 7 from the total each time and stop after 5 answers i.e. 93, 86, 79, 72, 65.
Score one point for each correct answer. It is fine to repeat the instruction whilst the patient is completing the task.
If the patient refuses to perform this task, ask them to spell the word **WORLD** backwards i.e. **DLROW**. Record the patient's spelling _____________ 5__

Recall:
Ask the patient to recall the three items that they were previously asked to remember (see registration section). Give one point for each correct answer given. Do not prompt any answers. **APPLE TABLE PENNY** 3 __

Language:

Naming:
Show the patient a **pencil** and then a **wristwatch** and ask the patient to name them. Do not prompt and do not accept descriptions e.g. a writer or a time-teller. Score one point for each correct answer. 2 __

Repetition:
Speak slowly and clearly and ask the patient to repeat the following saying,
"no ifs ands or buts" 1 __

Three stage command:
Ask the patient to listen carefully and then to follow the following task. "Please take this paper in your **right hand**....**fold it in half**......and then **place it on the table**. Score one point for each correct performance. Once the task has commenced do not prompt. 3 __

Reading:
Show the patient the second sheet and ask them to read the top line (close your eyes) and follow the task. Score 1 point only if they complete both instructions. 1 __

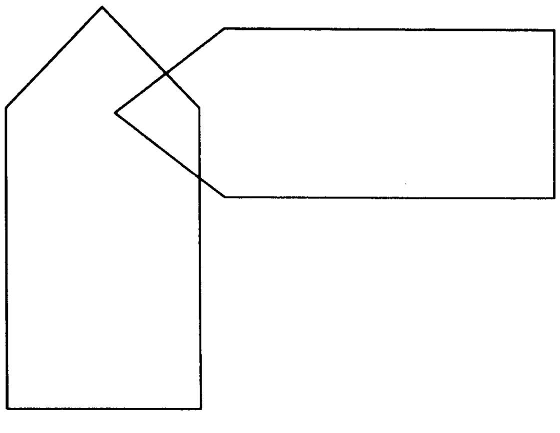
Writing:
Ask the patient to write any sentence they like on the second sheet. Score only if the sentence makes grammatical sense. 1 __

Copying:
Ask the patient to copy the intersecting pentagon design on the second page. 1 __

CLOSE YOUR EYES

Please write a sentence below:

Please copy the diagram below:



CORNELL SCALE FOR DEPRESSION IN DEMENTIA

Informant used: yes ☐ No ☐

	INFORMANT				PATIENT				RATER'S OPINION			
A. MOOD RELATED SIGNS												
1. **Anxiety** Anxious expression, ruminations, worrying	0	1	2	99	0	1	2	99	0	1	2	99
2. **Sadness** Sad expression, sad voice, tearfulness	0	1	2	99	0	1	2	99	0	1	2	99
3. **Lack of reactivity to pleasant events**	0	1	2	99	0	1	2	99	0	1	2	99
4. **Irritability** Easily annoyed, short tempered	0	1	2	99	0	1	2	99	0	1	2	99
B. BEHAVIOURAL DISTURBANCE												
5. **Agitation** Restlessness, handwringing, hairpulling	0	1	2	99	0	1	2	99	0	1	2	99
6. **Retardation** Slow movements, slow speech, slow reactions	0	1	2	99	0	1	2	99	0	1	2	99
7. **Multiple physical complaints** (score 0 if GI symptoms only)	0	1	2	99	0	1	2	99	0	1	2	99
8. **Loss of interest** less involved in usual activities (score only if change occurred acutely i.e.: in less than 1 month)	0	1	2	99	0	1	2	99	0	1	2	99
C. PHYSICAL SIGNS												
9. **Appetite loss** Eating less than usual	0	1	2	99	0	1	2	99	0	1	2	99
10. **Weight loss** (Score 2 if greater than 5 lbs. in 1 month)	0	1	2	99	0	1	2	99	0	1	2	99
11. **Lack of energy** Fatigues easily, unable to sustain activities (score only if change occurred acutely i.e.: in less than 1 month)	0	1	2	99	0	1	2	99	0	1	2	99
D. CYCLIC FUNCTIONS												
12. **Diurnal variation of mood** Symptoms worse in the morning	0	1	2	99	0	1	2	99	0	1	2	99
13. **Difficulty falling asleep** Later than usual for this individual	0	1	2	99	0	1	2	99	0	1	2	99
14. **Multiple awakenings during sleep**	0	1	2	99	0	1	2	99	0	1	2	99
15. **Early morning awakenings** Early than usual for this individual	0	1	2	99	0	1	2	99	0	1	2	99
E. IDEATIONAL DISTURBANCE												
16. **Suicide** Feels like is not worth living, has suicidal wishes, or make suicide attempt	0	1	2	99	0	1	2	99	0	1	2	99
17. **Self-depreciation** Self-blame, poor self esteem, feelings of failure	0	1	2	99	0	1	2	99	0	1	2	99
18. **Pessimism** Anticipation of the worst	0	1	2	99	0	1	2	99	0	1	2	99
19. **Mood congruent delusions** Delusions of poverty, illness, or loss	0	1	2	99	0	1	2	99	0	1	2	99

Health Status Questionnaire – 12 Item

Instructions: Circle one number per question only.

1. In general, would you say your health is:

Excellent	1
Very good	2
Good	3
Fair	4
Poor	5

The following questions are about activities you might do during a typical day. Does your health now limit you in these activities? If so, how much?

ACTIVITIES	**Yes, Limited A Lot**	**Yes, Limited A Little**	**No, Not Limited At All**
2. Lifting or carrying groceries	1	2	3
3. Climbing several flights of stairs	1	2	3
4. Walking several blocks	1	2	3

5. During the past 4 weeks, how much difficulty did you have doing your work or other daily regular activities as a result of your physical health?

Not at all	1
A little bit	2
Some	3
Quite a bit	4
Could not do daily work	5

6. During the past 4 weeks, to what extent have you accomplished less than you would like in your work or other daily activities as a result of emotional problems (such as feeling depressed or anxious)?

Not at all	1
Slightly	2
Moderately	3
Quite a bit	4
Extremely	5

7. During the past 4 weeks, to what extent has your physical health or emotional problems interfered with your normal social activities with family, friends, neighbours, or groups?

Not at all	1
Slightly	2
Moderately	3
Quite a bit	4
Extremely	5

8. How much bodily pain have you had during the past 4 weeks?

None	1
Very mild	2
Mild	3
Moderate	4
Severe	5
Very severe	6

These questions are about how you feel and how things have been with you during the past 4 weeks. For each question, please give the one answer that comes closest to the way you have been feeling. How much of the time during the past 4 weeks:

(Circle one number on each line)

	All of the Time	Most of the Time	A Good Bit of the Time	Some of the Time	A Little of the Time	None of the Time
9. Have you felt calm and peaceful?	1	2	3	4	5	6
10. Did you have a lot of energy?	1	2	3	4	5	6
11. Have you felt downhearted and blue?	1	2	3	4	5	6
12. Have you been a happy person?	1	2	3	4	5	6

Neuropsychiatric Inventory (NPI-D)

A. Delusions

Does the patient have beliefs that you know are not true? For example, insisting that people are trying to harm him/her or steal from him/her. Has he/she said the family members are not who they say they are or that the house is not their home? I'm not asking about mere suspiciousness, I am interested if the patient is convinced that these things are happening to him/her.

☐ not applicable ☐ no (proceed to next screening question) ☐ yes (proceed to subquestions)

☐ 1. does the patient believe that he/she is in danger – that others are planning to hurt him/her?

☐ 2. does the patient believe that others are stealing from him/her?

☐ 3. does the patient believe that his/her spouse is having an affair?

☐ 4. does the patient believe that unwelcome guests are living in his/her house?

☐ 5. does the patient believe that his/her spouse or others are not who they claim to be?

☐ 6. does the patient believe that his/her house is not his/her home?

☐ 7. does the patient believe that family members plan to abandon him/her?

☐ 8. does the patient believe that television or magazine figures are actually present in the home? (does he/she try to talk or interact with them?)

☐ 9. does the patient believe any other unusual things that I haven't asked about?

A-Frequency:
☐1 occasionally – less than once per week
☐2 often – about once per week
☐3 frequently – several times per week but less than every day
☐4 very frequently – once or more per day

B-Severity:
☐1 mild – delusions present but seem harmless and produce little distress in the patient
☐2 moderate – delusions are distressing and disruptive
☐3 marked – delusions are very disruptive and are a major source of behavioural disruption (if PRN medications are prescribed, their use signals that the delusions are of marked severity)

C-Distress: How emotionally distressing do you find this behaviour?
☐0 not at all
☐1 minimally
☐2 mildly
☐3 moderately
☐4 severely
☐5 very severely or extremely

B. Hallucinations

Does the patient have hallucinations such as false visions or voices? Does he/she seem to see, hear or experience things that are not present? By this question we do not mean just mistaken beliefs such as stating that someone who has died is still alive, rather we are asking if the patient actually has abnormal experiences of sounds, or visions.

☐ not applicable ☐ no (proceed to next screening question) ☐ yes (proceed to subquestions)

☐ 1. does the patient describe hearing voices or act as if he/she hears voices?

☐ 2. does the patient talk to people who are not there?

☐ 3. does the patient describe seeing things not seen by others or behave as if he/she is seeing things not seen by others (people, animals, lights etc)?

☐ 4. does the patient report smelling odours not smelled by others?

☐ 5. does the patient describe feeling things on his/her skin or otherwise appear to be feeling things crawling or touching him/her?

☐ 6. does the patient describe tastes that are without any known cause?

☐ 7. does the patient describe any other unusual sensory experience?

A-Frequency:
☐1 occasionally – less than once per week
☐2 often – about once per week
☐3 frequently – several times per week but less than every day
☐4 very frequently – once or more per day

B-Severity:
☐ 1 mild – hallucinations present but seem harmless and cause little distress for the patient
☐ 2 moderate – hallucinations are distressing and are disruptive to the patient
☐ 3 marked – hallucinations are very disruptive and are a major source of behavioural disturbance. PRN medications may be required to control them.

C-Distress: How emotionally distressing do you find this behaviour?
☐0 not at all
☐1 minimally
☐2 mildly
☐3 moderately
☐4 severely
☐5 very severely or extremely

C. Agitation/Aggression

Does the patient have periods when he/she refuses to cooperate or won't let people help him/her? Is he/she hard to handle?

☐ not applicable ☐ no (proceed to next screening question) ☐ yes (proceed to subquestions)

☐ 1. does the patient get upset with those trying to care for him/her or resist activities such as bathing or changing clothes?

☐ 2. is the patient stubborn, having to have things his/her way?

☐ 3. is the patient uncooperative, resistive to help from others?

☐ 4. does the patient have any other behaviours that make him/her hard to handle?

☐ 5. does the patient shout or curse angrily?

☐ 6. does the patient slam doors, kick furniture, throw things?

☐ 7. does the patient attempt to hurt or hit others?

☐ 8. does the patient have any other aggressive or agitated behaviours?

A-Frequency:
☐1 occasionally – less than once per week
☐2 often – about once per week
☐3 frequently – several times per week but less than every day
☐4 very frequently – once or more per day

B-Severity:
☐1 mild – behaviour is disruptive but can be managed with redirection or reassurance
☐2 moderate – behaviours disruptive and difficult to redirect or control
☐3 marked – agitation is very disruptive and difficult to redirect or control; there may be a threat of personal harm. Medications are often required

C-Distress: How emotionally distressing do you find this behaviour?
☐0 not at all
☐1 minimally
☐2 mildly
☐3 moderately
☐4 severely
☐5 very severely or extremely

D. Depression/Dysphoria

Does the patient seem sad or depressed? Does he/she say that he/she feels sad or depressed?

☐ not applicable ☐ no (proceed to next screening question) ☐ yes (proceed to subquestions)

☐ 1. does the patient have periods of tearfulness or sobbing that seem to indicate sadness?

☐ 2. does the patient say or act as if he/she is sad or in low spirits?

☐ 3. does the patient put him/herself down or say that he/she feels like a failure?

☐ 4. does the patient say that he/she is a bad person or deserves to be punished?

☐ 5. does the patient seem very discouraged or say that he/she has no future?

☐ 6. does the patient say he/she is a burden to the family or that the family would be better off without him/her?

☐ 7. does the patient express a wish for death or talk about killing him/herself?

☐ 8. does the patient show any other signs of depression or sadness?

A-Frequency:
☐1 occasionally – less than once per week
☐2 often – about once per week
☐3 frequently – several times per week but less than every day
☐4 very frequently – essentially continuously present

B-Severity:
☐1 mild – depression is present but usually responds to redirection or reassurance
☐2 moderate – depression is distressing, depressive symptoms are spontaneously voiced by the patient and difficult to alleviate
☐3 marked – depression is very distressing and a major source of suffering for the patient

C-Distress: How emotionally distressing do you find this behaviour?
☐0 not at all
☐1 minimally
☐2 mildly
☐3 moderately
☐4 severely
☐5 very severely or extremely

E. Anxiety

Is the patient very nervous, worried or frightened for no apparent reason? Does he/she seem very tense or fidgety? Is the patient afraid to be apart from you?

☐ not applicable ☐ no (proceed to next screening question) ☐ yes (proceed to subquestions)

☐ 1. does the patient say that he/she is worried about planned events?

☐ 2. does the patient have periods of feeling shaky, unable to relax, or feeling excessively tense?

☐ 3. does the patient have periods of (or complain of) shortness of breath, gasping or sighing for no other reason other than nervousness?

☐ 4. does the patient complain of butterflies in his/her stomach, or of racing or pounding of the heart in association with nervousness? (Symptoms not explained by ill health)

☐ 5. does the patient avoid certain places or situations that make him/her more nervous such as riding in the car, meeting with friends, or being in crowds?

☐ 6. does the patient become nervous and upset when separated from you (or his/her caregiver)? (does he/she cling to you to keep from being separated?)

☐ 7. does the patient show any other signs of anxiety?

A-Frequency:
☐1 occasionally – less than once per week
☐2 often – about once per week
☐3 frequently – several times per week but less than every day
☐4 very frequently – once or more per day

B-Severity:
☐1 mild – anxiety is distressing but usually responds to redirection or reassurance
☐2 moderate – anxiety is distressing, anxiety symptoms are spontaneously voiced by the patient and difficult to alleviate
☐3 marked – anxiety is very distressing and a major source of suffering for the patient

C-Distress: How emotionally distressing do you find this behaviour?
☐0 not at all
☐1 minimally
☐2 mildly
☐3 moderately
☐4 severely
☐5 very severely or extremely

F. Elation/Euphoria

Does the patient seem to be too cheerful or too happy for no reason? I don't mean the normal happiness that comes from seeing friends, receiving presents, or spending time with family members. I am asking if the patient has a persistent and abnormally good mood or finds humour where others do not.

☐ not applicable ☐ no (proceed to next screening question) ☐ yes (proceed to subquestions)

☐ 1. does the patient appear to feel too good or to be too happy, different from his/her usual self?

☐ 2. does the patient find humour and laugh at things that others do not find funny?

☐ 3. does the patient seem to have a childish sense of humour with a tendency to giggle or laugh inappropriately (such as when unfortunate things happens to others)?

☐ 4. does the patient tell jokes or make remarks that have little humour for others but seem funny to him/her?

☐ 5. does he/she play childish pranks such as pinking or playing "keep away" for the fun of it?

☐ 6. does the patient "talk big" or claim to have more abilities or wealth than is true?

☐ 7. does the patient show any other signs of feeling too good or being too happy?

A-Frequency:
☐1 occasionally – less than once per week
☐2 often – about once per week
☐3 frequently – several times per week but less than every day
☐4 very frequently – essentially continuously present

B-Severity:
☐1 mild – elation is notable to friends and family but is not disruptive
☐2 moderate – elation is notably abnormal
☐3 marked – elation is very pronounced, patient is euphoric and finds nearly everything to be humourous

C-Distress: How emotionally distressing do you find this behaviour?
☐0 not at all
☐1 minimally
☐2 mildly
☐3 moderately
☐4 severely
☐5 very severely or extremely

G. Apathy/Indifference

Has the patient lost interest in the world around him/her? Has he/she lost interest in doing things or lack motivation for starting new activities? Is he/she more difficult to engage in conversation or in doing chores? Is the patient apathetic or indifferent?

☐ not applicable ☐ no (proceed to next screening question) ☐ yes (proceed to subquestions)

☐ 1. does the patient seem less spontaneous and less active than usual?

☐ 2. is the patient less likely to initiate a conversation?

☐ 3. is the patient less affectionate or lacking in emotions when compared to his/her usual self?

☐ 4. does the patient contribute less to household chores?

☐ 5. does the patient seem less interested in the activities and plans of others?

☐ 6. has the patient lost interest in friends and family members?

☐ 7. is the patient less enthusiastic about his/her usual interests?

☐ 8. does the patient show any other signs that she doesn't care about doing new things?

A-Frequency:
☐1 occasionally – less than once per week
☐2 often – about once per week
☐3 frequently – several times per week but less than every day
☐4 very frequently – nearly always present

B-Severity:
☐1 mild – apathy is notable but produces little interference with daily routines; only mildly different from patient's usual behaviour; patient responds to suggestion to engage in activities
☐2 moderate – apathy is very evident; may be overcome by the caregiver with coaxing and encouragement; responds spontaneously only to powerful events such as visits from close relatives or family members
☐3 marked – apathy is very evident and usually fails to respond to any encouragement or external events

C-Distress: How emotionally distressing do you find this behaviour?
☐0 not at all
☐1 minimally
☐2 mildly
☐3 moderately
☐4 severely
☐5 very severely or extremely

H. Disinhibition

Does the patient seem to act impulsively without thinking? Does he/she do or say things that are not usually done or said in public? Does he/she do things that are embarrassing to you or others?

☐ not applicable ☐ no (proceed to next screening question) ☐ yes (proceed to subquestions)

☐ 1. does the patient act impulsively without appearing to consider the consequences?

☐ 2. does the patient talk to total strangers as if he/she knew them?

☐ 3. does the patient say things to people that are insensitive or hurt their feelings?

☐ 4. does the patient say crude things or make sexual remarks that they would not usually have said?

☐ 5. does the patient talk openly about very personal or private matters not usually discussed in public?

☐ 6. does the patient take liberties or touch or hug others in a way that is out of character for him/her?

☐ 7. does the patient show any other signs of loss of control of his/her impulses?

A-Frequency:
☐1 occasionally – less than once per week
☐2 often – about once per week
☐3 frequently – several times per week but less than every day
☐4 very frequently – essentially continuously present

B-Severity:
☐1 mild – disinhibition is notable but usually responds to redirection and guidance
☐2 moderate – disinhibition is very evident and difficult to overcome by the caregiver
☐3 marked – disinhibition usually fails to respond to any intervention by the caregiver, and is a source of embarrassment or social distress

C-Distress: How emotionally distressing do you find this behaviour?
☐0 not at all
☐1 minimally
☐2 mildly
☐3 moderately
☐4 severely
☐5 very severely or extremely

I. Irritability/Lability

Does the patient get irritated and easily disturbed? Are his/her moods very changeable? Is he/she abnormally impatient? We do not mean frustration over memory loss or inability to perform usual tasks; we are interested to know if the patient has abnormal irritability, impatience, or rapid emotional changes different from his/her usual self.

☐ not applicable ☐ no (proceed to next screening question) ☐ yes (proceed to subquestions)

☐ 1. does the patient have a bad temper, flying "off the handle" easily over little things?

☐ 2. does the patient rapidly change moods from one to another, being fine one minute and angry the next?

☐ 3. does the patient have sudden flashes of anger?

☐ 4. is the patient impatient, having trouble coping with delays or waiting for planned activities?

☐ 5. is the patient cranky and irritable?

☐ 6. is the patient argumentative and difficult to get along with?

☐ 7. does the patient show any other signs of irritability?

A-Frequency:
☐1 occasionally – less than once per week
☐2 often – about once per week
☐3 frequently – several times per week but less than every day
☐4 very frequently – essentially continuously present

B-Severity:
☐1 mild – irritability or lability is notable but usually responds to redirection and reassurance
☐2 moderate – irritability and lability are very evident and difficult to overcome by the caregiver
☐3 marked – irritability and lability are very evident, they usually fail to respond to any intervention by the caregiver, and they are a major sources of distress

C-Distress: How emotionally distressing do you find this behaviour?
☐0 not at all
☐1 minimally
☐2 mildly
☐3 moderately
☐4 severely
☐5 very severely or extremely

J. Aberrant motor behaviour

Does the patient pace, do things over and over such as opening closets or drawers, or repeatedly pick at things or wind string or threads?

☐ not applicable ☐ no (proceed to next screening question) ☐ yes (proceed to subquestions)

☐ 1. does the patient pace around the house without any apparent purpose?

☐ 2. does the patient rummage around opening and unpacking drawers or closets?

☐ 3. does the patient repeatedly put on and take off clothing?

☐ 4. does the patient have repetitive activities or "habits" that he/she performs over and over?

☐ 5. does the patient engage in repetitive activities such as handling buttons, picking, wrapping string, etc.?

☐ 6. does the patient fidget excessively, seem unable to sit still, or bounce his/her feet or tap his/her fingers a lot?

☐ 7. does the patient do any other activities over and over?

A-Frequency:
☐1 occasionally – less than once per week
☐2 often – about once per week
☐3 frequently – several times per week but less than every day
☐4 very frequently – essentially continuously present

B-Severity:
☐1 mild – abnormal motor activity is notable but produces little interference with daily routines
☐2 moderate – abnormal motor activity is very evident; can be overcome by the caregiver
☐3 marked – abnormal motor activity is very evident, it usually fails to respond to any intervention by the caregiver and is a major source of distress

C-Distress: How emotionally distressing do you find this behaviour?
☐0 not at all
☐1 minimally
☐2 mildly
☐3 moderately
☐4 severely
☐5 very severely or extremely

K. Sleep

Does the patient have difficulty sleeping (do not count as present if the patient simply gets up once or twice per night only to go to the bathroom and falls back asleep immediately)? Is he/she up at night? Does he/she wander at night, get dressed or disturb your sleep?

☐ not applicable ☐ no (proceed to next screening question) ☐ yes (proceed to subquestions)

☐ 1. does the patient have difficulty falling asleep?

☐ 2. does the patient get up during the night (do not count if the patient simply gets up once or twice per night only to go to the bathroom and falls back asleep immediately)?

☐ 3. does the patient wander, pace or get involved in inappropriate activities at night?

☐ 4. does the patient awaken you during the night?

☐ 5. does the patient awaken during the night, dress and plan to go out, thinking that it is morning and time to start the day?

☐ 6. does the patient awaken too early in the morning (earlier that was his/her habit)?

☐ 7. does the patient sleep excessively during the day?

☐ 8. does the patient have any other night-time behaviours that bother you that we haven't talked about?

A-Frequency:
☐1 occasionally – less than once per week
☐2 often – about once per week
☐3 frequently – several times per week but less than every day
☐4 very frequently – once or more per day

B-Severity:
☐1 mild – night-time behaviours occur but they are not particularly disruptive
☐2 moderate – night-time behaviours occur and disturb the patient and the sleep of the caregiver; more than one type of night-time behaviour may be present
☐3 marked – night-time behaviours occur; several types of night-time behaviour may be present; the patient is very distressed during the night and the caregiver's sleep is markedly disturbed

C-Distress: How emotionally distressing do you find this behaviour?
☐0 not at all
☐1 minimally
☐2 mildly
☐3 moderately
☐4 severely
☐5 very severely or extremely

L. Appetite and eating disorders

Has he/she had any change in appetite, weight, or eating habits (count as NA if the patient is incapacitated and has to be fed)? Has there been any change in type of food he/she prefers?

☐ not applicable ☐ no (proceed to next screening question) ☐ yes (proceed to subquestions)

☐ 1. has he/she had a loss of appetite?

☐ 2. has he/she had an increase in appetite?

☐ 3. has he/she had a loss of weight?

☐ 4. has he/she gained weight?

☐ 5. has he/she had a change in eating behaviour such as putting too much food in his/her mouth at once?

☐ 6. has he/she had a change in the kind of food he/she likes such as eating too many sweets or other specific types of food?

☐ 7. has he/she developed eating behaviours such as eating exactly the same types of food each day or eating the food in exactly the same order?

☐ 8. Have there been any other changes in appetite or eating that I haven't asked about?

A-Frequency:
☐1 occasionally – less than once per week
☐2 often – about once per week
☐3 frequently – several times per week but less than every day
☐4 very frequently – once or more per day

B-Severity:
☐1 mild – changes in appetite or eating are present but have not led to changes in weight and are not disturbing
☐2 moderate – changes in appetite or eating are present and cause minor fluctuations in weight
☐3 marked – obvious changes in appetite or eating are present and cause fluctuations in weight, are embarrassing, or otherwise disturb the patient

C-Distress: How emotionally distressing do you find this behaviour?
☐0 not at all
☐1 minimally
☐2 mildly
☐3 moderately
☐4 severely
☐5 very severely or extremely

NPI-D

Item	N.Ap[†]	Absent[†]	Frequency*	Severity*	F*S	Distress*
Delusion	☐	☐	1 2 3 4	1 2 3	☐☐	0 1 2 3 4 5
Hallucination	☐	☐	1 2 3 4	1 2 3	☐☐	0 1 2 3 4 5
Agitation	☐	☐	1 2 3 4	1 2 3	☐☐	0 1 2 3 4 5
Depression / dysphoria	☐	☐	1 2 3 4	1 2 3	☐☐	0 1 2 3 4 5
Anxiety	☐	☐	1 2 3 4	1 2 3	☐☐	0 1 2 3 4 5
Euphoria/elation	☐	☐	1 2 3 4	1 2 3	☐☐	0 1 2 3 4 5
Apathy/indifference	☐	☐	1 2 3 4	1 2 3	☐☐	0 1 2 3 4 5
Disinhibition	☐	☐	1 2 3 4	1 2 3	☐☐	0 1 2 3 4 5
Irritability/lability	☐	☐	1 2 3 4	1 2 3	☐☐	0 1 2 3 4 5
Aberrant motor behaviour	☐	☐	1 2 3 4	1 2 3	☐☐	0 1 2 3 4 5
Night-time behaviour	☐	☐	1 2 3 4	1 2 3	☐☐	0 1 2 3 4 5
Appetite/Eating change	☐	☐	1 2 3 4	1 2 3	☐☐	0 1 2 3 4 5

[†] Please tick when relevant; then do not complete the following corresponding numbered items (frequency, severity, F*S, and distress).

* Please circle the right answer; one answer only by domain.

Alzheimer's disease Co-operative Study – Activities of Daily Living Inventory (ADCS-ADL)

1. **Regarding eating, which best describes the patient's usual performance during the past 4 weeks?**

Ate without physical help, and used a knife	**3**
Used a fork or a spoon, but not a knife, to eat	**2**
Used fingers to eat	**1**
Usually or always was fed by someone else	**0**

2. **Regarding walking (or getting around with a wheelchair) in the past 4 weeks, which best describes the patient's performances?**

Mobile outside of home without physical help	**3**
Mobile across room without physical help	**2**
Transferred from bed to chair without help	**1**
Required physical help to walk or transfer	**0**

3. **Regarding bowel and bladder function <u>at the toilet</u>, which best describes the patient's usual performance in the past 4 weeks?**

Did everything necessary without supervision or help	**3**
Needed supervision, but no physical help	**2**
Needed physical help, and was usually continent	**1**
Needed physical help, and was usually incontinent	**0**

4. **Regarding <u>bathing</u>, in the past 4 weeks, which best describes the patient's <u>usual</u> performances?**

Bathed without reminding or physical help	**3**
No physical help, but needed supervision/reminders to bathe completely	**2**
Needed minor physical help (e.g. washing hair) to bathe completely	**1**
Needed to be bathed completely	**0**

5. Regarding grooming, in the past 4 weeks, which best describes the patient's optimal performance?

Cleaned and cut fingernails without physical help	**3**
Brushed and combed hair without physical help	**2**
Kept face and hands clean without physical help	**1**
Needed help for grooming of hair, face, hands and fingernails	**0**

6. Regarding dressing in the past 4 weeks:

6.A. Did the patient select his/her first set of clothes for the day?

No	**0**
Don't know	**0**

If yes: which best describes his/her usual performance?

Without supervision or help	**3**
With supervision	**2**
With physical help	**1**

6.B. Regarding physical getting dressed, which best describes the patient's usual performance in the past 4 weeks?

Dressed completely without supervision or physical help	**4**
Dressed completely with supervision but without help	**3**
Needed physical help only for buttons, clasps or shoelaces	**2**
Dressed without help if clothes needed to fastening or buttoning	**1**
Always needed help, regardless of the type of clothing	**0**

7. In the past 4 weeks, did the patient use a telephone?

No	**0**
Don't know	**0**

If yes: which best describes the patient's highest level of performance?

Made calls after looking up numbers in white or yellow pages, or by dialling directory assistance	**5**
Made calls to only well-known numbers, without referring to a directory or list	**4**
Made calls to only well-known numbers, by using a directory or list	**3**
Answered the phone; did not make calls	**2**
Did not answer the phone but spoke when put on the line	**1**

8. In the past 4 weeks, did the patient watch television?

No	**0**
Don't know	**0**

If yes: ask all following questions:

8.A. Usually select or ask for different programs or his/her favourite show?

Yes	**1**
No	**0**
Don't know	**0**

8.B. Usually talk about the content of a program while watching it?

Yes	**1**
No	**0**
Don't know	**0**

8.C. Talk about the content of a program within a day (24 hours) after watching it?

Yes	**1**
No	**0**
Don't know	**0**

9. In the past 4 weeks, did the patient ever appear to pay attention to conversation or small talk for at least 5 minutes?

(Note: the patient did not need to initiate the conversation)

No	**0**
Don't know	**0**

If yes: which best describes his/her usual degree of participation?

Usually said things that were related to the topic	**3**
Usually said things that were not related to the topic	**2**
Rarely or never spoke	**1**

10. Did the patient clear the dishes from the table after a meal or snack?

No	**0**
Don't know	**0**

If yes: which best describes his/her usual performance?

Without supervision or help	**3**
With supervision	**2**
With physical help	**1**

11. In the past 4 weeks, did the patient usually manage to find his/her personal belongings at home?

No	**0**
Don't know	**0**

If yes: which best describes his/her usual performance?

Without supervision or help	**3**
With supervision	**2**
With physical help	**1**

12. In the past 4 weeks, did the patient obtain a hot or cold beverage for him/herself? (a cold beverage includes a glass of water)

No	**0**
Don't know	**0**

If yes: which best describes his/her highest level of performance?

Made a hot beverage, usually without physical help	**3**
Made a hot beverage, usually if someone else heated the water	**2**
Obtained a cold beverage, usually without physical help	**1**

13. In the past 4 weeks, did the patient make him/herself a meal or a snack at home?

No	**0**
Don't know	**0**

If yes: which best describes the patient's highest level of performance?

Cooked or microwaved food, with little or no help	**4**
Cooked or microwaved food, with extensive help	**3**
Mixed or combined food items for a meal or snack, without cooking or microwaving (e.g. made a sandwich)	**2**
Obtained food for his/her own, without mixing or cooking it	**1**

14. In the past 4 weeks, did the patient dispose of garbage or litter in an appropriate place or container at home?

No	**0**
Don't know	**0**

If yes: which best describes how the patient usually performed?

Without supervision or help	**3**
With supervision	**2**
With physical help	**1**

15. In the past 4 weeks, did the patient get around (or travel) outside of his/her home?

No	**0**
Don't know	**0**

If yes: which best describes his/her optimal performance?

Alone, went at least 1 mile away from home	**4**
Alone, but remained within 1 mile of home	**3**
Only when accompanied or supervised, regardless of the trip	**2**
Only with physical help, regardless of the trip	**1**

16. In the past 4 weeks, did the patient ever go shopping?

No	**0**
Don't know	**0**

If yes: ask all following questions:

16.A. Which one best describes how the patient usually selects items?

Without supervision or physical help	**3**
With some supervision or physical help	**2**
Not at all or selected mainly random or inappropriate items	**1**

16.B. Did the patient usually pay for items without supervision or physical help?

Yes	**1**
No	**0**
Don't know	**0**

17. In the past 4 weeks, did the patient keep appointments or meetings with other people, such as relatives, a doctor, the hairdresser, etc?

No	**0**
Don't know	**0**

If yes: which best describes his/her awareness of the meeting ahead on time?

Usually remembered, may have needed written reminders, e.g. notes, a diary, or calendar	**3**
Only remembered the appointment after verbal reminders on the day	**2**
Usually did not remember, in spite of verbal reminders on the day	**1**

18. In the past 4 weeks, was the patient ever left on his/her own ?

No	**0**
Don't know	**0**

If yes: ask all following questions?

18.A. Away from home, for 15 minutes or longer, during the day?

Yes	**1**
No	**0**
Don't know	**0**

18.B. At home, for an hour or longer, during the day?

Yes	**1**
No	**0**
Don't know	**0**

18.C. At home, for less than 1 hour, during the day?

Yes	**1**
No	**0**
Don't know	**0**

19. In the past 4 weeks, did the patient talk about current events?
(this means events or incidents that occurred during the past month)

No	**0**
Don't know	**0**

If yes: ask all following questions:

Did the patient talk about events that:

19.A. he/she heard or read about or saw on TV but did not take part in?

Yes	**1**
No	**0**
Don't know	**0**

19.B. he/she took part in outside home involving family, friends or neighbours?

Yes	**1**
No	**0**
Don't know	**0**

19.C. occurred at home that he/she took part in or watched ?

Yes	**1**
No	**0**
Don't know	**0**

20. In the past 4 weeks, did the patient read a magazine, newspaper or book for more than 5 minutes at a time?

No	**0**
Don't know	**0**

If yes: ask all following questions:

Did the patient usually:

20.A. Talk about details of what he/she read while or shortly (< than 1 hour) after reading?

Yes	**1**
No	**0**
Don't know	**0**

20.B. Talk about what he/she read 1 hour or longer after reading?

Yes	**1**
No	**0**
Don't know	**0**

21. In the past 4 weeks, did the patient ever write anything down?
(Note: if the patient wrote things only after encouragement or with help, the response should still be « yes »)

No	**0**
Don't know	**0**

If yes: which best describes the most complicated things that the patient wrote?

Letters or long notes that other people understood	**3**
Short notes or messages that other people understood	**2**
Patient's signature or name	**1**

22. In the past 4 weeks, did the patient perform a pastime, hobby or game?

No	**0**
Don't know	**0**

If yes: which of the following did the patient perform?

(ask about all of the following, tick all that apply)

card or board games (including bridge, chess, checkers)	☐
bingo	☐
musical instrument	☐
reading	☐
tennis	☐
crosswords	☐
knitting	☐
gardening	☐
workshop	☐
art	☐
sewing	☐
golf	☐
fishing	☐
other: specify	☐

____

Note: Walking does NOT count as a hobby/pastime for this scale

If the patient performs hobbies/pastime only a **day care, check here**: ☐

If yes: how did the patient usually perform his/her most common pastimes?

Without supervision or help	**3**
With supervision	**2**
With help	**1**

23. In the past 4 weeks, did the patient use a household appliance to do chores?

No	**0**
Don't know	**0**

If yes: which of the following?
(tick all that apply)

Washer	☐
Vacuum	☐
Toaster	☐
Range	☐
Food processor	☐
Dryer	☐
Dishwasher	☐
Toaster oven	☐
Other: specify	☐

____

If yes: for the most commonly used appliances, which best describes how the patient usually used them?

Without help, operating more than on-off controls if needed	**4**
Without help, but operated only on-off controls	**3**
With supervision, but no physical help	**2**
With physical help	**1**

HOSPITAL ANXIETY AND DEPRESSION SCALE (HADS)

Read each item and tick the box next to the reply that comes closest to how you have been feeling in the past week.

A **I feel tense or wound up:**

3 ☐ Most of the time

2 ☐ A lot of the time

1 ☐ From time to time, occasionally

0 ☐ Not at all

D **I still enjoy the things I used to enjoy:**

0 ☐ Definitely as much

1 ☐ Not quite so much

2 ☐ Only a little

3 ☐ Hardly at all

A **I get a sort of frightened feeling as if something awful is about to happen:**

3 ☐ Very definitely and quite badly

2 ☐ Yes, but not too badly

1 ☐ A little, but it doesn't worry me

0 ☐ Not at all

HOSPITAL ANXIETY AND DEPRESSION SCALE (HADS)

Read each item and tick the box next to the reply that comes closest to how you have been feeling in the past week.

A **I feel tense or wound up:**

3 ☐ Most of the time

2 ☐ A lot of the time

1 ☐ From time to time, occasionally

0 ☐ Not at all

D **I still enjoy the things I used to enjoy:**

0 ☐ Definitely as much

1 ☐ Not quite so much

2 ☐ Only a little

3 ☐ Hardly at all

A **I get a sort of frightened feeling as if something awful is about to happen:**

3 ☐ Very definitely and quite badly

2 ☐ Yes, but not too badly

1 ☐ A little, but it doesn't worry me

0 ☐ Not at all

D **I can laugh and see the funny side of things:**

0 ☐ As much as I always could
1 ☐ Not quite so much now
2 ☐ Definitely not so much now
3 ☐ Not at all

A **Worrying thoughts go through my mind:**

3 ☐ A great deal of the time
2 ☐ A lot of the time
1 ☐ From time to time but not too often
0 ☐ Only occasionally

D **I feel cheerful:**

3 ☐ Not at all
2 ☐ Not often
1 ☐ Sometimes
0 ☐ Most of the time

A **I can sit at ease and feel relaxed:**

0 ☐ Definitely
1 ☐ Usually
2 ☐ Not often
3 ☐ Not at all

D **I feel as if I am slowed down:**

3 ☐ Nearly all the time

2 ☐ Very often

1 ☐ Sometimes

0 ☐ Not at all

A **I get a sort of frightened feeling like 'butterflies' in the stomach:**

0 ☐ Not at all

1 ☐ Occasionally

2 ☐ Quite often

3 ☐ Very often

D **I have lost interest in my appearance:**

3 ☐ Definitely

2 ☐ I don't take as much care as I should

1 ☐ I may not take quite as much care

0 ☐ I take just as much care as ever

A **I feel restless as if I have to be on the move:**

3 ☐ Very much indeed

2 ☐ Quite a lot

1 ☐ Not very much

0 ☐ Not at all

D **I look forward with enjoyment to things:**

0 ☐ As much as I ever did

1 ☐ Rather less than I used to

2 ☐ Definitely less than I used to

3 ☐ Hardly at all

A **I get sudden feelings of panic:**

3 ☐ Very often indeed

2 ☐ Quite often

1 ☐ Not very often

0 ☐ Not at all

D **I can enjoy a good book or radio or TV programme:**

0 ☐ Often

1 ☐ Sometimes

2 ☐ Not often

3 ☐ Very seldom

For office use only:

D: __________

A: __________

CAMBERWELL ASSESSMENT OF NEED FOR THE ELDERLY

CANE

Version IV

CODE	

Interviewee	Date	Interview Time
User		
Carer		
Staff		
Rater/Clinician		

Background Details

(Please fill in blanks, or circle whichever applies)

CODE NUMBER: ____________________

Date of Birth: _______________ AGE: _______(years)

SEX: male / female

ETHNICITY: Asian/ African/ African-American/ Black Caribbean / White/Other_______

RELIGION: Christian/Muslim/Hindu/Jewish/Other ____________________

FIRST LANGUAGE : English/Other ________________

MARITAL STATUS: single / married / divorced / separated / widowed

LIVING SITUATION: alone / with partner / with other relatives / with others

LIVING ENVIRONMENT: flat / house / sheltered / residential / nursing / other

PREVIOUS OCCUPATION (or partner's): ____________________________

EDUCATION: ____________________(years)

CURRENT STATUS: in-patient / day-patient / community patient (Psychiatric / Geriatric/other)

MAIN DIAGNOSES (DSM-IV/ICD 10): __________________________

____

____

____

CURRENT MEDICATION: ____

____

DISEASE PREVENTION: (e.g. blood pressure/smoking/sleep pattern/exercise/health screening/vaccination)

____

DOES THE PERSON HAVE A CARER? yes / no

IS THE PERSON A CARER? yes / no

Instructions for the CANE

The CANE is a comprehensive, person-centred needs assessment tool that has been designed for use with the elderly. It is suitable for use in a variety of clinical and research settings. The CANE has a person-centred approach which allows views of the professional, user, and carer to be recorded and compared. The instrument uses the principle that identifying a need means identifying a problem plus an appropriate intervention which will help or alleviate the need. Therefore the CANE models clinical practice and relies on professional expertise for ratings to be completed accurately. Professionals using the CANE need to have had training and experience working with older people and an adequate knowledge of clinical interviewing and decision making. They should also have good working knowledge of the concepts of need, met need, and unmet need. This knowledge can be gained with experience of full CANE assessments and reference to the manual.

There are 24 topics relating to the user and two (A & B) relating to the carer. There are four columns to document ratings so that one or more of the user (U), staff member (S), carer (C), or rater (clinician/researcher) (R) can each express their view. Note at the top of the column which person has been interviewed.

SECTION 1:
This section aims to assess whether there is currently a need in the specific area. A need is defined as a problem with a potential remedy or intervention. Use the prompts below each area in *italics* on the record form to establish the user's current status with regards to the need area. If there has been a need then assess whether it was met appropriately. Score each interviewee independently, even though their perceptions of need in each area may differ from one another. The administrator should ask additional questions probing into the area until he/she can establish whether the person has a significant need that requires assistance and whether they are getting enough of the right type of help. Once this information has been gathered a rating of need can be made. Judgement of rating in this section should be based on normal clinical practice. The CANE is intended to be a framework for assessment grounded in good professional practise and expertise. Although Section 1 in each problem area is the main section of interest to CANE administrators, it often can not be rated until adequate information has been collected about the area. Indeed, some administrators have found it easier to rate section 1 once information has been collected from the other sections 2 to 5. When adequate information has been gathered the rater should clearly be able to make a clinical judgement as to whether the area is a met need, an unmet need, or is not a need for the person. Confusion with ratings can be avoided by not directly asking a closed question about whether there is a problem in a certain area (e.g., "Do you have any problems with the food here?") because the person can answer "No". This response may then be mistaken as a 'No Need' where in fact it is a 'Met Need' because the person is assisted by someone else.

- *No Need:* Score 0 there if there is no need in the area then go on to the next page. In this situation the user is coping well independently and does not need any further assistance. For example, the user has reported that they are successfully administering their own medication and do not have any problematic side effects. Or the staff member reports that the user appeared to be comfortable in his/her home environment and that no alterations to the building are needed or planned.

- *Met Need:* Score 1 if the need is met or if there is a minor need requiring no significant intervention. A need is met when there is a mild, moderate or serious problem which is receiving an intervention which is appropriate and potentially of benefit. This category is also used for problems which would normally not be of clinical significance and would not require a specific intervention. For example, the user is receiving an assessment for poor eyesight or a district nurse is overseeing the administration of medications each day.

- *Unmet Need:* Score 2 if the need is currently unmet. An unmet need is a serious problem requiring intervention or assessment, which is currently receiving no assistance or the *wrong* type or level of help. For example, if a staff member reported that the user was incontinent of large amounts of urine every night despite toileting twice during the night and the use of pads and further assessment or an intervention was required. Or a carer reported that the user had become very hard of hearing and had not received an assessment or suitable hearing aids.

- *Unknown:* Score 9 if the person does not know about the nature of the problems or about the assistance the person receives and go on to the next page. Such a score may mean that further information is needed to make a rating.

For any topic if Section 1 is rated as 1 or 2 complete sections 2-4.

If Section 1 for the topic is rated as 0 or 9 do not complete sections 2-4 but go to the next topic area.

SECTION 2:
This section asks about assistance from informal sources during the past month. Informal sources include family, friends or neighbours. Use the examples on the assessment form to prompt the interviewee. Score 1 when assistance is given very occasionally or infrequently. Score 2 when assistance is given more frequently or involves more time/effort. Score 3 when assistance is given daily or is intensive (e.g., long periods of respite). Score 4 when assistance is very intensive and/or daily (e.g., family lives with the user and gives them full assistance with most tasks). Score 9 if the interviewee is unsure of the level of assistance provided.

SECTION 3:
i). This section asks whether the user receives any assistance from local services to help with the problem. These formal supports are defined above to include paid carers, residential care, long-term wards, formal respite, day-care centres, hospitals, community psychiatric nurses or other staff. Use the examples on the assessment form to prompt the interviewee. Score 1 for minimal support, occasional, or light support. Score 2 for more regular assistance, maybe once a week or more significant support occasionally. Score 3 for specialist assistance, currently under assessment or more frequent assistance. Score 9 if the interviewee is unsure of the level of assistance provided.
ii). The second part to Section 3 asks what formal supports the interviewer feels the user *requires*, using the same scale as in (i) of Section 3. This second part indicates under-met need where the person is getting (part i) less than they require (part ii) or over-provision of need, where the person is getting (part i) a higher level of service than they require (part ii).

SECTION 4:
i). This section asks whether the person feels that the user is receiving the right type of help with the problem. The answer to this question may have been obvious from the responses to the previous section, especially section 1. However, if in doubt ask more specifically. As well as highlighting unmet needs, this section can point out over-provision of needs, where the person reported that the user was receiving a higher level of assistance than they required.
ii). The second question in Section 4 asks about the user's satisfaction with the assistance they are receiving. Again this may be obvious from prior responses, but please ask specifically.

SECTION 5:
This section is for noting the individual details of the assessment and the details of the help the user receives and requires (particularly the nature of the unmet needs identified) in order to formulate an action plan. Problems with current interventions or care plans and indicating plans in progress should also be documented in this section. Use codes to document which informant has provided the information (i.e., U = user, S= staff, C = carer, R = rater/professional). User perspectives on their expectations, personal strengths and resources should be noted here. Individual spiritual and cultural information should also be noted in this section. This information is vital for establishing an effective individualised care plan.

SCORING

It is to be noted that scoring is a secondary aspect of the CANE as its primary purpose is to identify and assess individual unmet needs. The total CANE score is based on the rating of section 1 of each of the 24 problem areas. The two areas (A and B) relating to carer's needs are not added into this total score. Count total number of met needs (rated as a 1 in Section 1), out of a maximum 24. Count total number of unmet needs identified (rated as a 2 in Section 1) out of a maximum score 24. Count total number of needs identified (rated as a 1 or 2 in Section 1), out of a maximum 24. The 'Raters' (clinicians or researchers) ratings are made based on all the information gathered through the assessment. Raters ratings of section 1 are used as the basis for total CANE scores.

	ASSESSMENTS user	carer	staff	rater
1. ACCOMMODATION				
DOES THE PERSON HAVE AN APPROPRIATE PLACE TO LIVE?	☐	☐	☐	☐

What kind of home do you live in? Do you have any problems with accommodation?

0 = NO NEED e.g. Has an adequate and appropriate home (even if currently in hospital). No need for assistance with accommodation

1 = MET NEED e.g. Home undergoing adaptation/redecoration. Needs and is getting help with accommodation, e.g., in residential care, sheltered housing.

2 = UNMET NEED e.g. Homeless, inappropriately housed or home lacks basic facilities such as water, electricity, heating or essential alterations.

9 = NOT KNOWN

IF RATED 0 OR 9 GO TO QUESTION 2

	user	carer	staff	rater
HOW MUCH HELP DOES THE PERSON RECEIVE FROM RELATIVES OR FRIENDS WITH THEIR ACCOMMODATION	☐	☐	☐	☐

0 = NONE

1 = LOW HELP e.g. Occasionally does odd jobs concerning accommodation e.g., minor redecorations.

2 = MODERATE HELP e.g. Substantial help with improving accommodation such as organising redecoration or specific adaptations.

3 = HIGH HELP e.g. Living with a relative because own accommodation is unsatisfactory.

9 = NOT KNOWN

	user	carer	staff	rater
HOW MUCH HELP DOES THE PERSON RECEIVE FROM LOCAL SERVICES WITH THEIR ACCOMMODATION?	☐	☐	☐	☐
HOW MUCH HELP DOES THE PERSON NEED FROM LOCAL SERVICES WITH THEIR ACCOMMODATION?	☐	☐	☐	☐

0 = NONE

1 = LOW HELP e.g. Minor redecoration; Referral to housing agency/ assisted housing.

2 = MODERATE HELP e.g. Major improvements; actively pursuing change in accommodation.

3 = HIGH HELP e.g. Being rehoused; living in supported accommodation residential care, nursing home or continuing care hospital ward.

9 = NOT KNOWN

	user	carer	staff	rater
DOES THE PERSON RECEIVE THE RIGHT TYPE OF HELP WITH THEIR ACCOMMODATION (0 = NO 1 = YES 9 = NOT KNOWN)	☐	☐	☐	☐
OVERALL, IS THE PERSON SATISFIED WITH THE AMOUNT OF HELP THEY ARE RECEIVING WITH ACCOMMODATION? (0 = NOT SATISFIED 1 = SATISFIED 9 = NOT KNOWN)	☐			

COMMENTS

2. LOOKING AFTER THE HOME

	ASSESSMENTS user	carer	staff	rater
DOES THE PERSON HAVE DIFFICULTY IN LOOKING AFTER THEIR HOME?	☐	☐	☐	☐

Are you able to look after your home?
Does anyone help you?

0 = NO NEED e.g. Independent in looking after the home, home may be untidy but kept basically clean.
1 = MET NEED e.g. Limited in looking after home and has appropriate level of domestic help.
2 = UNMET NEED e.g. Not receiving appropriate level of domestic assistance. Home is a potential health/fire/escape hazard.
9 = NOT KNOWN

IF RATED 0 OR 9 GO TO QUESTION 3

HOW MUCH HELP DOES THE PERSON RECEIVE FROM RELATIVES OR FRIENDS WITH LOOKING AFER THE HOME?	☐	☐	☐	☐

0 = NONE
1 = LOW HELP e.g. Prompts or helps tidy up or clean occasionally.
2 = MODERATE HELP e.g. Prompts or helps cleans at least once a week.
3 = HIGH HELP e.g. Does most or all of the household tasks.
9 = NOT KNOWN

HOW MUCH HELP DOES THE PERSON RECEIVE FROM LOCAL SERVICES WITH LOOKING AFTER THE HOME?	☐	☐	☐	☐
HOW MUCH HELP DOES THE PERSON NEED FROM LOCAL SERVICES WITH LOOKING AFTER THE HOME?	☐	☐	☐	☐

0 = NONE
1 = LOW HELP e.g. Prompting / supervision by staff.
2 = MODERATE HELP e.g. Some assistance with household tasks.
3 = HIGH HELP e.g. Majority of household asks done by staff.
9 = NOT KNOWN

DOES THE PERSON RECEIVE THE RIGHT TYPE OF HELP WITH LOOKING AFTER THE HOME? (0 = NO 1 = YES 9 = NOT KNOWN)	☐	☐	☐	☐
OVERALL, IS THE PERSON SATISFIED WITH THE AMOUNT OF HELP THEY ARE RECEIVING WITH LOOKING AFTER THE HOME? (0 = NOT SATISFIED 1 = SATISFIED 9 = NOT KNOWN)	☐			

COMMENTS

3. FOOD

	ASSESSMENTS user	carer	staff	rater
DOES THE PERSON HAVE DIFFICULTY IN GETTING ENOUGH TO EAT?	☐	☐	☐	☐

Are you able to prepare your own meals and do your own shopping?
Are you getting the right sort of food?

0 = NO NEED	e.g. Able to buy and/or prepare adequate meals independently.
1 = MET NEED	e.g. Unable to prepare food and has meals or assistance provided to met need.
2 = UNMET NEED	e.g. Very restricted diet; culturally inappropriate food; unable to obtain adequate food; difficulty swallowing normal food.
9 = NOT KNOWN	

IF RATED 0 OR 9 GO TO QUESTION 5

HOW MUCH HELP DOES THE PERSON RECEIVE FROM RELATIVES OR FRIENDS WITH GETTING ENOUGH TO EAT?	☐	☐	☐	☐

0 = NONE	
1 = LOW HELP	e.g. Occasional meal provided and/or occasional help with shopping.
2 = MODERATE HELP	e.g. Help with weekly shopping and/or meals provided more than weekly, but not daily.
3 = HIGH HELP	e.g. Assistance with food provided daily.
9 = NOT KNOWN	

HOW MUCH HELP DOES THE PERSON RECEIVE FROM LOCAL SERVICES WITH GETTING ENOUGH TO EAT	☐	☐	☐	☐
HOW MUCH HELP DOES THE PERSON NEED FROM LOCAL SERVICES WITH GETTING ENOUGH TO EAT	☐	☐	☐	☐

0 = NONE	
1 = LOW HELP	e.g. 1-4 meals a week provided or assisted for one meal a week.
2 = MODERATE HELP	e.g. More than 4 meals a week provided or assisted for all meals. Weekly shopping.
3 = HIGH HELP	e.g. All meals provided

DOES THE PERSON RECEIVE THE RIGHT TYPE OF HELP WITH GETTING ENOUGH TO EAT? (0 = NO 1 = YES 9 = NOT KNOWN)	☐	☐	☐	☐
OVERALL, IS THE PERSON SATISFIED WITH THE AMOUNT OF HELP THEY ARE RECEIVING WITH GETTING ENOUGH TO EAT? (0 = NOT SATISFIED 1 = SATISFIED 9 = NOT KNOWN)	☐			

COMMENTS

4. SELF CARE

	ASSESSMENTS user	carer	staff	rater
DOES THE PERSON HAVE DIFFICULTY WITH SELF CARE?				

Are you have any difficulty with personal care like washing, cutting your nails or dressing? Do you ever need help?

0 = NO NEED	e.g. Appropriately dressed and groomed independently.
1 = MET NEED	e.g. Needs and gets appropriate help with self care.
2 = UNMET NEED	e.g. Poor personal hygiene, unable to wash or dress, not receiving appropriate help.
9 = NOT KNOWN	

IF RATED 0 OR 9 GO TO QUESTION 5

HOW MUCH HELP DOES THE PERSON RECEIVE FROM RELATIVES OR FRIENDS WITH SELF CARE?				

0 = NONE	
1 = LOW HELP	e.g. Prompts (e.g. to change clothes) or helps occasionally.
2 = MODERATE HELP	e.g. Regular assistance e.g. weekly or more often.
3 = HIGH HELP	e.g. Daily assistance with care e.g. dressing, bathing: weekly laundry.
9 = NOT KNOWN	

HOW MUCH HELP DOES THE PERSON RECEIVE FROM LOCAL SERVICES WITH SELF CARE?				
HOW MUCH HELP DOES THE PERSON NEED FROM LOCAL SERVICES WITH SELF CARE?				

0 = NONE		
1 = LOW HELP	e.g.	Occasional prompting by staff.
2 = MODERATE HELP	e.g.	Supervise weekly washing and some other aspects of self-care
3 = HIGH HELP	e.g.	Supervise most aspects of self care: assist most days.
9 = NOT KNOWN		

DOES THE PERSON RECEIVE THE RIGHT TYPE OF HELP WITH SELF CARE? (0 = NO 1 = YES 9 = NOT KNOWN)				
OVERALL, IS THE PERSON SATISFIED WITH THE AMOUNT OF HELP THEY ARE RECEIVING WITH SELF CARE? (0 = NOT SATISFIED 1 = SATISFIED 9 = NOT KNOWN)				

COMMENTS

5. CARING FOR SOMEONE ELSE	ASSESSMENTS			
	user	carer	staff	rater

DOES THE PERSON HAVE DIFFICULTY CARING FOR ANOTHER PERSON?	☐	☐	☐	☐

Is there anyone that you are caring for? Do you have any difficulty in looking after them?

0 = NO NEED e.g. No-one to care for or no problem in caring.
1 = MET NEED e.g. Difficulties with caring and receiving help.
2 = UNMET NEED e.g. Serious difficulty in looking after or caring for another person.
9 = NOT KNOWN

IF RATED 0 OR 9 GO TO QUESTION 6

HOW MUCH HELP DOES THE PERSON RECEIVE FROM RELATIVES OR FRIENDS WITH LOOKING AFTER SOMEONE ELSE?	☐	☐	☐	☐

0 = NONE
1 = LOW HELP e.g. Occasional help, less than once a week.
2 = MODERATE HELP e.g. Help most days.
3 = HIGH HELP e.g. Cared for person goes to stay with friends or relatives, assistance required everyday.
9 = NOT KNOWN

HOW MUCH HELP DOES THE PERSON RECEIVE FROM LOCAL SERVICES WITH CARING?	☐	☐	☐	☐
HOW MUCH HELP DOES THE PERSON NEED FROM LOCAL SERVICES WITH CARING?	☐	☐	☐	☐

0 = NONE
1 = LOW HELP e.g. Person goes to day care: weekly assistance at home.
2 = MODERATE HELP e.g. Nearly daily assistance at home, on-going carer support/training for user
3 = HIGH HELP e.g. Respite care, 24 hour package or plans for alternative care for the cared for person.
9 = NOT KNOWN

DOES THE PERSON RECEIVE THE RIGHT TYPE OF HELP WITH CARING? (0 = NO 1 = YES 9 = NOT KNOWN)	☐	☐	☐	☐
OVERALL, IS THE PERSON SATISFIED WITH THE AMOUNT OF HELP THEY ARE RECEIVING WITH CARING? (0 = NOT SATISFIED 1 = SATISFIED 9 = NOT KNOWN)	☐			

COMMENTS

6. DAYTIME ACTIVITIES

	ASSESSMENTS user	carer	staff	rater
DOES THE PERSON HAVE DIFFICULTY WITH REGULAR, APPROPRIATE DAYTIME ACTIVITIES?	☐	☐	☐	☐

How do spend your day? Do you have enough to do?

0 = NO NEED	e.g. Adequate social, work, leisure or learning activities, can arrange own activities.
1 = MET NEED	e.g. Some limitation in occupying self, has appropriate activities organised by others.
2 = UNMET NEED	e.g. No adequate social, work or leisure activities.
9 = NOT KNOWN	

IF RATED 0 OR 9 GO TO QUESTION 7

HOW MUCH HELP DOES THE PERSON RECEIVE FROM RELATIVES OR FRIENDS IN FINDING OR KEEPING REGULAR AND APPROPRIATE DAYTIME ACTIVITIES?	☐	☐	☐	☐

0 = NONE	
1 = LOW HELP	e.g. Occasional help in arranging activities.
2 = MODERATE HELP	e.g. Help at least weekly.
3 = HIGH HELP	e.g. Daily help with arranging or providing activities.
9 = NOT KNOWN	

HOW MUCH HELP DOES THE PERSON RECEIVE FROM LOCAL SERVICES IN FINDING OR KEEPING REGULAR AND APPROPRIATE ACTIVITIES?	☐	☐	☐	☐
HOW MUCH HELP DOES THE PERSON NEED FROM LOCAL SERVICES IN FINDING OR KEEPING REGULAR AND APPROPRIATE ACTIVITIES?	☐	☐	☐	☐

0 = NONE	
1 = LOW HELP	e.g. Adult Education. Weekly day activity.
2 = MODERATE HELP	e.g. Day centre 2-4 days a week. Day Hospital attendance. Adequate activities 2-4 days week
3 = HIGH HELP	e.g. Provision of suitable activity 5 or more days per week e.g., day hospital or day centre
9 = NOT KNOWN	

DOES THE PERSON RECEIVE THE RIGHT TYPE OF HELP WITH ACTIVITIES? (0 = NO 1 = YES 9 = NOT KNOWN)	☐	☐	☐	☐
OVERALL, IS THE PERSON SATISFIED WITH THE AMOUNT OF HELP THEY ARE RECEIVING WITH ACTIVITIES? (0 = NOT SATISFIED 1 = SATISFIED 9 = NOT KNOWN)	☐			

COMMENTS

7. MEMORY	ASSESSMENTS			
	user	carer	staff	rater

DOES THE PERSON HAVE A PROBLEM WITH MEMORY?	☐	☐	☐	☐

Do you often have a problem remembering things that happened recently?
Do you often forget where you've put things?

0 = NO NEED	e.g. Occasionally forgets, but remembers later. No problem with memory.
1 = MET NEED	e.g. Some problems, but having investigations / assistance.
2 = UNMET NEED	e.g. Clear deficit in recalling new information: loses things: becomes disorientated in time and/or place, not receiving appropriate assistance.
9 = NOT KNOWN	

IF RATED 0 OR 9 GO TO QUESTION 8

HOW MUCH HELP DOES THE PERSON RECEIVE FROM RELATIVES OR FRIENDS FOR MEMORY LOSS?	☐	☐	☐	☐

0 = NONE	
1 = LOW HELP	e.g. Prompting, occasional notes, reminders.
2 = MODERATE HELP	e.g. Assistance / supervision most days.
3 = HIGH HELP	e.g. Living with relative. Constant supervision.
9 = NOT KNOWN	

HOW MUCH HELP DOES THE PERSON RECEIVE FROM LOCAL SERVICES FOR MEMORY LOSS?	☐	☐	☐	☐
HOW MUCH HELP DOES THE PERSON NEED FROM LOCAL SERVICES FOR MEMORY LOSS?	☐	☐	☐	☐

0 = NONE	
1 = LOW HELP	e.g. Some advice/ assistance with memory, GP clinic reviews.
2 = MODERATE HELP	e.g. Undergoing investigations. Regularly sees health care professional, e.g. Memory Clinic, Day Hospital, Specialist day facility. Modified environment.
3 = HIGH HELP	e.g. Specially modified care because of memory needs. Intensive assistance.
9 = NOT KNOWN	

DOES THE PERSON RECEIVE THE RIGHT TYPE OF HELP FOR MEMORY LOSS? (0 = NO 1 = YES 9 = NOT KNOWN)	☐	☐	☐	☐
OVERALL, IS THE PERSON SATISFIED WITH THE AMOUNT OF HELP THEY ARE RECEIVING FOR MEMORY LOSS? (0 = NOT SATISFIED 1 = SATISFIED 9 = NOT KNOWN)	☐			

COMMENTS

8. EYESIGHT / HEARING /COMMUNICATION

	ASSESSMENTS user	carer	staff	rater
DOES THE PERSON HAVE A PROBLEM WITH SIGHT OR HEARING?	☐	☐	☐	☐

Do you have any difficulty hearing what someone says to you in a quiet room?
Do you have difficulty in seeing newsprint or watching television?
Are you able to express yourself clearly?

0 = NO NEED e.g. No difficulties (wears appropriate corrective lenses or hearing aid, is independent).

1 = MET NEED e.g. Some difficulty, but aids help to some extent, receiving appropriate investigations or assistance to care for aids.

2 = UNMET NEED e.g. A lot of difficulty seeing or hearing, does not receive appropriate assistance.

9 = NOT KNOWN

IF RATED 0 OR 9 GO TO QUESTION 9

HOW MUCH HELP DOES THE PERSON RECEIVE FROM RELATIVES OR FRIENDS WITH EYESIGHT/HEARING?	☐	☐	☐	☐

0 = NONE

1 = LOW HELP e.g. Help making appointments for sight/ hearing problems. Occasional assistance

2 = MODERATE HELP e.g. Regular help with difficult tasks e.g. reading correspondence.

3 = HIGH HELP e.g. Help with most tasks that are difficult because of hearing/vision problem.

9 = NOT KNOWN

HOW MUCH HELP DOES THE PERSON RECEIVE FROM LOCAL SERVICES WITH EYESIGHT/ HEARING	☐	☐	☐	☐
HOW MUCH HELP DOES THE PERSON NEED FROM LOCAL SERVICES WITH EYESIGHT/ HEARING?	☐	☐	☐	☐

0 = NONE

1 = LOW HELP e.g. Advice about impairment, aids provided or monitored.

2 = MODERATE HELP e.g. Investigations/ treatment. Aids regularly formally reviewed. Regularly assistance with tasks.

3 = HIGH HELP e.g. Assistance several days a week. Hospital appointments / specialist services or specialist day facilities.

9 = NOT KNOWN

DOES THE PERSON RECEIVE THE RIGHT TYPE OF HELP WITH EYESIGHT / HEARING? (0 = NO 1 = YES 9 = NOT KNOWN)	☐	☐	☐	☐
OVERALL, IS THE PERSON SATISFIED WITH THE AMOUNT OF HELP THEY ARE RECEIVING WITH EYESIGHT/ HEARING? (0 = NOT SATISFIED 1 = SATISFIED 9 = NOT KNOWN)	☐			

COMMENTS

9. MOBILITY / FALLS

	ASSESSMENTS user	carer	staff	rater
DOES THE PERSON HAVE RESTRICTED MOBILITY, FALLS OR ANY PROBLEMS USING PUBLIC TRANSPORT?	☐	☐	☐	☐

Do you have trouble moving about your home? Do you have falls?
Do you have trouble with transport?

0 = NO NEED e.g. Physically able and mobile.

1 = MET NEED e.g. Some difficulty walking, climbing steps or using public transport, but able with assistance (e.g. walking aids, wheelchair). Occasional fall. Safety plan in place.

2 = UNMET NEED e.g. Very restricted mobility even with walking aid. Frequent falls. Lack of appropriate help.

9 = NOT KNOWN

IF RATED 0 OR 9 GO TO QUESTION 10

HOW MUCH HELP DOES THE PERSON RECEIVE FROM RELATIVES OR FRIENDS FOR MOBILITY PROBLEMS	☐	☐	☐	☐

0 = NONE

1 = LOW HELP e.g. Occasional help e.g. with transport, support.

2 = MODERATE HELP e.g. Regular help with mobility/ public transport. Help organising home access alterations.

3 = HIGH HELP e.g. Daily help and supervision with mobility/ transport.

9 = NOT KNOWN

HOW MUCH HELP DOES THE PERSON RECEIVE FROM LOCAL SERVICES FOR MOBILITY PROBLEMS	☐	☐	☐	☐
HOW MUCH HELP DOES THE PERSON NEED FROM LOCAL SERVICES FOR MOBILITY PROBLEMS?	☐	☐	☐	☐

0 = NONE

1 = LOW HELP e.g. Advice, one or more aids.

2 = MODERATE HELP e.g. Currently undergoing investigations and/ or O.T./ Physiotherapy assessments, regular transport, e.g. to day centre, light mobility assistance given.

3 = HIGH HELP e.g. Fully appropriate home alterations and aids. Substantial assistance most days. Care home because of mobility needs.

9 = NOT KNOWN

DOES THE PERSON RECEIVE THE RIGHT TYPE OF HELP FOR MOBILITY PROBLEMS? (0 = NO 1 = YES 9 = NOT KNOWN)	☐	☐	☐	☐
OVERALL, IS THE PERSON SATISFIED WITH THE AMOUNT OF HELP THEY ARE RECEIVING FOR MOBILITY PROBLEMS (0 = NOT SATISFIED 1 = SATISFIED 9 = NOT KNOWN)	☐			

COMMENTS

10. CONTINENCE

	ASSESSMENTS user	 carer	 staff	 rater
DOES THE PERSON HAVE INCONTINENCE?	☐	☐	☐	☐

Do you ever have accidents/ find yourself wet if you can't get to the toilet quickly? (How much of a problem? Ever any soiling? Are you getting any help?)

0 = NO NEED e.g. No incontinence. Independent in managing incontinence.

1 = MET NEED e.g. Some incontinence. Receiving appropriate help/ investigations.

2 = UNMET NEED e.g. Regularly wet or soiled. Deteriorating in continence needing assessment.

9 = NOT KNOWN

IF RATED 0 OR 9 GO TO QUESTION 11

HOW MUCH HELP DOES THE PERSON RECEIVE FROM RELATIVES OR FRIENDS FOR INCONTINENCE?	☐	☐	☐	☐

0 = NONE

1 = LOW HELP e.g. Prompts to maintain continence.

2 = MODERATE HELP e.g. Regularly assists with laundry, hygiene and use of aids.

3 = HIGH HELP e.g. Full assistance with continence (laundry, hygiene, aids).

9 = NOT KNOWN

HOW MUCH HELP DOES THE PERSON RECEIVE FROM LOCAL SERVICES FOR INCONTINENCE?	☐	☐	☐	☐
HOW MUCH HELP DOES THE PERSON NEED FROM LOCAL SERVICES FOR INCONTINENCE?	☐	☐	☐	☐

0 = NONE

1 = LOW HELP e.g. Prompts to maintain continence and provision of aids.

2 = MODERATE HELP e.g. Investigations/ treatment. Regular help with laundry, hygiene and aids.

3 = HIGH HELP e.g. Planned medical intervention (e.g. surgery). Constant care and assistance because of incontinence (e.g. in care home). Substantial continence programme in place.

9 = NOT KNOWN

DOES THE PERSON RECEIVE THE RIGHT TYPE OF HELP FOR INCONTINENCE? (0 = NO 1 = YES 9 = NOT KNOWN)	☐	☐	☐	☐
OVERALL, IS THE PERSON SATISFIED WITH THE AMOUNT OF HELP THEY ARE RECEIVING FOR INCONTINENCE? (0 = NOT SATISFIED 1 = SATISFIED 9 = NOT KNOWN)	☐			

COMMENTS

11. PHYSICAL HEALTH	ASSESSMENTS user	 carer	 staff	 rater
DOES THE PERSON HAVE ANY PHYSICAL ILLNESS?	☐	☐	☐	☐

How well do you feel physically?
Are you getting any treatment from your doctor for physical problems?

0 = NO NEED	e.g. Physically well. Receiving no medical interventions.
1 = MET NEED	e.g. Physical ailment such as high blood pressure under control, receiving appropriate treatment / investigation. Reviews of physical conditions.
2 = UNMET NEED	e.g. Untreated serious physical ailment. Significant pain. Awaiting major surgery.
9 = NOT KNOWN	

IF RATED 0 OR 9 GO TO QUESTION 12

HOW MUCH HELP DOES THE PERSON RECEIVE FROM RELATIVES OR FRIENDS FOR PHYSICAL HEALTH PROBLEMS?	☐	☐	☐	☐

0 = NONE	
1 = LOW HELP	e.g. Arranging appointments to see doctor.
2 = MODERATE HELP	e.g. Accompanied regularly to doctor / clinics.
3 = HIGH HELP	e.g. Daily help with condition arising out of physical health problems, e.g. living with a relative while convalescing or ill.
9 = NOT KNOWN	

HOW MUCH HELP DOES THE PERSON RECEIVE FROM LOCAL SERVICES FOR PHYSICAL HEALTH PROBLEMS?	☐	☐	☐	☐
HOW MUCH HELP DOES THE PERSON NEED FROM LOCAL SERVICES FOR PHYSICAL HEALTH PROBLEMS?	☐	☐	☐	☐

0 = NONE	
1 = LOW HELP	e.g. Given dietary or health advice. Occasional visit to GP for medicines.
2 = MODERATE HELP	e.g. Prescribed significant medications. Regularly seen by health care professional (GP, nurse, day hospital staff, out patient clinic).
3 = HIGH HELP	e.g. Inpatient admissions, 24-hour nursing care. Very regular or intensive treatment.
9 = NOT KNOWN	

DOES THE PERSON RECEIVE THE RIGHT TYPE OF HELP FOR PHYSICAL HEALTH PROBLEMS? (0 = NO 1 = YES 9 = NOT KNOWN)	☐	☐	☐	☐
OVERALL, IS THE PERSON SATISFIED WITH THE AMOUNT OF HELP THEY ARE RECEIVING FOR PHYSICAL HEALTH PROBLEMS? (0 = NOT SATISFIED 1 = SATISFIED 9 = NOT KNOWN)	☐			

COMMENTS

NB: consider oral health, skin care and foot care particularly in those people who are very frail or who have chronic medical conditions

12. DRUGS	ASSESSMENTS user	 carer	 staff	 rater
DOES THE PERSON HAVE PROBLEMS WITH MEDICATION OR DRUGS?	☐	☐	☐	☐

Do you have any problems (e.g. side effects) with medication. How many different tablets are you on? Has your medication been recently reviewed by your doctor? Do you take any drugs that are not prescribed?

0 = NO NEED e.g. No problems with compliance, side effects, drug abuse or dependency.

1 = MET NEED e.g. Regular reviews, advice, District Nurse/ CPN administers medication, Dosette boxes/ aids

2 = UNMET NEED e.g. Poor compliance, dependency or abuse of prescribed or non-prescribed drugs, inappropriate medication given.

9 = NOT KNOWN

IF RATED 0 OR 9 GO TO QUESTION 13

HOW MUCH HELP DOES THE PERSON RECEIVE FROM RELATIVES OR FRIENDS WITH THEIR MEDICATION?	☐	☐	☐	☐

0 = NONE

1 = LOW HELP e.g. Occasional prompt. Advice about drug misuse.

2 = MODERATE HELP e.g. Collection, regular reminding and checking of medication. Advice about agencies.

3 = HIGH HELP e.g. Administers and holds medication. Support during drug withdrawal programme.

9 = NOT KNOWN

HOW MUCH HELP DOES THE PERSON RECEIVE FROM LOCAL SERVICES WITH THEIR MEDICATION?	☐	☐	☐	☐
HOW MUCH HELP DOES THE PERSON NEED FROM LOCAL SERVICES WITH THEIR MEDICATION?	☐	☐	☐	☐

0 = NONE

1 = LOW HELP e.g. Advice from GP. Prompts to take medication.

2 = MODERATE HELP e.g. Supervision by District Nurse/ CPN/ Day Hospital/ care facility administers drugs.

3 = HIGH HELP e.g. Intensive program regarding drug administration, compliance, abuse, or dependency (e.g., supervised withdrawal programme for drug dependency.

9 = NOT KNOWN

DOES THE PERSON RECEIVE THE RIGHT TYPE OF HELP WITH MEDICATION? (0 = NO 1 = YES 9 = NOT KNOWN)	☐	☐	☐	☐
OVERALL, IS THE PERSON SATISFIED WITH THE AMOUNT OF HELP THEY ARE RECEIVING WITH THEIR MEDICATION? (0 = NOT SATISFIED 1 = SATISFIED 9 = NOT KNOWN)	☐			

COMMENTS

13. PSYCHOTIC SYMPTOMS

ASSESSMENTS	user	carer	staff	rater
DOES THE PERSON HAVE SYMPTOMS SUCH AS DELUSIONAL BELIEFS, HALLUCINATIONS, FORMAL THOUGHT DISORDER OR PASSIVITY?	☐	☐	☐	☐

Do you ever hear voices, see strange things or have problems with your thoughts?
Are you on medication for this?

0 = NO NEED e.g. No definite symptoms. Not at risk or in distress from symptoms and not on medication for psychotic symptoms.

1 = MET NEED e.g. Symptoms helped by medication or other help e.g., coping strategies, safety plan.

2 = UNMET NEED e.g. Currently has symptoms or is at risk.

9 = NOT KNOWN

IF RATED 0 OR 9 GO TO QUESTION 14

	user	carer	staff	rater
HOW MUCH HELP DOES THE PERSON RECEIVE FROM RELATIVES OR FRIENDS FOR THESE PSYCHOTIC SYMPTOMS?	☐	☐	☐	☐

0 = NONE

1 = LOW HELP e.g. Some support.

2 = MODERATE HELP e.g. Carers involved in helping with coping strategies or medication compliance.

3 = HIGH HELP e.g. Constant supervision of medication and helping with coping strategies.

9 = NOT KNOWN

	user	carer	staff	rater
HOW MUCH HELP DOES THE PERSON RECEIVE FROM LOCAL SERVICES FOR THESE PSYCHOTIC SYMPTOMS?	☐	☐	☐	☐
HOW MUCH HELP DOES THE PERSON NEED FROM LOCAL SERVICES FOR THESE PSYCHOTIC SYMPTOMS?	☐	☐	☐	☐

0 = NONE

1 = LOW HELP e.g. Mental state and medication reviewed three monthly or less often, support group.

2 = MODERATE HELP e.g. Mental state and medication reviewed more frequently than three monthly. Frequent specific therapy e.g. day hospital, high CPN input.

3 = HIGH HELP e.g. Active treatment/ 24 hour hospital care, daily day care or crisis care at home.

9 = NOT KNOWN

	user	carer	staff	rater
DOES THE PERSON RECEIVE THE RIGHT TYPE OF HELP FOR THESE SYMPTOMS? (0 = NO 1 = YES 9 = NOT KNOWN)	☐	☐	☐	☐
OVERALL, IS THE PERSON SATISFIED WITH THE AMOUNT OF HELP THEY ARE RECEIVING FOR THESE SYMPTOMS? (0 = NOT SATISFIED 1 = SATISFIED 9 = NOT KNOWN)	☐			

COMMENTS

14. PSYCHOLOGICAL DISTRESS	ASSESSMENTS user	 carer	 staff	 rater
DOES THE PERSON SUFFER FROM CURRENT PSYCHOLOGICAL DISTRESS?	☐	☐	☐	☐

Have you recently felt very sad or fed up? Have you felt very anxious, frightened or worried?

0 = NO NEED	e.g. Occasional or mild distress. Copes independently
1 = MET NEED	e.g. Needs and gets on-going support.
2 = UNMET NEED	e.g. Distress affects life significantly, e.g. prevents person going out.
9 = NOT KNOWN	

IF RATED 0 OR 9 GO TO QUESTION 15

HOW MUCH HELP DOES THE PERSON RECEIVE FROM RELATIVES OR FRIENDS FOR THIS DISTRESS?	☐	☐	☐	☐

0 = NONE	
1 = LOW HELP	e.g. Some sympathy and support.
2 = MODERATE HELP	e.g. Has opportunity at least once a week to talk about distress and get help with coping strategies.
3 = HIGH HELP	e.g. Constant support and supervision.
9 = NOT KNOWN	

HOW MUCH HELP DOES THE PERSON RECEIVE FROM LOCAL SERVICES FOR THIS DISTRESS?	☐	☐	☐	☐
HOW MUCH HELP DOES THE PERSON NEED FROM LOCAL SERVICES FOR THIS DISTRESS?	☐	☐	☐	☐

0 = NONE	
1 = LOW HELP	e.g. Assessment of mental state or occasional support.
2 = MODERATE HELP	e.g. Specific psychological or social intervention for distress. Counselled by staff at least once a week e.g. at Day Hospital.
3 = HIGH HELP	e.g. 24 hour hospital care, or crisis care at home, daily assistance for distress.
9 = NOT KNOWN	

DOES THE PERSON RECEIVE THE RIGHT TYPE OF HELP FOR THIS DISTRESS? (0 = NO 1 = YES 9 = NOT KNOWN)	☐	☐	☐	☐
OVERALL, IS THE PERSON SATISFIED WITH THE AMOUNT OF HELP THEY ARE RECEIVING FOR THIS DISTRESS (0 = NOT SATISFIED 1 = SATISFIED 9 = NOT KNOWN)	☐			

COMMENTS

15. INFORMATION (ON CONDITION & TREATMENT)	ASSESSMENTS user	 carer	 staff	 rater
HAS THE PERSON HAD CLEAR VERBAL OR WRITTEN INFORMATION ABOUT THEIR CONDITION AND TREATMENT?				

Have you been given clear information about your condition, medication or other treatment? Do you want such information? How helpful has the information been?

0 = NO NEED e.g. Has received and understood adequate information. Has not received but does not want information.

1 = MET NEED e.g. Receives assistance to understand information. Information given that is appropriate for the person's level of communication / understanding.

2 = UNMET NEED e.g. Has received inadequate or no information.

9 = NOT KNOWN

IF RATED 0 OR 9 GO TO QUESTION 16

HOW MUCH HELP DOES THE PERSON RECEIVE FROM RELATIVES OR FRIENDS IN OBTAINING SUCH INFORMATION?				

0 = NONE

1 = LOW HELP e.g. Some advice.

2 = MODERATE HELP e.g. Given leaflets/ fact-sheets or put in touch with self help groups.

3 = HIGH HELP e.g. Regular liaison with mental health staff or voluntary groups (e.g. Alzheimer's Society) by friends or relatives.

9 = NOT KNOWN

HOW MUCH HELP DOES THE PERSON RECEIVE FROM LOCAL SERVICES IN OBTAINING SUCH INFORMATION?				
HOW MUCH HELP DOES THE PERSON NEED FROM LOCAL SERVICES IN OBTAINING SUCH INFORMATION?				

0 = NONE

1 = LOW HELP e.g. Brief verbal or written information on illness/ problem/ treatment.

2 = MODERATE HELP e.g. Given details of self-help groups. Long verbal information sessions e.g. during Day Hospital attendance.

3 = HIGH HELP e.g. Has been given specific personal education with or without detailed written information.

9 = NOT KNOWN

DOES THE PERSON RECEIVE THE RIGHT TYPE OF HELP IN OBTAINING INFORMATION? (0 = NO 1 = YES 9 = NOT KNOWN)				
OVERALL, IS THE PERSON SATISFIED WITH THE AMOUNT OF HELP THEY ARE RECEIVING IN OBTAINING INFORMATION? (0 = NOT SATISFIED 1 = SATISFIED 9 = NOT KNOWN)				

COMMENTS

16. DELIBERATE SELF-HARM

	ASSESSMENTS user	carer	staff	rater
IS THE PERSON A DANGER TO THEMSELVES?	☐	☐	☐	☐

Do you ever think of harming yourself or actually harm yourself?

0 = NO NEED e.g. No thoughts of self-harm or suicide.

1 = MET NEED e.g. Suicide risk monitored by staff, receiving counselling, adequate safety plan in place.

2 = UNMET NEED e.g. Has expressed suicidal intent, deliberately neglected self or exposed self to serious danger in the last month.

9 = NOT KNOWN

IF RATED 0 OR 9 GO TO QUESTION 17

HOW MUCH HELP DOES THE PERSON RECEIVE FROM RELATIVES OR FRIENDS TO REDUCE RISK OF DELIBERATE SELF HARM?	☐	☐	☐	☐

0 = NONE

1 = LOW HELP e.g. Able to contact friends or relatives if feeling unsafe.

2 = MODERATE HELP e.g. Friends or relatives are usually in contact and are likely to know if feeling unsafe.

3 = HIGH HELP e.g. Friends or relatives in regular contact and are very likely to know and provide help if feeling unsafe.

9 = NOT KNOWN

HOW MUCH HELP DOES THE PERSON RECEIVE FROM LOCAL SERVICES TO REDUCE THE RISK OF DELIBERATE SELF-HARM?	☐	☐	☐	☐
HOW MUCH HELP DOES THE PERSON NEED FROM LOCAL SERVICES TO REDUCE THE RISK OF DELIBERATE SELF-HARM?	☐	☐	☐	☐

0 = NONE

1 = LOW HELP e.g. Someone to contact if feeling unsafe.

2 = MODERATE HELP e.g. Staff check at least once a week: regular supportive counselling.

3 = HIGH HELP e.g. Daily supervision: inpatient care because of risk.

9 = NOT KNOWN

DOES THE PERSON RECEIVE THE RIGHT TYPE OF HELP TO REDUCE RISK OF DELIBERATE SELF-HARM? (0 = NO 1 = YES 9 = NOT KNOWN)	☐	☐	☐	☐
OVERALL, IS THE PERSON SATISFIED WITH THE AMOUNT OF HELP THEY ARE RECEIVING TO REDUCE RISK OF DELIBERATE SELF-HARM? (0 = NOT SATISFIED 1 = SATISFIED 9 = NOT KNOWN)	☐			

COMMENTS

17. INADVERTANT SELF-HARM

	ASSESSMENTS user	carer	staff	rater
IS THE PERSON AT INADVERTENT RISK TO THEMSELVES?	☐	☐	☐	☐

Do you ever do anything that accidentally puts yourself in danger (e.g. leaving gas taps on, leaving fire unattended or getting lost)?

0 = NO NEED	e.g. No accidental self-harm.
1 = MET NEED	e.g. Specific supervision or help to prevent harm: e.g. memory notes, prompts, secure environment, observation.
2 = UNMET NEED	e.g. Dangerous behaviour, e.g. getting lost, gas/ fire hazard, no appropriate safety plan
9 = NOT KNOWN	

IF RATED 0 OR 9 GO TO QUESTION 18

HOW MUCH HELP DOES THE PERSON RECEIVE FROM RELATIVES OR FRIENDS TO REDUCE RISK OF INADVERTENT SELF HARM	☐	☐	☐	☐

0 = NONE	
1 = LOW HELP	e.g. Periodic supervision: weekly or less.
2 = MODERATE HELP	e.g. Supervision on 3-5 days a week.
3 = HIGH HELP	e.g. Almost constant supervision/ 24 hour care because of risk.
9 = NOT KNOWN	

HOW MUCH HELP DOES THE PERSON RECEIVE FROM LOCAL SERVICES TO REDUCE THE RISK OF INADVERTENT SELF-HARM?	☐	☐	☐	☐
HOW MUCH HELP DOES THE PERSON NEED FROM LOCAL SERVICES TO REDUCE THE RISK OF INADVERTENT SELF-HARM?	☐	☐	☐	☐

0 = NONE	
1 = LOW HELP	e.g. Check on behaviour weekly or less, risk assessment completed.
2 = MODERATE HELP	e.g. Daily Supervision, specific plan to prevent harm
3 = HIGH HELP	e.g. Constant supervision e.g. residential care because of risk for inadvertent self-harm.
9 = NOT KNOWN	

DOES THE PERSON RECEIVE THE RIGHT TYPE OF HELP TO REDUCE RISK OF INADVERTENT SELF-HARM? (0 = NO 1 = YES 9 = NOT KNOWN	☐	☐	☐	☐
OVERALL, IS THE PERSON SATISFIED WITH THE AMOUNT OF HELP THEY ARE RECEIVING TO REDUCE RISK OF HARM? (0 = NOT SATISFIED 1 = SATISFIED 9 = NOT KNOWN)	☐			

COMMENTS

18. ABUSE/ NEGLECT

ASSESSMENTS
user carer staff rater

IS THE PERSON AT RISK FROM OTHERS? ☐ ☐ ☐ ☐

Has anyone done anything to frighten or harm you, or taken advantage of you?

0 = NO NEED e.g. No abuse/ neglect issues over past month.
1 = MET NEED e.g. Needs and gets ongoing support or protection. Safety plan in place.
2 = UNMET NEED e.g. Regular shouting, pushing or neglect, financial misappropriation, physical assault.
9 = NOT KNOWN

IF RATED 0 OR 9 GO TO QUESTION 19

HOW MUCH HELP DOES THE PERSON RECEIVE FROM RELATIVES OR FRIENDS TO REDUCE RISK OF ABUSE? ☐ ☐ ☐ ☐

0 = NONE
1 = LOW HELP e.g. Occasional advice.
2 = MODERATE HELP e.g. Regular support and protection.
3 = HIGH HELP e.g. Constant support: very regular protection: negotiation.
9 = NOT KNOWN

HOW MUCH HELP DOES THE PERSON RECEIVE FROM LOCAL SERVICES TO REDUCE THE RISK OF ABUSE? ☐ ☐ ☐ ☐

HOW MUCH HELP DOES THE PERSON NEED FROM LOCAL SERVICES TO REDUCE THE RISK OF ABUSE? ☐ ☐ ☐ ☐

0 = NONE
1 = LOW HELP e.g. Someone to contact when feeling threatened.
2 = MODERATE HELP e.g. Regular support: occasional respite.
3 = HIGH HELP e.g. Constant supervision: legal involvement via services: separation from abuser.
9 = NOT KNOWN

DOES THE PERSON RECEIVE THE RIGHT TYPE OF HELP TO REDUCE RISK OF ABUSE? (0 = NO 1 = YES 9 = NOT KNOWN) ☐ ☐ ☐ ☐

OVERALL, IS THE PERSON SATISFIED WITH THE AMOUNT OF HELP THEY ARE RECEIVING TO REDUCE RISK OF ABUSE? (0 = NOT SATISFIED 1 = SATISFIED 9 = NOT KNOWN) ☐

COMMENTS

19. BEHAVIOUR

	ASSESSMENTS user	carer	staff	rater
IS THE PERSON'S BEHAVIOUR DANGEROUS, THREATENING, INTERFERING OR ANNOYING TO OTHERS?				

Do you come into conflict with others e.g. by interfering with their affairs, frequently annoying, threatening or disturbing them? What happens?

0 = NO NEED	e.g. No history of disturbance to others.
1 = MET NEED	e.g. Under supervision / treatment because of potential risk.
2 = UNMET NEED	e.g. Recent violence, threats or seriously interfering behaviour.
9 = NOT KNOWN	

IF RATED 0 OR 9 GO TO QUESTION 20

HOW MUCH HELP DOES THE PERSON RECEIVE FROM RELATIVES OR FRIENDS TO REDUCE ANNOYING OR DISTURBING BEHAVIOUR?				

0 = NONE	
1 = LOW HELP	e.g. Help/ supervision weekly or less.
2 = MODERATE HELP	e.g. Help/ supervision more often than weekly.
3 = HIGH HELP	e.g. Almost constant help/ supervision due to persistently disturbing behaviour.
9 = NOT KNOWN	

HOW MUCH HELP DOES THE PERSON RECEIVE FROM LOCAL SERVICES TO REDUCE ANNOYING OR DISTURBING BEHAVIOUR?				
HOW MUCH HELP DOES THE PERSON NEED FROM LOCAL SERVICES TO REDUCE ANNOYING OR DISTURBING BEHAVIOUR?				

0 = NONE	
1 = LOW HELP	e.g. Check on behaviour weekly or less.
2 = MODERATE HELP	e.g. Daily supervision or night-sitting service, active care plan in place.
3 = HIGH HELP	e.g. Constant supervision: intensive behaviour management programme.
9 = NOT KNOWN	

DOES THE PERSON RECEIVE THE RIGHT TYPE OF HELP TO REDUCE ANNOYING OR DISTURBING BEHAVIOUR? (0 = NO 1 = YES 9 = NOT KNOWN)				
OVERALL, IS THE PERSON SATISFIED WITH THE AMOUNT OF HELP THEY ARE RECEIVING TO REDUCE DISTURBING BEHAVIOUR? (0 = NOT SATISFIED 1 = SATISFIED 9 = NOT KNOWN)				

COMMENTS

20. ALCOHOL

	ASSESSMENTS user	carer	staff	rater
DOES THE PERSON DRINK EXCESSIVELY OR HAVE A PROBLEM CONTROLLING THEIR DRINKING?	☐	☐	☐	☐

Do you drink alcohol? How much? Does drinking cause you any problems?
Do you ever feel guilty about it? Do you ever wish you could cut down your drinking?

0 = NO NEED e.g. Doesn't drink or drinks sensibly.

1 = MET NEED e.g. At risk from alcohol abuse and receiving assistance.

2 = UNMET NEED e.g. Current drinking harmful or uncontrollable, not receiving appropriate assistance.

9 = NOT KNOWN

IF RATED 0 OR 9 GO TO QUESTION 21

	user	carer	staff	rater
HOW MUCH HELP DOES THE PERSON RECEIVE FROM RELATIVES OR FRIENDS FOR THEIR DRINKING?	☐	☐	☐	☐

0 = NONE

1 = LOW HELP e.g. Advised to cut down.

2 = MODERATE HELP e.g. Advised about helping agencies, e.g. Alcoholics Anonymous.

3 = HIGH HELP e.g. Constant support and/ or monitoring of alcohol intake.

9 = NOT KNOWN

	user	carer	staff	rater
HOW MUCH HELP DOES THE PERSON RECEIVE FROM LOCAL SERVICES FOR THEIR DRINKING?	☐	☐	☐	☐
HOW MUCH HELP DOES THE PERSON NEED FROM LOCAL SERVICES FOR THEIR DRINKING?	☐	☐	☐	☐

0 = NONE

1 = LOW HELP e.g. Given information and told about risks.

2 = MODERATE HELP e.g. Given support and details of helping agencies, access to drink is supervised.

3 = HIGH HELP e.g. Attends alcohol clinic, supervised withdrawal programme.

9 = NOT KNOWN

	user	carer	staff	rater
DOES THE PERSON RECEIVE THE RIGHT TYPE OF HELP FOR THEIR DRINKING? (0 = NO 1 = YES 9 = NOT KNOWN)	☐	☐	☐	☐
OVERALL, IS THE PERSON SATISFIED WITH THE AMOUNT OF HELP THEY ARE RECEIVING FOR THEIR DRINKING? (0 = NOT SATISFIED 1 = SATISFIED 9 = NOT KNOWN)	☐			

COMMENTS

21. COMPANY

	ASSESSMENTS user	 carer	 staff	 rater
DOES THE PERSON NEED HELP WITH SOCIAL CONTACT?	☐	☐	☐	☐

Are you happy with your social life? Do you wish you had more social contact with others?

0 = NO NEED e.g. Able to organise enough social contact, has enough contact with friends.

1 = MET NEED e.g. Lack of company identified as a problem. Has specific intervention for company needs e.g., lonely at night but attends drop-in or day centre or Lunch Club. Social work involvement.

2 = UNMET NEED e.g. Frequently feels lonely and isolated. Very few social contacts.

9 = NOT KNOWN

IF RATED 0 OR 9 GO TO QUESTION 22

HOW MUCH HELP DOES THE PERSON RECEIVE FROM RELATIVES OR FRIENDS WITH SOCIAL CONTACT?	☐	☐	☐	☐

0 = NONE

1 = LOW HELP e.g. Friends help with social contact or visit less than weekly to provide company.

2 = MODERATE HELP e.g. Friends help with social contact weekly or more often.

3 = HIGH HELP e.g. Friends help with social contact at least four times a week.

9 = NOT KNOWN

HOW MUCH HELP DOES THE PERSON RECEIVE FROM LOCAL SERVICES IN ORGANISING SOCIAL CONTACT?	☐	☐	☐	☐
HOW MUCH HELP DOES THE PERSON NEED FROM LOCAL SERVICES IN ORGANISING SOCIAL CONTACT?	☐	☐	☐	☐

0 = NONE

1 = LOW HELP e.g. Occasional visits from befriender or voluntary worker. Referral to centre.

2 = MODERATE HELP e.g. Regular attendance at day centre: regular luncheon club, organised social activity.

3 = HIGH HELP e.g. Day centre or social home visits 3 or more times a week, social skills training, social worker involvement.

9 = NOT KNOWN

DOES THE PERSON RECEIVE THE RIGHT TYPE OF HELP WITH SOCIAL CONTACT? (0 = NO 1 = YES 9 = NOT KNOWN)	☐	☐	☐	☐
OVERALL, IS THE PERSON SATISFIED WITH THE AMOUNT OF HELP THEY ARE RECEIVING WITH THEIR SOCIAL CONTACT? (0 = NOT SATISFIED 1 = SATISFIED 9 = NOT KNOWN)	☐			

COMMENTS

22. INTIMATE RELATIONSHIPS

	ASSESSMENTS user	carer	staff	rater
DOES THE PERSON HAVE A PARTNER, RELATIVE OR FRIEND WITH WHOM THEY HAVE A CLOSE EMOTIONAL/ PHYSICAL RELATIONSHIP?	☐	☐	☐	☐

Do you have a partner, relative or friend you feel close to? Do you get on well?
Can you talk about your worries or problems? Do you lack physical contact/ intimacy?

0 = NO NEED e.g. Happy with current relationships or does not want any intimate relationship.

1 = MET NEED e.g. Has problems concerning intimate relationships, specific plan, counselling/ advice/ support which is helpful.

2 = UNMET NEED e.g. Desperately lonely. Lack of confidant.

9 = NOT KNOWN

IF RATED 0 OR 9 GO TO QUESTION 23

HOW MUCH HELP DOES THE PERSON RECEIVE FROM RELATIVES OR FRIENDS WITH INTIMATE RELATIONSHIPS OR LONELINESS?	☐	☐	☐	☐

0 = NONE

1 = LOW HELP e.g. Occasional emotional support.

2 = MODERATE HELP e.g. Regular support.

3 = HIGH HELP e.g. Help contacting counselling services (e.g. bereavement/ marriage counselling) and possibly accompanying the person there.

9 = NOT KNOWN

HOW MUCH HELP DOES THE PERSON RECEIVE FROM LOCAL SERVICES WITH INTIMATE RELATIONSHIPS OR LONELINESS?	☐	☐	☐	☐
HOW MUCH HELP DOES THE PERSON NEED FROM LOCAL SERVICES WITH INTIMATE RELATIONSHIPS OR LONELINESS?	☐	☐	☐	☐

0 = NONE

1 = LOW HELP e.g. Some support/ advice

2 = MODERATE HELP e.g. Regular support/ advice /contact.

3 = HIGH HELP e.g. Intensive support. Specific therapy, e.g. marital or bereavement counselling.

9 = NOT KNOWN

DOES THE PERSON RECEIVE THE RIGHT TYPE OF HELP WITH RELATIONSHIPS? (0 = NO 1 = YES 9 = NOT KNOWN)	☐	☐	☐	☐
OVERALL, IS THE PERSON SATISFIED WITH THE AMOUNT OF HELP THEY ARE RECEIVING WITH RELATIONSHIPS? (0 = NOT SATISFIED 1 = SATISFIED 9 = NOT KNOWN)	☐			

COMMENTS

23. MONEY / BUDGETING

ASSESSMENTS

	user	carer	staff	rater
DOES THE PERSON HAVE PROBLEMS MANAGING OR BUDGETING THEIR MONEY?	☐	☐	☐	☐

Do you have any difficulty managing your money? Are you able to pay your bills?

0 = NO NEED e.g. Able to buy essential items and pay bills independently.
1 = MET NEED e.g. Benefits from help with managing affairs or budgeting
2 = UNMET NEED e.g. Often has no money for essential items or bills. Unable to manage finances.
9 = NOT KNOWN

IF RATED 0 OR 9 GO TO QUESTION 24

	user	carer	staff	rater
HOW MUCH HELP DOES THE PERSON RECEIVE FROM RELATIVES OR FRIENDS IN MANAGING THEIR MONEY?	☐	☐	☐	☐

0 = NONE
1 = LOW HELP e.g. Occasional help sorting out household bills.
2 = MODERATE HELP e.g. Frequent assistance, calculating weekly budget, collecting pension.
3 = HIGH HELP e.g. Complete management of finances. Power of Attorney.
9 = NOT KNOWN

	user	carer	staff	rater
HOW MUCH HELP DOES THE PERSON RECEIVE FROM LOCAL SERVICES IN MANAGING THEIR MONEY?	☐	☐	☐	☐
HOW MUCH HELP DOES THE PERSON NEED FROM LOCAL SERVICES IN MANAGING THEIR MONEY?	☐	☐	☐	☐

0 = NONE
1 = LOW HELP e.g. Occasional help with budgeting
2 = MODERATE HELP e.g. Supervised in paying rent, given weekly spending money
3 = HIGH HELP e.g. Virtual or complete management of finances: Court of protection: Enduring Power of Attorney
9 = NOT KNOWN

	user	carer	staff	rater
DOES THE PERSON RECEIVE THE RIGHT TYPE OF HELP IN MANAGING THEIR MONEY? (0 = NO 1 = YES 9 = NOT KNOWN)	☐	☐	☐	☐
OVERALL, IS THE PERSON SATISFIED WITH THE AMOUNT OF HELP THEY ARE RECEIVING IN MANAGING THEIR MONEY? (0 = NOT SATISFIED 1 = SATISFIED 9 = NOT KNOWN)	☐			

COMMENTS

24. BENEFITS

ASSESSMENTS

	user	carer	staff	rater
IS THE PERSON DEFINITELY RECEIVING ALL THE BENEFITS THAT THEY ARE ENTITLED TO?				

Are you sure that you are getting all the money that you are entitled to?

0 = NO NEED e.g. Has no need of benefits or receiving full entitlement of benefits.

1 = MET NEED e.g. Receives appropriate help in claiming benefits, social worker involvement over past month.

2 = UNMET NEED e.g. Not sure/ not receiving full entitlement of benefits.

9 = NOT KNOWN

IF RATED 0 OR 9 GO TO CARER'S SECTION OVERLEAF

	user	carer	staff	rater
HOW MUCH HELP DOES THE PERSON RECEIVE FROM RELATIVES OR FRIENDS IN OBTAINING THEIR FULL BENEFIT ENTITLEMENT?				

0 = NONE

1 = LOW HELP e.g. Occasionally asks whether person is getting any money.

2 = MODERATE HELP e.g. Make enquiries about entitlements and help fill in forms.

3 = HIGH HELP e.g. Has ensured full benefits are being received.

9 = NOT KNOWN

	user	carer	staff	rater
HOW MUCH HELP DOES THE PERSON RECEIVE FROM LOCAL SERVICES IN OBTAINING THEIR FULL BENEFIT ENTITLEMENT?				
HOW MUCH HELP DOES THE PERSON NEED FROM LOCAL SERVICES IN OBTAINING THEIR FULL BENEFIT ENTITLEMENT?				

0 = NONE

1 = LOW HELP e.g. Occasional advice about entitlements.

2 = MODERATE HELP e.g. Help with applying for extra entitlements.

3 = HIGH HELP e.g. Comprehensive evaluation of current entitlement in past month.

9 = NOT KNOWN

	user	carer	staff	rater
DOES THE PERSON RECEIVE THE RIGHT TYPE OF HELP IN OBTAINING THEIR FULL BENEFIT ENTITLEMENT? (0 = NO 1 = YES 9 = NOT KNOWN)				
OVERALL, IS THE PERSON SATISFIED WITH THE AMOUNT OF HELP THEY ARE RECEIVING IN OBTAINING THEIR FULL BENEFIT ENTITLEMENT? (0 = NOT SATISFIED 1 = SATISFIED 9 = NOT KNOWN)				

COMMENTS

A. CARERS NEED FOR INFORMATION

	ASSESSMENTS			
	user	carer	staff	rater
HAS THE CARER BEEN GIVEN CLEAR INFORMATION ABOUT THE PERSONS CONDITION AND ALL THE TREATMENT AVAILABLE?	☐	☐	☐	☐

Have you been given clear information about X's condition and all the treatment and services available? How helpful has this information been?

0 = NO NEED	e.g. Received and understood
1 = MET NEED	e.g. Has not received or understood all information, receives help with information.
2 = UNMET NEED	e.g. Has received little or no information, has not understood information given.
9 = NOT KNOWN	

IF RATED 0 OR 9 GO TO QUESTION B

HOW MUCH HELP DOES THE CARER RECEIVE FROM RELATIVES OR FRIENDS IN OBTAINING SUCH INFORMATION?	☐	☐	☐	☐

0 = NONE	
1 = LOW HELP	e.g. Has had some advice.
2 = MODERATE HELP	e.g. Given leaflets/ fact sheets or put in touch with self-help groups.
3 = HIGH HELP	e.g. Regular liaison with doctors, other professionals, self help or support groups by friends or relatives.
9 = NOT KNOWN	

HOW MUCH HELP DOES THE CARER RECEIVE FROM LOCAL SERVICES IN OBTAINING SUCH INFORMATION?	☐	☐	☐	☐
HOW MUCH HELP DOES THE CARER NEED FROM LOCAL SERVICES IN OBTAINING SUCH INFORMATION?	☐	☐	☐	☐

0 = NONE	
1 = LOW HELP	e.g. Brief verbal or written information on condition/ problem/ treatment.
2 = MODERATE HELP	e.g. Given details of self help groups. Personal explanations of drugs, alternative treatments/ services and likely course of the condition.
3 = HIGH HELP	e.g. Has been given detailed written information or has had specific personal education: e.g. from key worker.
9 = NOT KNOWN	

DOES THE CARER RECEIVE THE RIGHT TYPE OF HELP IN OBTAINING SUCH INFORMATION? (0 = NO 1 = YES 9 = NOT KNOWN)	☐	☐	☐	☐
OVERALL, IS THE CARER SATISFIED WITH THE AMOUNT OF HELP THEY ARE RECEIVING IN OBTAINING SUCH INFORMATION? (0 = NOT SATISFIED 1 = SATISFIED 9 = NOT KNOWN)	☐			

COMMENTS

B. CARERS PSYCHOLOGICAL DISTRESS

	ASSESSMENTS user	carer	staff	rater
IS THE CARER CURRENTLY PSYCHOLOGICALLY DISTRESSED?	☐	☐	☐	☐

Do you find it difficult or stressful caring for X? Do you feel you need a break or much more support for yourself?

0 = NO NEED	e.g. Coping well.
1 = MET NEED	e.g. Some stress: receiving help/ contact/ support that is beneficial.
2 = UNMET NEED	e.g. Very stressed or depressed. Wants relief from caring.
9 = NOT KNOWN	

IF RATED 0 OR 9 FINISH

	user	carer	staff	rater
HOW MUCH HELP DOES THE CARER RECEIVE FROM RELATIVES OR FRIENDS FOR THIS DISTRESS?	☐	☐	☐	☐

0 = NONE	
1 = LOW HELP	e.g. Occasional advice/ support.
2 = MODERATE HELP	e.g. Weekly practical and/ or emotional support and/ or relief from caring.
3 = HIGH HELP	e.g. Regular respite and assistance with tasks (e.g. 3-4 times per week).
9 = NOT KNOWN	

	user	carer	staff	rater
HOW MUCH HELP DOES THE CARER RECEIVE FROM LOCAL SERVICES FOR THIS DISTRESS?	☐	☐	☐	☐
HOW MUCH HELP DOES THE CARER NEED FROM LOCAL SERVICES FOR THIS DISTRESS?	☐	☐	☐	☐

0 = NONE	
1 = LOW HELP	e.g. Advice e.g. about other options such as residential care.
2 = MODERATE HELP	e.g. Weekly day care: occasional respite: CPN visits: carers support groups.
3 = HIGH HELP	e.g. Regular respite admissions. Treatment and/ or counselling for stress/depression.
9 = NOT KNOWN	

	user	carer	staff	rater
DOES THE CARER RECEIVE THE RIGHT TYPE OF HELP FOR THIS DISTRESS? (0 = NO 1 = YES 9 = NOT KNOWN)	☐	☐	☐	☐
OVERALL, IS THE CARER SATISFIED WITH THE AMOUNT OF HELP THEY ARE RECEIVING FOR THIS DISTRESS? (0 = NOT SATISFIED 1 = SATISFIED 9 = NOT KNOWN)	☐			

COMMENTS

CANE Summary Sheet

User Name:________________________________ Date:____________

(Section 2-4b rater's overall ratings)

Section of the CANE	Section 1 Need				Section 2 Informal help	Section 3a Formal help	Section 3b Help needed	Section 4a Type of help	4b User Satisfaction
	U	C	S	R					
1. Accommodation									
2. Looking after the home									
3. Food									
4. Self Care									
5. Caring for someone else									
6. Daytime activities									
7. Memory									
8. Eyesight / Hearing									
9. Mobility / Falls									
10. Continence									
11. Physical Health									
12. Drugs									
13. Psychotic symptoms									
14. Psychological distress									
15. Information									
16. Safety to self									
17. Inadvertant self harm									
18. Abuse / Neglect									
19. Behaviour									
20. Alcohol									
21. Company									
22. Intimate relationships									
23. Money/Budgeting									
24. Benefits									
A. Carers need for Information	▨	▨	▨	▨	▨	▨	▨	▨	▨
B. Carers psychological distress	▨	▨	▨	▨	▨	▨	▨	▨	▨
Met needs: Number of 1s in the column					▨	▨	▨	▨	▨
Unmet Needs: Number of 2s in the column					▨	▨	▨	▨	▨
Total Needs: Add number of Met needs and Unmet needs					▨	▨	▨	▨	▨
Total level of help given, needed, and satisfaction. (Add scores, rate 9 as 0)	▨	▨	▨	▨					

The Clinical Dementia Rating Scale: Chronic Care Version

Name:____________________ Rater:____________________ Date:__________

CDR Total Score:______

	None CDR 0	Questionable CDR 0.5	Mild CDR 1	Moderate CDR 2	Severe CDR 3
Memory ☐	No memory loss or slight inconsistent forgetfulness	Consistent slight forgetfulness; partial recollection of events, "benign" forgetfulness	Moderate memory loss more marked for recent events; defect interferes with everyday activities.	Severe memory loss; only highly learned material retained; new material rapidly lost.	Severe memory loss; only fragments remain.
Orientation ☐	Fully orientated	Fully orientated except for slight difficulty with time relationships.	Moderate difficulty with time relationships; oriented for familiar places, but may have geographical disorientation elsewhere.	Severe difficulty with time relationships, usually disorientated in time, often for place.	Orientation to person only
Judgment and Problem Solving ☐	Solves everyday problems well; judgment good in relation to past performance.	Slight impairment in solving problems, similarities or differences, or chooses to let staff make all decisions; does not always seek appropriate help.	Moderate difficulty in handling problems; similarities, differences, and social judgment usually maintained.	Severely impaired in handling problems, similarities, differences, social judgment usually impaired, never seeks appropriate help.	Unable to make judgments or solve problems; unable to seek appropriate help; needs staff help in all matters.
Community Affairs/Life in Institution or on Unit ☐	Independent function within the institution, attends classes, activities, and meals off the unit; participation in activities is meaningful; any level of assistance is for physical reasons and not due to cognitive impairment.	Slight impairment in these activities.	Unable to function independently at these activities though may still engage in some; appears normal to casual appearance.	No pretense of independent functioning outside of room or off the unit; appears well enough to be taken to functions off the unit.	No pretense of independent function off the unit; appears too ill to be taken to functions off the unit, or needs one to one attendance in all activities off the unit.
Home Life in Room and Hobbies ☐	Life on the unit and in room includes well maintained interests such as reading listening to music, or other hobbies or handicrafts. If resident is unable to maintain such interests it is due to physical limitations (including vision and hearing problems), or other physical illness and is not due to cognitive impairment.	Life on the unit and in room is slightly impaired.	Life in the unit and in room mildly but defiantly impaired more difficult tasks or hobbies abandoned.	Only simple chores preserved; even TV watching poorly maintained may still tidy up room; spends most of time just sitting in room or in day room, or wandering.	No significant function in room or on unit.
Personal Care ☐	Fully capable of self-care or level of care required is for physical reasons and not due to cognitive impairment.		Needs prompting and this is at least partially due to cognitive impairment	Requires assistance in dressing, hygiene, keeping of personal effects	Requires much help with personal care; often incontinent.
Profound (4)	Speech usually unintelligible or irregular unable to follow simple instructions or comprehend commands. Occasionally recognizes visitors or staff. Uses finger more than utensils, requires much assistance. Frequently incontinent despite assistance or training. Able to walk a few steps with help, usually wheelchair bound rarely out of room or unit, purposeless movements often present				
Terminal (5)	No response or comprehension, no recognition, needs to be feed, may have NG tube and/or swallowing difficulties. Total incontinence, bed ridden, unable to sit or stand.				

RATING ANXIETY IN DEMENTIA - RAID

Patients Name: **Dob:** **Hospital No:**

Rater Name: **Occupation:** **Date:**

Patient's status at the time of evaluation

1. Inpatient 2. Outpatient 3. Day hospital/Day centre 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.
- Total score is the sum of items 1 to 18. A score of 11 or more suggests significant clinical anxiety.

			Score
WORRY	1.	Worry about physical health	
	2.	Worry about cognitive performance (failing memory, getting lost when goes out, not able to follow conversation.)	
	3.	Worry over finances, family problems, physical health of relatives.	
	4.	Worry associated with false belief and/or perception	
	5.	Worry over trifles (repeatedly call for attention over trivial matters).	
APPREHENSION & VIGILANCE	6.	Frightened and anxious (keyed up and on the edge).	
	7.	Sensitivity to noise (exaggerated startle response).	
	8.	Sleep disturbance (trouble falling or staying asleep).	
	9.	Irritability (More easily annoyed than usual, short tempered and angry outbursts)	
MOTOR TENSION	10.	Trembling	
	11.	Motor tension (complain of headache, other body aches and pains)	
	12.	Restlessness (Fidgeting, cannot sit still, pacing, wringing hands, picking at clothes).	
	13.	Fatigueability, Tiredness	
AUTONOMIC HYPERSENSITIVITY	14.	Palpitations (complains of heart racing or thumping).	
	15.	Dry mouth, (not due to medication), sinking feeling in stomach.	
	16.	Hyperventilating, Shortness of breath (even when not exerting).	
	17.	Dizziness or light-headedness (complains as if going to faint).	
	18.	Sweating, flushes or chills, tingling or numbness of fingers and toes.	
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.) Describe			
PANIC ATTACKS: (Feelings of anxiety or dread that think they are going to die or have a heart attack and they simply have to do something to stop them, like immediately leaving the place, phoning the relatives, going to see a neighbour etc.) Describe			

THE CHALLENGING BEHAVIOUR SCALE (CBS) FOR OLDER PEOPLE LIVING IN CARE HOMES

Name..
Age...........................
Sex....M / F
Diagnosis of Dementia... Y / N / Don't know
Residence...
Date.....................................
Checklist Completed By..

PHYSICAL ABILITY (delete as applicable)

1. Able to walk unaided / Able to walk with aid of walking frame / In a wheelchair
2. Continent / Incontinent of urine / Incontinent of faeces / Incontinent of urine + faeces
3. Able to get in or out of bed/chair unaided / needs help to get in or out of bed/chair
4. Able to wash and dress unaided / needs help to wash and dress
5. Able to eat and drink unaided / needs help to eat and drink

Over the page the page is a list of challenging behaviours that can be shown by older adults in residential or nursing settings.
For each behaviour listed consider the person over past 8 weeks and mark:

INCIDENCE: Yes / Never. If Yes move to frequency

FREQUENCY:
4: The person displays this behaviour **daily or more**
3: This person displays this behaviour **several time a week**
2. This person displays this behaviour **several times a month**
1. This person displays this behaviour **occasionally**

DIFFICULTY:
Then *for each behaviour* shown mark down how difficult that behaviour is to cope with, when that person shows it, according to the following scale:

4: This causes a lot of problems
3: This causes quite a lot of problems
2: this is a bit of a problem
1: This is not a problem

N.B. If a person does not show a behaviour no frequency or difficulty score is needed.

If the person causes a range of difficulty with anyone behaviour, mark down the score for the worst it has been over the last few (eight) weeks. E.Moniz-Cook 2000

	CHALLENGING BEHAVIOUR	INCIDENCE		FREQUENCY	DIFFICULTY	CHALLENGE
		Yes	Never	1=occasionally 2=several/month 3=several/week 4=daily or more	1=no problem 2=bit of problem 3=quite a lot of problem 4=lots of problems	Frequency x Difficulty
1	**Physical Aggression** (hits, kicks, scratches, grabbing, etc.)					
2	**Verbal Aggression** (insults, swearing, threats, etc.)					
3	**Self Harm** (cuts/hits self, refuses food/starves self, etc.)					
4	**Shouting**					
5	**Screaming/Crying out**					
6	**Perseveration** (constantly repeating speech or actions, repetitive questioning or singing)					
7	**Wandering** (walks aimlessly around home)					
8	**Restlessness** (fidgets, unable to settled down, pacing, 'on the go', etc.)					
9	**Lack of motivation** (difficult to engage, shows no interest in activities, apathy, etc.)					
10	**Clinging** (follows/holds on to other residents/staff, etc.)					
11	**Interfering with other people**					
12	**Pilfering or Hoarding** (possessions, rubbish, paper, food, etc.)					
13	**Suspiciousness** (accusing others, etc.)					
14	**Manipulative** (takes advantage of others, staff, etc.)					
15	**Lack of Self Care** (hygiene problems, dishevelled, etc.)					
16	**Spitting**					
17	**Faecal Smearing**					
18	**Inappropriate Urinating** (in public, not in toilet, etc.)					
19	**Stripping** (removes clothes inappropriately, flashes, etc.)					
20	**Inappropriate Sexual Behaviour** (masturbates in public, makes inappropriate 'advances' to others, etc.)					
21	**Sleep Problems** (waking in night, insomnia, etc.)					
22	**Non-compliance** (deliberately ignores staff requests, refuses food, resists self care help, etc.)					
23	**Dangerous Behaviour** (causes fires or floods, etc.)					
24	**Demands Attention**					
25	**Lack of Occupation** (sits around doing nothing, etc.)					
	TOTALS Add scores (1 – 25) for each column		25	100	100	400

© cb checklist / handout 2

CLIFTON ASSESSMENT PROCEDURES FOR THE ELDERLY (CAPEBRS)
Behaviour Rating Scale

PLEASE RING THE APPROPRIATE NUMBER FOR EACH ITEM

PHYSICAL DEPENDENCY	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
APATHY	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 occupies	1
		• almost never occupies	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

COMMUNICATION DIFFICULTIES

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

SOCIAL DISTURBANCE

14. He/she is objectionable to others during the day (loud or constant talking, pilfering, soiling furniture, interfering in affairs of others, wandering about, etc):

• 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 is:

• almost never awake	0
• sometimes awake	1
• often awake	2

Eyesight: (tick which applies)	Can see (or can see with glasses) Partially blind Totally blind
Hearing: (tick which applies)	No hearing difficulties, without hearing aid No hearing aid, through requires hearing aid Has hearing difficulties which interfere with communication Is very deaf

Score: _____

Rated by : ______________________ Date : _______________

Staff/Relative

THE BARTHEL INDEX

Patient Name: ________________

Rater Name: ________________

Date: ________________

ACTIVITY **Score**

FEEDING
0 = unable ____
5 = needs help cutting, spreading butter, etc., or requires modified diet ____
10 = independent ____

BATHING
0 = dependent ____
5 = independent (or in shower) ____

GROOMING
0 = needs help with personal care ____
5 = independent face/hair/teeth/shaving (implements provided) ____

DRESSING
0 = dependent ____
5 = needs help but can do about half unaided ____
10 = independent (including buttons, zips, laces, etc.) ____

BOWELS
0 = incontinent (or needs to be given enemas) ____
5 = occasional accident ____
10 = continent ____

BLADDER
0 = incontinent, or catheterized and unable to manage alone ____
5 = occasional accident ____
10 = continent ____

TOILET USE
0 = dependent ____
5 = needs some help, but can do something alone ____
10 = independent (on and off, dressing, wiping) ____

TRANSFER (BED TO CHAIR AND BACK)
0 = unable, no sitting balance ____
5 = major help (one or two people, physical), can sit ____
10 = minor help (verbal or physical) ____
15 = independent ____

MOBILITY (ON LEVEL SURFACES)
0 = immobile or < 50 yards ____
5 = wheelchair independent, including corners, > 50 yards ____
10 = walks with help of one person (verbal or physical) > 50 yards ____
15 = independent (but may use any aid; for example, stick) > 50 yards ____

STAIRS
0 = unable ____
5 = needs help (verbal, physical, carrying aid) ____
10 = independent ____

TOTAL (0-100) ____

APPENDIX TO CHAPTER 3 RESULTS

3.13.6.i. FACTORS CORRELATED WITH OVERALL QoL SCORES

Correlations were calculated between the overall QoL scores and the clinical variables using the matched people with dementia and caregiver (191) completed QOL-AD scales (Table 13). The total QOL-AD score for the people with dementia and caregiver perceptions of the individual's QoL was significantly correlated with each other (rho = .436, p<0.001). There was no significant correlation of total QoL score with age, gender or years of education. Higher QoL scores were highly significantly associated with increased cognition (p<0.001) and ADL functioning (p<0.001), less depressed mood (p<0.001) and fewer neuropsychiatric symptoms (p<0.001). Significant negative correlations with overall QoL ratings were observed with individual NPI items depression (p<0.005) and apathy (p<0.001).

Table 13: Correlations with QOL-AD scores and pathological variables.

Variables	**QOL-AD total score** (n) 191
	rho
MMSE	.258 *
CORNELL	-.427 *
ACDS-ADL	.383 *
NPI Total	-.285 *
NPI – delusions	-.046
NPI hallucinations	-.052
NPI – agitation /aggression	-.133
NPI – depression	-.218 **
NPI – anxiety	-.111
NPI – elation	.103
NPI – apathy	-.289 *
NPI – disinhibition	.032
NPI – irritability	-.162
NPI – aberrant motor behaviour	-.110
NPI – sleep	-.074
NPI - appetite	.031
HADS Depression	-.188
HADS Anxiety	-.175

$p \leq 0.001$ = *; $p \leq 0.005$ =**

3.10.9.i. PREDICTORS OF OVERALL QoL

In step 1, the total QoL rating (weighted combined caregiver and people with dementia scores) was significantly higher when the person with dementia was not in 24-hour care ($p<0.001$). In step 2, QoL was higher in those people with dementia not in 24 hour care ($p<0.005$) and those taking AChEI ($p<0.01$). In step 3 QoL was higher when the people with dementia had less depressive symptoms ($p=.001$), ADL was better ($p=.01$), when taking AChEI ($p<0.05$) and when they were not in 24 hour care ($p<0.05$). In step 4 the model remained the same.

Table 16i: Identified predictors of people with dementia and caregiver rated QoL using regression analysis

Variables	**QOL-AD total scores** (n) = 191	
	Beta	*p≤*
CORNELL	-.356	.001
ADL	.199	.01
NPI – apathy		
NPI – irritability		
24 hour care	-.106	.05
AChEI	.156	.05
Model %	29	
F =	19.4	
Adjusted R^2	28	