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Quality of Life Measures in Old Age

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Introduction

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.[1,2] Traditionally, outcomes of treatment have been evaluated in terms of mortality or symptoms, but a more important outcome measure may be the patient's perspective; as symptoms may improve in one area while overall quality of life decreases because of the negative effects of treatment.[3] The emergence of QoL as a fundamental measure for evaluating and monitoring health outcomes in old age is attributed to the ethical and economic concerns associated with the ageing population and the concomitant increase in chronic illness and disability. Birren & Dieckmann[4] identify three main areas of concern associated with this increase: first is the impact on health service resources and the potential financial burden anticipated; second is the intrusive use of medical technologies and thirdly the QoL for people in institutions. In chronic illness, people can suffer both from the disability and the treatment.[5] Moreover, treatment can often result in limited gains in terms of survival, or absence of cure, which changes the balance as to acceptable side effects. Aggressive interventions may have therapeutic benefits that are overshadowed by the negative effects, thus leading to reduced QoL overall. Any detrimental impact on QoL needs to be weighed against the advantages offered through treatment.[6] It is the individual's perception that predicts whether they seek help, accept treatment or regard themselves to be well and recovered, and therefore, should be part of any outcome measures.[7] Thus, subjective health measures can be used to help provide a fuller picture of the individual's health state.

The meaning of QoL

The term quality of life is used frequently in everyday life, with most people assuming they know what it means without considering how to define or measure it. In terms of health, QoL has become a popular, broadly used expression, that is frequently taken for granted without the meaning being clear. There is debate about the true definition and meaning of QoL, particularly whether ratings should be 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'.[8] QoL is argued to be less related to basic needs than 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.[9-11] What is apparent is that QoL is a multidimensional concept 'just as is life itself'.[12] A wide range of domains are suggested for inclusion as QoL indicators, including physical and mental health, intellectual and emotional function, social and role function, activities of daily living, economic aspects, job and life satisfaction.[13-15] The expression QoL may also overlap with the terms health status and functional status and have been considered interchangeable.[16] Perceptions of wellbeing may however be influenced by psychological factors unrelated to health or function.[17]

Definitions and conceptualisations of QOL

There are several meanings of the term QoL which remains a vague, elusive concept for which there is no single widely accepted definition. The definitions provided are broad and varied; indeed, there may be as many QoL definitions as there are people.[18] QoL is viewed as 'a concept which incorporates all aspects of an individual's existence'[19] and as 'an abstraction which integrates and summarises all those features of our lives that we find more or less desirable and satisfying'.[20] 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.[21] Alternatively, life satisfaction, self-esteem, and physical health are argued to be key dimensions of QoL.[22] Lawton[23] 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. Fundamentally, QoL is perceived as being continuous and dynamic in nature and may be evaluated negatively or positively depending on the individual's own internal perceptions and response to their environment.

Health related QoL

Within the context of health, QoL is 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.[24,25] This definition is in keeping with that given by the World Health Organisation Quality of Life Group (WHOQOL), as “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”.[26] 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 is not regarded as so important in all cultures.[27] 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.[28] 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.[29] There are however both positive and negative elements that impact on an older person’s QoL and Hughes[30] identifies the key domains that should be evaluated when measuring older people’s QoL, these include: physical environment, social environment, socio-economic, cultural, health status, personality and personal autonomy factors.

Measuring QoL in health

Lerner[31] argues 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’. 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.[3] Hence health related QoL has become important in measuring the impact of chronic disease.[16] This is of particular significance as patients with the same clinical symptoms often differ in their evaluation of what the illness means to their life. The term ‘disability paradox’, is used to describe how patients with significant health and functional problems frequently have high QoL scores despite their health status.[32] QoL measures can be used to evaluate human and financial costs-benefits of interventions and care provided through assessing change in physical, functional, mental and social health.[33]

Calman[34] suggests that people perceive QoL in relationship to 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, QoL can therefore be improved by narrowing this gap either by improving experience or lowering expectations.[34] Importantly, the model recognises the highly individual nature of QoL and the influence of culture and past experience.[35] Carr et al[36] 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 health expectations. The impact of the disability on their QoL may thus be reduced. [36]

Subjective and Objective dimensions of QOL

Testa & Simonson[33] 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. Objective factors are primarily needs–based and incorporate basic needs that determine people's well-being in society such as environment and material resources, including levels of income, crime, pollution, transport, housing type, access to amenities and employment.[2,37] Whereas subjective factors include 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.[1] Whilst health status is defined through the objective components, QoL is determined through subjective perception and expectations (see Figure 1).[33] The subjective perceptions thus translate that objective assessment into the actual QoL experienced.[33] Nevertheless, Bowling[3] cautions that subjective measures are not designed to be used as substitutes for traditional measures of clinical endpoints but to complement existing measures and provide a fuller picture of health state.

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.[33] The overall satisfaction an individual has with life is argued to be the most important domain of QoL.[2,38] This means the importance of the individual's personal sense of satisfaction with various areas of life is recognised; these include physical comfort, emotional well-being, and interpersonal connections.[38]

Validity and Reliability

QoL scales should be able to demonstrate validity but this is complicated as there is no measure of criterion validity; as no scale can provide a full picture of people's life quality or be relevant to all individuals.[33,39,40] Content validity includes evaluation in terms of the applicability of the questionnaire and its comprehensiveness; as well as its clarity, simplicity, and likelihood of bias.[41] Scales should also have predictive validity, sensitivity and be responsive to change in QoL, particularly for clinically important changes.[3,33,42,43] 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. Orley et al[44] argues that QoL is influenced by a broad range of facets and is therefore unlikely to alter markedly from day to day. Fallowfield[45] recommends that QoL measures should discriminate between patient groups and identify those patients experiencing good QoL and those that are not. In addition, QoL measures used in clinical practice must be appropriate and acceptable for their intended use and the results meaningful and amenable to clinical interpretation.[43]

Generic v Disease Specific Measures of QoL

Generic as opposed to disease specific 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 specific aspects of the clinical condition is required.[3,33] Generic measures include single indicators, health profiles, and utility measures. Health profiles attempt to measure all aspects of health related QoL potentially affected by a condition or its treatment, thus generic instruments tend to be lengthy to ensure sensitivity and adequate psychometric properties.[3.] They can be applied irrespective of the underlying condition but may be unresponsive to changes in specific conditions. Disease specific instruments aim to have greater discrimination between severity levels of a particular disease and thus have increased sensitivity to clinical outcomes.[44] They are more concise and should be able to reflect clinically significant change in health status or disease severity. Therefore in order to detect significant clinical changes generic measures may need to be supplemented with disease specific measures,[16] particularly for evaluating therapeutic interventions within clinical trials.[33] 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, which could disadvantage arguments for additional resources.[24,46]

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 interventions.[3,16,24]

Methods of QOL measurement

Self-assessment scales

The use of visual analogue scales is a common method for measuring subjective experiences such as QoL.[47] They are however, time consuming to complete and may not be relevant to the experience being considered.[45] Self reports are 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). Standardised measures have fixed questions and a range of answers and Carr & Higginson[32] 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 of overall life satisfaction. 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 loss of information about the individual components of the scale.[48] Muldoon et al[17] and Lawton[49] 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.[12,30,49] Alternatively, Gill & Feinstein[25] 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

Direct Observation

Where self ratings of QoL are difficult to elicit, such as in dementia, observational ratings may be of more benefit.[50-52] 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 it has been argued, provides the most objective method of rating QoL in dementia as the subjective component is removed.[49,53] Observation requires a degree of interpretation by the rater and training to reduce any influence on 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.[54] Observational tools have however been devised that can be used to reliably measure health related QoL and well-being in people with dementia,[55,56] with the use of Dementia Care Mapping[56] 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.[57]

Proxy ratings

Proxy ratings involve a judgement of the person's QoL being made by another person to whom they are known and may be provided by a paid or family caregiver. Proxy reports may be the only source of information available, particularly for those people with the most severe levels of cognitive impairment.[58] Proxy ratings have been shown to be a reliable and valid indicator of patient QoL.[59,60] Nevertheless, proxies impose there own judgment, and in dementia these are thought to be influenced by feelings of caregiver burden and depression as well as by how the person with dementia is feeling.[59,61] Moreover, QoL is consistently rated lower by caregivers than patients with mild-moderate dementia.[62-66] Whilst proxy ratings may be considered necessary where cognitive impairment exists, the inclusion of the individual's own rating of QoL is the preferred method for assessment, as QoL ultimately reflects the person's with the disease experience.[67,68]

Utility assessments (cost-effectiveness)

Utility measures of QoL originate from economic and decision theory and are devised to reflect the health status and value of that health status to a patient,[16] 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.[3] 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.[8] 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 marginalises the most disabled, elderly and chronically ill.[48] 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.[43] There are however other measures of cost effectiveness which consider the cost per unit of health gain and do not involve years. Cost-utility ratios are being calculated in some trials in dementia using utility scores computed from the EQ-5D and societal weights. The National Institute of Clinical Effectiveness (NICE) now uses cost-effectiveness in consideration of all interventions in the UK.[69]

Measuring QOL in Older Age

Early studies identify retirement, bereavement, loneliness and isolation as important influences on older people's lives.[70] Whereas, more recent studies found that older people define good QoL as family, social contacts, health, mobility/ability, material circumstances, activities, happiness, youthfulness and living environment.[71] Hyde et al[72] argue that the improved health and financial status of older people means the lives of older people has changed over recent decades, with increased healthy life expectancy and access to personal incomes, such as private pensions, share dividends and rent. The QoL of people entering old age who are younger, healthier, and wealthier will differ from those much older people who are more likely to experience chronic and degenerative ill health or require palliative care. Not all older people can be assumed to suffer poor QoL and whilst health status is an essential component of QoL it cannot be used as a proxy for QoL in older age.[72] Individual perceptions are therefore essential in assessing health related QoL in people of all age groups. Magaziner[73] reported that a fifth of older adults living in the community and half of those living in institutions are reluctant or unable to be interviewed. In contrast, Livingston et al[74] administered the Index of Health-Related Quality of Life

(IHQL)[75] 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 included those people with dementia. Those experiencing somatic symptoms or subjective memory impairment were less likely to complete the questionnaires. They found that the scale was not valid in older people. Pettit et al[76] administered the 12-item Health Status Questionnaire (HSQ-12)[77] or the 12-item Short Form Health Survey (SF-12)[78] 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 people with dementia and the SF-12 was found not to distinguish between people with and without dementia. It is clear therefore that most older people and those experiencing dementia are able to complete instruments assessing their own QoL.

Measuring QOL in Mental Illness

Orley et al[44] 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. Whilst psychiatric symptoms such as depression may affect a persons' QoL they do not distort it or make their perceptions invalid. In addition, whilst institutionalisation may mean psychiatric patients perceive a good QoL due to lowered expectations their assessments are still valid. Proxy ratings for patients with cognitive impairment may be useful for planning and evaluating care, but they should not be taken as a measure of perceived QoL[44].

Measuring QoL in dementia

The nature of dementia which affects cognition and communication means assessing QoL in dementia offers a unique challenge. The progression of dementia is non-linear and has multiple causes and outcomes and is a complex disorder when compared with other health states.[46] Difficulties are routinely assumed in people with dementia providing subjective assessments of their QoL or care, owing to limitations with comprehension and reliability.[79] Providing an answer does not mean that the question is necessarily understood, and QoL may also be perceived differently as the disease progresses.[80] However, it is logical to assume that people with dementia will have likes and dislikes[55]. Even in the most severe dementia it is possible to display preferences and aversions through emotional expression. Lawton[49] reasons that although subjective measures demand a degree of cognitive skill people with dementia can provide reliable assessments of their mood and QoL. The patient's subjective ratings of QoL are suggested as the gold standard for measuring QoL.

Several studies have now shown that QoL can be reliably measured in people with mild, moderate and severe dementia using self rating QoL scales.[51,61,81,82] However, there are differences in QoL ratings as given by caregiver proxies and the person with dementia's own ratings.[62,83-86] 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.

Few studies have employed QoL as an outcome measure for interventions in dementia and at present the evidence is not consistent, possibly due to the variety of measures used. Studies have indicated both an increase and decrease in QoL as dementia advances.[65,87,88] Some studies which have identified cognition and dementia severity as a predictor of QoL in dementia,[59,89] were based on caregiver proxy ratings of the person, although more recent studies found caregiver proxy ratings of QoL were strongly associated with depression, disability, and neuropsychiatric symptoms of the person with dementia.[64,83,84,90,91,] Depressive symptoms have most consistently been identified as a predictor of lower QoL in dementia.[59,62-64,66,81-84] A review of recent studies of QoL in dementia found that depression was most strongly associated with lower QoL in dementia, but found no consistent association between lower QoL and socio-demographic factors or a decline in cognition and functional ability.[92]

Choosing a QoL measure

There are a broad range of QoL scales which may be used for people with psychiatric disorder[3,93] and for older people.[42,94] The evidence for the validity, reliability and acceptability of generic QoL scales with older people is mixed, although their use is encouraged within research and clinical practice to promote evidence based healthcare.[1,42,74,94,95] Table 1 gives some examples of generic scales[72,77,78,96] that have been used in studies involving older people with mental health needs.[76,97,98] Haywood et al's[42,94] review of QoL measures in old age found the SF-36 showed the best reliability and recommend its use where a comprehensive assessment of health is required in older people. Alternatively, the EQ-5D[96] (see figure 2) is recommended where a briefer assessment is needed and significant changes in health are anticipated.[42,94]

Table 2 gives examples of disease specific QoL scales in dementia.[51,61,88,99,100] Each of the disease specific QoL scales have been included in previous literature reviews examining the validity and reliability of QoL scales in dementia and their use is supported.[68,80,101-105] The QOL-AD[61] (see figure 3) is the preferred measure of choice, as it is brief and has demonstrated sensitivity to psychosocial interventions.[101] However, none of the reviews conclusively identifies a QoL scale for use with people with dementia and Schölzel-Dorenbos et al[102] state that no QoL scale can be used across all stages of dementia.

Overall, QoL measures should be brief, easy to use, valid and reliable, sensitive to change and useful for both clinical and research settings. In dementia these should where possible include both patient and proxy ratings. It is also possible to generate QALY's from the scores of some QoL scales such as the SF-12, EQ-5D and DEMQOL, to provide an economic evaluation.

Conclusion

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 to older people. Moreover, in chronic and disabling disorders where symptomatic and functional recovery is unrealistic, improving quality of life is a particularly worthwhile outcome. QoL is now an established outcome measure for older people and should be routinely included within studies evaluating the effectiveness of care and treatment. Further evidence is needed to show how interventions influence QoL provided to older people with mental health needs. The research undertaken in recent years has established the validity and reliability of a number of QoL measures for use with older people, particularly, within dementia. Where possible the individual's perceptions should be sought in preference to the views of others and this may offer a challenge to health professionals working with older people experiencing increasing physical and mental frailty.

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Figure 1: Conceptual scheme of the domains and variables involved in a Quality-of-Life Assessment (Taken from Testa & Simonson, 1996)

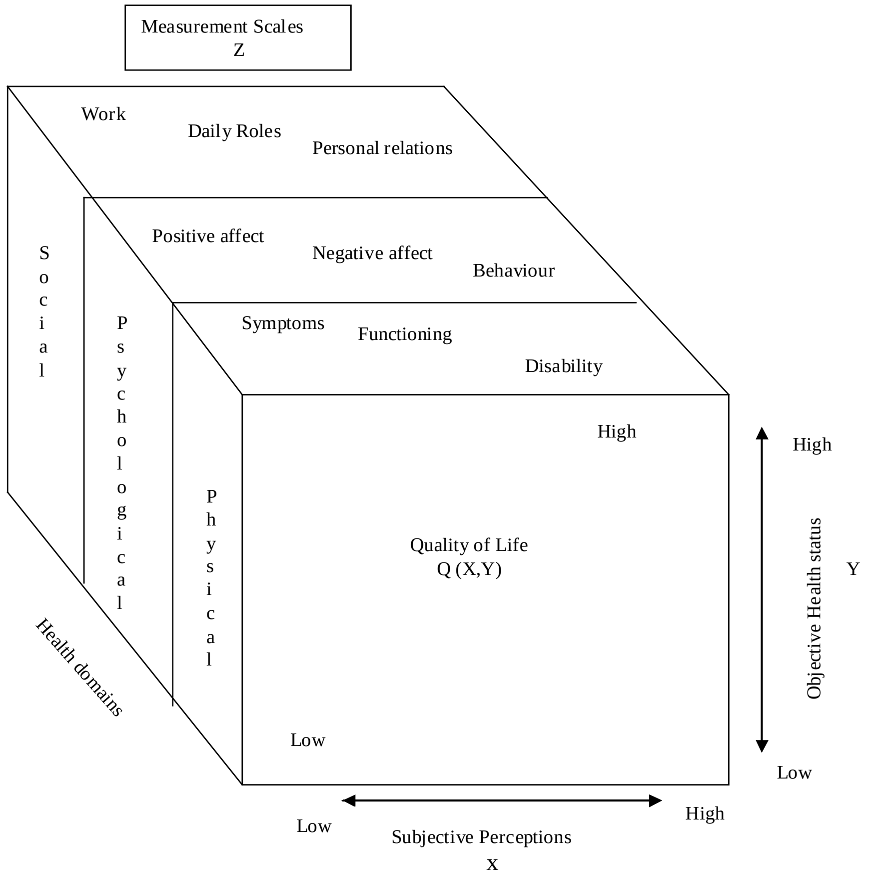

Table 1: Generic quality of life instruments for use with older people

QoL Measure	Target population	Respondent	Item No	Domains	Single score	Time taken
EQ-5D EuroQol group, (1990)	General	Self-report	5	Mobility Self-care Usual activities Pain/discomfort Anxiety/depression	Yes	5mins
SF-12 Ware et al., (1996)	General	Self-report	12-36	Physical functioning Role - physical Bodily pain General Health Vitality Social functioning Role emotional Mental Health Health Transition	Yes	10 mins
HSQ – 12 item Radosevich & Pruitt, (1996)	General	Self-report	12-39	Physical functioning Role - physical Bodily pain Health perception Energy/fatigue Social functioning Role mental Mental Health	Yes	10 mins
CASP-19 Hyde et al., (2003)	Early Old Age	Self-report	19	Control Autonomy Self-realization Pleasure	No	Not specified

Table 2: 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

Figure 2 : EuroQol (EQ-5D) UK English version

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

Mobility

1. I have no problems in walking about ☐
2. I have some problems in walking about ☐
3. I am confined to bed ☐

Self-Care

1. I have no problems with self-care ☐
2. I have some problems washing or dressing myself ☐
3. I am unable to wash or dress myself ☐

Usual Activities (*e.g. work, study, housework, family or leisure activities)*

1. I have no problems with performing my usual activities ☐
2. I have some problems with performing my usual activities ☐
3. I am unable to perform my usual activities ☐

Pain/Discomfort

1. I have no pain or discomfort ☐
2. I have moderate pain or discomfort ☐
3. I have extreme pain or discomfort ☐

Anxiety/Depression

1. I am not anxious or depressed ☐
2. I am moderately anxious or depressed ☐
3. I am extremely anxious or depressed ☐

Taken from EQ-5D User Guide, Version 1.0., Nov 2007. The EuroQol Group

Figure 3: Quality of Life in Alzheimer's Disease (QOL-AD)

(Participant Version)

ID Number Assessment Number Interview Date

Instructions: Interviewer administer according to standard instructions.
Circle your responses.

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

Total

Comments:

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