

Quality of life in dementia: a systematically conducted narrative review of dementia-specific measurement scales

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Objectives: Ascertaining the quality of life (QoL) in people with dementia is important for evaluating service outcomes and cost-effectiveness. This paper identifies QoL measures for people with dementia and assesses their properties.

Method: A systematic narrative review identified articles using dementia QoL measures. Electronic databases searched were AMED, CINAHL, EMBASE, Index to Theses, IBSS, MEDLINE, PsycINFO, Sociological Abstracts, and Web of Science. All available years and languages (if with an English language abstract) were included.

Results: Searches yielded 6806 citations; 3043 were multiple duplicates (759 being true duplicates). Abstracts were read; 182 full papers were selected/obtained, of which 126 were included as relevant. Few measures were based on rigorous conceptual frameworks. Some referenced Lawton's model (Dementia Quality of Life [DQOL] and Quality of Life in Alzheimer's Disease [QOL-AD]), though these tapped part of this only; others claimed relationship to a health-related QoL concept (e.g. DEMQOL), though had less social relevance; others were based on limited domains (e.g. activity, affect) or clinical opinions (Quality of Life in Late-Stage Dementia [QUALID]). Many measures were based on proxy assessments or observations of people with dementia's QoL, rather than their own ratings. The Bath Assessment of Subjective Quality of Life in Dementia (BASQID) was developed involving people with dementia and caregivers, but excluded some of their main themes. All measures were tested on selective samples only (ranging from community to hospital clinics, or subsamples/waves of existing population surveys), in a few sites. Their general applicability remains unknown, and predictive validity remains largely untested.

Conclusion: The lack of consensus on measuring QoL in dementia suggests a need for a broader, more rigorously tested QoL measure.

Keywords: dementia; cognitive impairment; quality of life; measurement scale; measures; psychometrics

Introduction: the importance of measuring the 'quality of life'

'Quality of life' (QoL) is a key endpoint of health and social service interventions. That is, with increasing emphasis on evidence-based clinical practice and the inclusion of patient-based outcomes, patient-reported outcome measures (PROMs) of health-related or disease-specific QoL are increasingly used in *clinical trials*, and in other *evaluations of health and social care*. Information from PROMs has a key role to play in policy-making, as well as in empowering patients and giving them a voice (www.mentalhealthconcern.org/files/MHCO509.pdf [accessed 24 February 2014]). For example, in the NHS, all patients having hip or knee replacements, varicose vein surgery, or groin hernia surgery are invited to fill in outcome measures against which to evaluate health policy and practice (<http://www.nhs.uk/NHSEngland/thenhs/records/proms/Pages/aboutproms.aspx>; www.hscic.gov.uk/proms [accessed 24 February 2014]). The policy focus on patient-based measures has led to a focus on QoL outcome measures – for a variety of issues, as well as dementia.

Quality of life

Definitions of health-related QoL overlap with those of broader health status, and include physical, mental, social and role functioning, and health perceptions (e.g. Ware & Sherbourne, 1992). Broader QoL incorporates more than health; it is more multidimensional than health-related or disease-specific QoL, and is relevant when examining the whole person, and also in evaluating interventions – or conditions – that can affect one's whole life, as in many long-term mental and physical illnesses, particularly in older age (Bowling, 2005). Broader models of QoL were heavily influenced by early social science literature on well-being and satisfaction with life (e.g. Andrews & Withey, 1976; Campbell, Converse, & Rogers, 1976). Some consider life satisfaction to be a major component of QoL in later life (as will be discussed), along with psychological components that can be affected by life's challenges (e.g. self-esteem) (George & Bearon, 1980).

Given the lack of agreement on optimal measurement instruments, it has been common practice for investigators to use broader health status scales as proxy measures of QoL, or Health-Related Quality of Life (HRQoL). These

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types of measures are sometimes combined with disease-specific measures of symptoms, mental and/or physical functioning, generic and disease-specific ‘quality of life’, and well-being. The wide range of measures used, and their varying or overlapping emphases, has led to the adoption of the term ‘patient-reported outcome measures’ (PROMS), in recognition of this diversity (Fitzpatrick, Davey, Buxton, & Jones, 1998).

The models of QoL and their measures that are used to evaluate health and social service interventions are primarily health related, with a heavy emphasis on physical and mental functioning, although people themselves have identified a wider range of life areas as important to them, and as affected by health conditions (Bowling, 1995, 1996; Bowling et al., 2003). Measures of self-assessed health-related and disease-specific QoL commonly use patient-based outcome indicators for various long-term and acute health conditions and their treatment. They are intended to focus only on the areas of life directly influenced by their health or the condition, and its treatment, and aim to quantify an individual’s subjective perceptions about their experiences as affected by their health and treatment. Subjective perceptions are of value, as overall QoL may be perceived differently by different people.

The current lack of consensus on best measurement, and the diversity of approaches used, can be problematic for attempts to evaluate service outcomes, and for evidence-synthesis on the cost-effectiveness of interventions. Homogenisation of diverse measures in combined data sets is challenging, and the validity of attempts is questionable when measures have different conceptual backgrounds, question aims (e.g. questions about ability versus performance in measures of functioning), and question wording and response choices. Ideally, broader, multidimensional perspectives of QoL, and the impact of long-term conditions, are required if measures are to enable the comprehensive evaluation of services. In view of the subjectivity of the QoL concept, and in order to achieve social significance (especially in ethnically and socially diverse societies), lay perspectives, not just those of experts, need to be incorporated. Indeed, Bond and Corner (2004) suggested that the true perspectives of people with dementia (the topic of this paper) have often been neglected, although Corner conducted qualitative interviews with people with dementia and their caregivers in order to begin to address this gap (Corner, 2003), while Bowling and colleagues addressed this issue among population samples of older people, developing a measure based on respondents’ own views (Bowling, 2009; Bowling & Stenner, 2011).

The case of dementia

As Moniz-Cook et al. (2008) pointed out, it is increasingly recognised that psychosocial interventions contribute to the care of people with dementia and their families in a wide range of domains. This has led to the need for measures which capture a broader range of relevant areas of life. Due to the lack of consensus about appropriate outcome measures for the evaluation of effectiveness of interventions in dementia care, Moniz-Cooke et al. (2008)

undertook consensus workshops, a pan-European consultation, and a systematic literature review to identify the best, psychometrically sound outcome measures in this context. They identified 22 measures, and concluded that, for people with dementia, these covered *quality of life*, mood, global function, behaviour, and skills in daily living. For family carers, these covered mood and burden, including coping with behaviour, and *quality of life*.

There are specific challenges in QoL research with people with dementia (that is, who are cognitively impaired and may have a diagnosis of Alzheimer’s disease or other syndrome), which include the reliability of self-assessments in relation to people who have severe impairments potentially influencing their awareness, as well as the questionable reliability of proxy assessments (Addington-Hall & Kalra, 2001). Further challenges emerge from the different settings in which people who are cognitively impaired might live – from their own or others’ homes, to care homes, while some may not have a fixed abode. Each offers different environments, opportunities, and restrictions.

Several measures of broader QoL, embedded within holistic models of functioning, life and needs satisfaction, have been developed for use with people with long-term mental illnesses (Bowling, 2005; Thornicroft & Tansella, 1996; World Health Organization, 2001). Their development for use with people with dementia has been slower, although there is a long history of measurement of stress and coping among caregivers.

Nevertheless, several instruments *have* been developed to assess HRQOL and QoL in dementia specifically, and these have been characterised in a small number of reviews – perhaps the earliest of which is that of Ready and Ott (2003). These authors searched the literature from 1966 to 2002 in MEDLINE and PsychINFO only, identifying just nine measures in 14 papers. Since then, there has been a considerable expansion of interest in measuring QoL in people with dementia, with a rise in the number of reviews – though most of such reviews have tended to be limited in one way or another. For example, Ettema et al. (2005) searched for papers published on the topic between 1990 and 2003 from just two databases; Thompson and Kingston (2004) also searched reviews up to 2003, and only sought English language articles; Smith et al.’s (2005) work was based on limited keyword searches; Schlözel-Dorenbos, van der Steen, Engels, and Olde Rikkert (2007) conducted a systematic review of use of QoL measures in randomised controlled trials (RCTs) only, and only of interventions in people with mild cognitive impairment or dementia (and found relatively few studies); Banerjee et al.’s (2009) literature review was limited to disease-specific measures of HRQOL in dementia (and furthermore used only a few keywords); and Gräske, Fischer, Kuhlmeier, and Wolf-Ostermann (2012) aimed to identify dementia-specific QoL measures appropriate for use in shared housing arrangements solely (hence finding little).

It is worth noting some of the findings from these reviews. Smith et al. (2005) summarised their overview of five measurement reviews, and noted a lack of evaluation of responsiveness, questionable applicability, and lack of standardised content among the included measures. Most

placed a heavy emphasis on symptoms and physical and emotional functioning, with little emphasis on wider areas of life. Meanwhile, Banerjee et al.'s (2009) review (of research up to 2007) reported that little is known about the natural history of HRQOL in dementia, or what attributes or interventions enhance or decrease it. Further, reviews of concepts only have also been conducted in relation to specific topics (e.g. nursing care) (Kwasky, Harrison, & Whall, 2010).

Some have suggested preferences amongst the measures. For example, the analysis of Moniz-Cook et al. (2008) suggested that the Quality of Life in Alzheimer's Disease (QOL-AD) by Logsdon, Gibbons, McCurry, and Teri (1999), with a version for both the person with dementia and the carer, is the measure of choice as it is brief (13 items) and has evidence of psychometric acceptability, sensitivity to psychosocial interventions, and can be used with people with poor cognitive scores (as low as 3 on the Mini Mental State Examination). They also concluded that the Dementia Quality of Life (DQOL) (Brod, Stewart, Sands, & Walton, 1999) may be preferred when more details about QoL are required, although it may appear repetitive to respondents and the self-rated version is limited to people with mild to moderate dementia. However, the current review identifies more than half-a-dozen dementia-specific QoL measures that *were not* considered by Moniz-Cooke et al. (2008). In this paper, a systematic review on measures of QoL in dementia is reported. A systematic review aims to identify, appraise, select, and synthesise all high-quality research evidence relevant to a specified research question. While we systematically searched the literature, selected and appraised relevant papers (as described below), it was not appropriate to undertake meta-analyses of results, as the target was QoL measures in dementia, rather than, for example, identifying risks or a clinical outcome. In such cases, the term *narrative review* is used. As the target was about measurement, we followed the principles for reviewing measurement scales established by Fitzpatrick, Bowling, Mackintosh, and Gibbons (2006) and Fitzpatrick et al. (2007). This review is more comprehensive than past reviews, focusing on the characteristics of the different measures. The next section specifies the aims of this review.

Aim of the review

Our systematic narrative review aimed to

- (1) identify studies using QoL measures (structured and semi-structured) with people with dementia, including observational studies, controlled evaluations, and RCTs of health and social service interventions;
- (2) assess the scope and domains included in the QoL measures, theoretical and conceptual frameworks, and the extent of user or patient involvement in their development, by type of users;
- (3) assess the measurement properties of each scale identified – by population type and type/severity of dementia – for validity, reliability, sensitivity (including to models and settings of care),

precision, item completion rates, factor structure, responsiveness to pre-defined changes over time, and acceptability and feasibility, including item response and ability of people with different severities of dementia to complete the measures.

Method

The aim was to review papers reporting on the measurement of QoL of people with dementia (including reviews), considering the psychometric properties of the measures. Search terms were agreed upon by the research team and included: QoL, health-related QoL, life satisfaction, well-being, scale, questionnaires, patient/client-reported outcomes, dementia, Alzheimer's disease and cognitive disorders. The key terms were then developed using MESH terms and keywords, augmented by the inclusion of keywords used in studies as they were identified. Strategies were tailored to each bibliographic database as necessary. The keywords by database are shown in the tables of keywords by search strategy in supplementary web file #1 (refer to the 'Supplemental data' section available with the online version of this review).

Electronic databases searched were AMED, CINAHL, EMBASE, Index to Theses, IBSS, MEDLINE, PsycINFO, Sociological Abstracts, and Web of Science. There were no language restrictions; all available years were searched. Searches were conducted by P. Sands, with A. Bowling. A. Bowling selected potentially relevant papers from abstracts and titles, independently checked by G. Rowe, with disagreements resolved by discussion. Selected printed papers were provided by S. Adams. In addition, the NIHR Health Technology Assessment (HTA) database was searched, along with the Cochrane database and Google Scholar. Searches were conducted for all years up to summer of 2012 (see the supplementary file for month, reflecting search sequences, in the 'Supplemental data' section).

Database searches yielded 6806 citations, of which there were 3043 multiple duplicates (i.e. were labelled as 'Trash' by EndNote). If a reference was picked up three times as a duplicate, then EndNote counted one as a duplicate entry and removed the other two records, meaning that there were 759 true duplicates.

The totals, with duplicates removed, identified in each database were as follows (with totals *including* duplicates in brackets):

- AMED: 300 (424)
- CINAHL: 1500 (1595)
- EMBASE (1974–2012): 1927 (2694)
- IBSS: 125 (203)
- Index to Theses: 2 (2)
- MEDLINE (1946–2012): 1817 (3178)
- PsycINFO: 774 (1108)
- Sociological Abstracts: 251 (434)
- Web of Science: 54 (118)

Abstracts and titles were read and 182 full papers were selected and obtained. This included searches of HTA publications, the Cochrane database, Google Scholar, and relevant citations from included papers. Box 1 summarises the

Box 1. Number of papers not available and exclusions:

Not available: 1 thesis; 3 journal papers were unobtainable from British Library.

Exclusions: number of papers obtained and excluded from review:

- (i) Papers all in non-English language [all languages included in the search but excluded once paper obtained if all, including abstract, in non-English]: N = 16 (German: 6, Spanish 4, Dutch 2, Polish 2, French 1, Chinese 1).
- (ii) Papers reporting only on generic health status, HR-QoL, utility, life satisfaction, QoL measures and cognitive impairment. These were included in the search, but excluded from this review and table, which focuses on dementia specific measures of QoL: N = 58 (see below for breakdown by type).

Number of papers focusing only on generic QoL, well-being, life satisfaction (N = 17):

COOP-WONCA Charts = 1

Philadelphia Geriatric Centre Affect Rating Scale = 3

Positive Affect Scale = 2

Life Satisfaction questionnaire = 1

Schedule for Individual QoL (SEIQOL) = 1

Spitzer global index of QoL = 1

Unspecified global item of QoL = 2

WHOQOL (Brief/WHOQOL 100) = 6

Papers focusing only on measuring health-status (N = 10):

SF-36 Health Survey questionnaire = 7

SF-12 Health Survey questionnaire = 1

SF-8 Health Survey questionnaire = 1

Nottingham Health Profile = 1

Utility measures (N = 31):

EUROQOL (EQ-5D) = 17

EQ-5D-C (C = cognitive symptoms) = 1

Health Utilities Index - mark 1 (HUI) = 4

Health Utilities Index - mark 2 = 5

Health Utilities Index - mark 3 = 2

Quality of Well-Being Scale = 2

- (iii) Remaining exclusions focused solely on carers' own QoL; commentaries; and conditions outside the aims of the review (neurological impairment due to physical illness; cardiovascular disease, stroke, respiratory disease, HIV/AIDS, Parkinson's disease, multiple sclerosis, cancer, epilepsy; psychotic conditions).

Searches conducted by Paula Sands, University of Southampton Library; papers obtained by Sue Adams, UCL.

numbers and reasons for excluding items from the list of 182 papers. In addition, one thesis was not accessible and three papers were not obtainable by the British Library (these were: #135 *Dementia and Neuropsychologia*, 2009, 3: 241–247; #167 *Revista de Neurologia*, 1998, 26: 582–584; #236 *Current Aging Science*, 2008, 1: 140–143). Specific reasons for exclusion were: papers which were in a non-English language (no English abstract); reported on broader health status, QoL, or utility measures only; not relevant (e.g. study only of caregivers' QoL; commentaries and overviews; studies of neurological impairment due to physical illness (coronary heart disease, stroke, respiratory disease, HIV/AIDS, Parkinson's disease, multiple sclerosis, cancer, epilepsy, and psychotic conditions). A total of 126 articles remained and were included in this review.

Results

The 126 papers reviewed are shown in Table SF1 in supplementary web file #2 (refer to the 'Supplemental data'

section available with the online version of this review), which presents results. This shows that the measures identified (listed from most-to-least articles) were:

- QOL-AD ($n = 46$)
- DQOL ($n = 14$)
- ADRQL ($n = 12$)
- DEMQOL ($n = 10$)
- QUALIDEM ($n = 8$)
- QUALID ($n = 6$)
- Observational DCM ($n = 5$)
- BASQID ($n = 4$)
- Cornell–Brown scale ($n = 3$)
- Activity and Affect rating scales ($n = 2$)
- Pleasant events schedule ($n = 2$)
- QOL-D ($n = 2$)
- QOLAS ($n = 1$)
- Observational OQOLD and OQOLDA ($n = 1$)
- Progressive Deterioration Scale ($n = 1$)
- Psychological well-being in cognitively impaired persons ($n = 1$)

Note that in several papers a number of measures were used: the numbers in the list above refer to the number of papers where the method noted was the predominant focus of attention. In addition to the 118 papers that included psychometric information on measures, there were 11 reviews, which are discussed later briefly.

Identified measures of QoL for people with dementia

The measures identified are described next – in order of the most-to-least researched (see the list above). A summary of the measures is provided in Table 1 – which is based, in form, on the table of Ready and Ott (2003), but extended to include additional QoL measures and updated to take account of changes (e.g. in evidence) on the measures that they previously identified. Table 2 provides details of the psychometric evidence related to each of these measures. This table is based upon one from Smith et al. (2005), but again extended and updated to account for new information. Both tables list the measures alphabetically. Similarities, differences, and trends between and across the measures are discussed after the individual measure descriptions and critiques.

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

QOL-AD is a brief, 13-item self-report (and 15-item caregiver-report) measure. Its items were selected to reflect domains of QoL in older adults based on a literature review of QoL in geriatric populations, with face validity and comprehensiveness being ensured by having people with Alzheimer's disease, caregivers, older people without dementia, and dementia experts review potential items. It includes assessment of physical health, mental health, social and functional domains, and an overall QoL score. People complete the QOL-AD questionnaire in interview format about their own QoL (completion time about 10–15 minutes); caregivers complete it as a self-administered questionnaire about the person with dementia's QoL (completion time about 5 minutes).

The QOL-AD appears to be the best researched of all the measures (used in over 40 identified studies). It has good psychometric properties overall, and can be completed with people with a wide range of severity of dementia. The QOL-AD appears to be reliable and valid for individuals with Mini-Mental State Examination (MMSE) scores greater than 10. It also benefits from being relatively brief and having people rate themselves (non-proxy). The measure has also been translated and tested in French, Portuguese, Spanish, Japanese, Cantonese, Mandarin, and Korean. However, further research is needed to clarify the relationship between the person with dementia and caregiver reports of the former's QoL, as some discrepancy between the different ratings have been found (e.g. Huang, Chang, Tang, Chiu, & Weng, 2008; Shin, Carter, Masterman, Fairbanks, & Cummings, 2005; Spector & Orrell, 2006).

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

DQOL was designed for people with dementia's administration only, and assesses feeling states and mood. The developers were influenced by the definition of QoL by Birren, Lubben and Rowe (1991) as a multidimensional concept encompassing *social*, *psychological*, and *physical* domains, being both *subjective* and *objective*. They distinguished QoL from HRQOL – the latter referring to aspects of QoL most likely to be affected by disease. They suggested that more disease-specific QoL instruments target appropriate domains affected by a condition and should have increased likelihood of capturing changes over time. It was proposed that five areas related to QoL could be relevant for people with dementia, notably aesthetics (ability to appreciate beauty, nature, and surroundings), positive affect (humour, feelings of happiness, contentment, hopefulness), absence of negative affect (worry, frustration, depression, anxiety, sadness, loneliness, fear, irritability, nervousness, embarrassment, anger), belonging (feeling loveable, liked, useful), and self-esteem. The final version of the measure contains 29 items, forming 5 subscales. Screening questions ensure that people understand questionnaire instructions and the response format for the scale. The instrument has also been translated into French, Spanish, German, and Chinese.

On the positive side, the DQOL was developed through an involved process (an iterative conceptual and statistical process that included a literature review and consultation with expert panels composed of people with dementia, caregivers, and professional care providers), and the developers concluded that people with mild to moderate dementia can be considered to be good informants of their own subjective states, thus paving the way for people's own, rather than proxy, measures of QoL in dementia. However, the scale has been tested on single-area and non-generalisable samples, largely limited to memory clinic populations. Psychometric testing has produced inconsistent results, although small numbers may have been responsible for poor results in some studies. Furthermore, Ready, Ott, and Grace (2004) found that informant's and people with dementia's own self-reports of QoL for mild Alzheimer's disease and mild cognitive impairment were discrepant, although they suggested that analyses showed this was *not* due to the latter's lack of insight into symptoms and limitations. They suggested that proxy informants' (caregivers') own symptoms of depression might influence their perceptions of the person with dementia's QoL, and/or the standards of both the person with dementia and informant vary. The discrepancy between such perceptions has been recorded elsewhere (e.g. Ready, Ott, & Grace, 2006).

ADRQL (also known as ADRQOL) (Rabins, Kasper, Kleinman, Black, & Patrick, 1999)

The Alzheimer Disease Related Quality of Life (ADRQL), also known as ADRQOL, is a proxy instrument that was developed to assess multidimensional

Table 1. Characteristics of dementia quality of life scales.

Instrument	Conceptual basis for measure?	Patient report	Proxy report	Patient population ^a	Subscales	Items	Measurement
Affect and Activity Ratings	The affect component was derived from Lawton's Affect Rating Scale (Lawton et al., 1996); the activity component was derived from Teri and Logsdon's Pleasant Events Schedule-AD (Teri & Logsdon, 1991). Assumption is that the experience of living is the key component of QoL.	Yes	Yes	Mild to severe dementia Institutional- and home-care settings	Activity Positive affect Negative affect	21 Activity involves 15 items – 5 outside the home (e.g. going outdoors, riding in a car, going with a caregiver to a public place); 10 indoor (including exercising, reading, handicraft to watching television and visiting with family). Affect involves six items – three on positive affect and three on negative affect (depression, anxiety, anger, contentment, interest, pleasure).	Coding occurs over one week (activity) or two weeks (affect). There are three frequency response categories: frequently (\geq three times per week), occasionally (\geq three times per week), and never. The activity variables can be combined into a composite summary activity measure, which ranges from 0 to 30, with higher scores indicating more activity.
Alzheimer Disease Related Quality of Life (ADROL)	Described as being based on Lawton's (1994) generic QoL. Instrument items developed by experts, discussed by caregivers, and finally chosen by researchers.	No	Yes	Mild to severe dementia	Social interaction Awareness of self >Feelings and mood >Enjoyment of activities >Response to surroundings >(three only in one of the Japanese variants)	48 (24 in one Japanese variant)	Four-point Likert rating scales (0 = not at all applicable, 1 = not very applicable, 2 = somewhat applicable, 3 = very much applicable). Preference weighting is used, that is, the weights of the indicators vary according to the importance of the domain.
BASQID	This questions the medical model of QoL, that is, the more the symptoms present, the poorer the QoL. QoL was stated to be the person with dementia's perspective of multiple domains of QoL. The measure was then developed from the perspectives of people with dementia. Initially, used items from nine different domains of QoL, then reduced these through field testing.	Yes	No	Mild – moderate dementia	Satisfaction Feelings or experience	14 Section A health: three items (self-rated overall QoL, self-rated health, self-rated memory) Section B satisfaction: eight items (health, ability to look after self, level of energy, enthusiasm for doing things, the way usually spend day, level of independence, personal relationships, ability to talk to other people) Section C: six items (able to move around local community, able to do all the activities want to, able to do things enjoy, have the choice to do things want to, extent feel useful, extent feel happy)	Section A: five-point scale, from 0 to 4 (very poor, poor, fair, good, very good) (excluded from BASQID – analysed individually) Section B: five-point scale, from 0 to 4 (not at all satisfied, a little satisfied, satisfied, very satisfied, extremely satisfied) Section C: five-point scale, from 0 to 4 (not at all, a little, a moderate amount, quite a lot, a great deal) Total and subscale scores can be derived, that is, the total and the two subscale raw scores can be converted into transformed scores ranging from 0 to 100, using transformation charts.

(continued)

Table 1. (Continued)

Instrument	Conceptual basis for measure?	Patient report	Proxy report	Patient population ^a	Subscales	Items	Measurement
Cornell–Brown Scale for Quality of Life (CBS)	Based on the concept that high QoL is indicated by positive affect, physical and psychological satisfaction, self-esteem and relative absence of negative affect and experiences.	Yes (patient involved in interview along with caregiver)	Yes (clinician completes scale based on joint interview)	Mild–moderate dementia Home-care setting	None (four domains, but these are not treated as subscales)	19 including: Negative affectivity (i.e. sadness, anxiety, irritability); Physical complaints (i.e. weight loss, lack of energy); Positive affectivity (i.e. serenity, self-esteem, happiness); Satisfactions (i.e. weight satisfaction, restful sleep)	19 bipolar items rated on a five-point scale ranging from –2 to +2, where –2 = severe or constant presence of the negative end of an item, –1 = mild or intermittent presence, 0 = neutral (or rating not possible), +1 = mild or intermittent presence of positive characteristic, +2 = very or constant presence of the positive pole. CBS yields a single QoL score, ranging from –38 to +38, with more positive scores equalling higher QoL.
Dementia Care Mapping (DCM)	DCM is based on Kitwood's (1993, 1997) psychosocial theories of dementia, suggesting there are four sentient states relevant to QoL in dementia: sense of personal growth, sense of agency, social confidence, and hope.	No	Yes	Mild to severe dementia Institutional-care setting	Well/ill-being Social withdrawal activity	Not specified well: some variation in descriptions between studies: apparently 24 behaviours and a number of well/ill-being values	Involves observations of each individual's activity and associated levels of well-being on a –5 to +5 scale at five minute intervals over a minimum five hour period. A mean well-being score is calculated, resulting in a score placed in one of five categories (with different specifications of these). An additional category of overall ill-being has also been created (<0) for a more sensitive measure of poor well-being.
Dementia Quality of Life (DQOL)	Referred to the definition by Birren et al. (1991) of QoL as a multidimensional concept, encompassing social, psychological, and physical domains, being subjective, objective, and evaluative. QoL reflects the individual's subjective perception of the impact of a health condition on everyday living.	Yes	No	Mild–moderate dementia Home-care setting	Self-esteem Positive affect Negative affect Aesthetics Feelings of belonging	30: Self-esteem (four items) Positive affect/humour (six items) Negative affect (11 items) Feelings of belonging (three items) Sense of aesthetics (five items)	Five-point Likert scales of the frequency of enjoyment or occurrence (not at all to a lot, and never to very often) High scores on negative affect and low scores on the other subscales indicate poor QoL. Each domain generates a scale (mean of component items). Optional additional item (Overall, how would you rate your quality of life) to examine the link between global QoL and its constituent parts.

(continued)

Instrument	Conceptual basis for measure?	Patient report	Proxy report	Patient population ^a	Subscales	Items	Measurement
DEMQOL/ DEMQOL-Proxy	DEMQOL is distinct from broader QoL measures, relating only to condition and related to, but not conceptually equivalent to, the impact of symptoms and functional status. HRQOL is defined as a multidimensional concept reflecting an individual's subjective perception of the impact of a health condition on everyday living (based on Bullinger et al., 1993).	Yes	Yes	Mild–moderate dementia	Daily activities and looking after self Health and well-being Cognitive functioning Social relationships Self-concept	28 (DEMQOL); 31 (DEMQOL-Proxy)	Four-point response scales (a lot, quite a bit, a little, not at all). The DEMQOL score range is thus 28–112 and DEMQOL-Proxy score range is 31–124, with higher scores equalling better QoL.
OOOLD and OOQLDA	No explicit QoL theory. Reviewed dementia-specific QoL instruments, apparently informed to some degree by DCM (which in turn was based on work by Kitwood).	No	Yes	Mild–moderate (OOOLD) and severe (OOQLDA) dementia, Institutional- and home-care settings	None (simply yields seven single codes for several areas of wellness)	Six	There are seven codes for each of the six wellness dimensions, with 1 = no observable impact in any of the dimensions.
Pleasant Events Schedule (PES- AD)	No particular conceptual basis: items generated from interviews with caregivers, expert opinions, and literature reviews.	No	Yes	Mild–moderate dementia Institutional- and home-care settings	Frequency (of item) Availability (in the past three months) Now (whether enjoyed now) Past (whether enjoyed in the past)	53 initially; 20 item now available	Items rated by frequency/availability in the past month, on three-point scales: not at all, a few times (one to six times), and often (7+ times). Results are analysed by the four subscales and summed scores. An overall summary score of the frequency of enjoyable activities is calculated.
Progressive Deterioration Scale	No QoL theory: conducted in-depth interviews with caregivers of AD patients to generate items.	No	Yes	Mild to severe dementia	None (contains 27 QoL areas)	27 concerning: Extent to which can leave immediate neighbourhood Ability to travel distances alone Confusion in familiar settings Use of familiar household implements Participation/enjoyment of leisure/cultural activities Extent to which does household chores Involvement in family finances/budgeting Interest in doing household tasks Travel on public transport Self-care and routine tasks Social function/behaviour in social settings	Rated on bipolar analogue scales.

Table 1. (Continued)

Instrument	Conceptual basis for measure?	Patient report	Proxy report	Patient population ^a	Subscales	Items	Measurement
Psychological Well-being in Cognitively Impaired Persons (PWB-CIP)	Referred to Lawton's (1983, 1994, 1997) models of QoL as informative of the instrument (encompassing psychological well-being; behavioural competence; objective environment; perceived QoL).	No	Yes	Mild–moderate dementia Home-care setting	Positive interaction Frustrated/agitated Discontent	11	Likert response scales, where higher scores represent higher psychological well-being.
Quality of Life in Alzheimer's Disease (QOL-AD)	No conceptual framework noted in pioneering articles (although other authors have suggested it is based on Lawton's (1994) model, e.g. Léon-Salas et al. (2011) . Domains of measure validated during focus groups with people with dementia and caregivers.	Yes	Yes	Mild to severe dementia Home-care setting	None (includes assessment of several QoL domains, providing an overall QoL score)	13 (15 for caregiver) Physical health Energy level Mood Living situation Memory Family Marriage Friends Self as a whole Ability to do chores around the house Ability to do things for fun Money Life as a whole (caregiver removes 'marriage' and 'money'; adds: people who work here; ability to take care of oneself; ability to live with others; ability to make choices in one's life)	Four-point scales (poor, fair, good, excellent) People with dementia's and caregivers scores are summed separately, for a total possible score ranging from 13 to 52 and 15 to 60, respectively, with higher scores equating to higher QoL.
Quality of Life Assessment Schedule (QOLAS) ^b	No particular conceptual framework. Apparently a generic, individualised, patient-centred QOL assessment technique was adapted.	Yes	Yes	Mild–moderate dementia Home-care setting	Physical Psychological Social/family Usual activities Cognitive	10	Ratings collected by the person with dementia and by the caregiver about them.
QOL-D	Not precisely described, though QoL is stated as a multidimensional concept with social, psychological, and physical domains. Items generated from interviews with caregivers, expert opinions, and literature reviews.	Yes	Yes	Mild to severe dementia Institutional setting	Positive affect Negative affect and actions Ability of communication Restlessness Attachment with others Spontaneity and activity	31	Three-point response options.

(continued)

Table 1. (Continued)

Instrument	Conceptual basis for measure?	Patient report	Proxy report	Patient population ^a	Subscales	Items	Measurement
QUALID	To the extent that this was developed from Albert et al.'s (1996) affect and activity measures (for use with late-stage dementia patients), this could be said to be based on Lawton's (1994) model (which informed the prior measure).	No	Yes	Severe dementia Institutional setting	None (ratings of several observable behaviours assumed to be indicative of their QoL, proving a single QoL score)	11	Five-point Likert response scale captures the frequency of each item (total score ranging from 11 to 55). Lower scores reflected a higher QoL.
QUALIDEM	QoL defined as: 'multidimensional evaluation of the person – environment system of the individual, in terms of adaptation to the perceived consequences of the dementia' (Ettema et al., 2005). It is based on an adaptation – coping theoretical framework of Droes (1991), which notes seven adaptive tasks as important domains of QoL.	No	Yes	Two versions: one for mild to moderate dementia and the other for severe dementia Institutional setting	Care relationship* Positive affect* Negative affect* Restless tense behaviour* Positive self-image Social relations* Social isolation* Feeling at home Having something to do [* = in the 18-item version]	37 (mild to severe version) 18 (very severe version)	Four-point scale (never, rarely/seldom, sometimes, frequently/ often). Subscale scores are linearly transformed into a range of 1 – 100.

^aPatient population for which the instrument was developed and/or from which psychometric data have been collected.

^bThe QOLAS instrument is unique in that it can be tailored to each individual (the other instruments all have a standard administration procedure).

Table 2. The psychometric properties of the QoL dementia instruments.

	A&A	ADRQL	BASQID	CBS	DCM	DQOL	DEM-QOL (proxy)	OQOLD/ OQOL-DA	PES- AD	PDS	PWB- CIP	QOL-AD patient (proxy)	QOLAS	QOL- D	QUAL- ID	QUAL- IDEM
Acceptability	+	0	+	0	0	++	++(+++)	0	0	0	0	0(0)	0	++	0	++
<i>Reliability</i>																
Internal consistency	0	+++	++	++	+	++	+++(++++)	0	+	0	++	+++(++++)	++	+++	+	++
Test-retest	++	0	+	0	0	++	++(+)	0	0	+++	+	+++(++++)	0	0	+++	0
Inter-rater reliability	0	+	NA	++	++	NA	NA(0)	+	0	0	0	NA(+)	NA	++	+++	+
<i>Validity</i>																
Content	++	+++	+	+	+	+++	++(+++)	0	0	+	0	+++(++++)	+++	++	+	++
Criterion-related	+	0	0	++	++	0	0	0	0	0	0	0(0)	+	0	++	+
Construct: convergent validity	+	+++	+	+	0	++	+(+)	++	+	0	0	+++(++++)	+++	++	++	++
Construct: discriminant validity	0	0	+	0	0	0	+(+)	0	0	0	0	0(0)	0	0	++	++
Known groups differences	+	0	0	0	0	++	0	+	0	+	++	+++ (0)	+++	0	+	++
Factor structure: principal components analysis	0	0	+	0	+	+++	+(+)	0	0	0	+	+(+)	0	++	+	+
Responsiveness	0	0	+	0	0	0	+(+)	0	0	0	0	0(0)	0	0	++	0
Respondent burden	0	+	0	0	0	+++	+(+)	0	++	+	0	+++ (++++)	0	0	0	+
Cultural and language adaptations	0	+	0	0	0	0	0	0	0	0	0	+(+)	0	0	+	++

Notes: 0: no supportive evidence or not tested; +: some limited evidence; ++: some good evidence (although some aspects do not meet criteria or some aspects not tested/reported); +++: good evidence; NA, not applicable. Ratings are also affected by the quantity of evidence, e.g. good inter-rater reliability from a single study may receive a ++ rating instead of +++, and so on. In the case of 'factor analysis': 0: no analysis or evidence reported; +: evidence in terms of hypothetical factor structure is not good (e.g. a different number of factors have emerged); ++: factors largely emerge as expected; +++: the factor structure is confirmed (in at least one study).

domains of QoL in dementia that caregivers of people with Alzheimer's disease, people with Alzheimer's disease, and experts identified as important. It is used for family caregivers' proxy ratings of the person with dementia's QoL. Most items (of which there are 48, grouped into 5 domains) rely on observable behaviours and actions (over the preceding two weeks), although some are based on assessment of subjective and internal states. It measures positive and negative behaviours, but excludes the domain of physical functioning. Its development was based on the belief that people with Alzheimer's disease are unable to make assessments of their QoL, and caregivers and health professionals are best placed to assess this in people with Alzheimer's disease.

Instrument development relied heavily on experts (the authors and health care professionals) to form the domains and items, and then comments from a focus group of 12 family caregivers of people with Alzheimer's disease. Final sorting of items within domains was made by researchers in gerontology and health services research. This was followed by three cognitive interviews with caregivers to identify words or phrases that were difficult to understand. That is, the development was informed by opinions of relevant parties, not theory *per se* (except to the extent that selected experts brought knowledge of theory to initial domains/items and in the final sorting). The instrument has been translated into Japanese.

Internal consistency appears to be adequate in care and nursing facility settings, although not all results are good, and samples have been selective or site-specific. The assumption of the scale developers that people with Alzheimer's disease are unable to make assessments of their QoL is now regarded as invalid in the case of mild to moderate dementia (e.g. Trigg, Jones, & Skevington, 2007). Furthermore, people with Alzheimer's disease had minimal input into design, raising questions of validity.

DEMQOL (Smith et al., 2005)

The Dementia Quality of Life questionnaire (DEMQOL) aims to assess QoL in people with mild to moderate dementia. A proxy version was developed for caregivers: DEMQOL-Proxy. It is presented by an interviewer for self-administration (DEMQOL) by the person with dementia and/or informant, and proxy assessments by caregivers (DEMQOL-Proxy).

DEMQOL is distinct from broader QoL as it relates only to areas of QoL affected by a health condition, and is related to, but not conceptually equivalent to, the impact of symptoms and functional status. The conceptual framework of DEMQOL is thus based on HRQOL, which is defined as a multidimensional concept reflecting an individual's subjective perception of the impact of a health condition on everyday living (based on Bullinger, Anderson, Cella, & Aaronson, 1993). The instrument finally included five domains (subscales) (daily activities and looking after self; health and well-being; cognitive functioning; social relationships; self-concept). A Spanish version has also been produced.

Overall DEMQOL is among the best measures of HRQOL for people with mild to moderate dementia and DEMQOL-Proxy is judged to be comparable to the best available proxy measures for those with mild to moderate dementia (according to Smith et al., 2005). That is, these measures have performed consistently well in psychometric tests with regard to the concepts of reliability, validity, and response burden (see Table 2).

Interviews underpinning the development of DEMQOL were described as 'bottom-up', but they were based on topics from the existing literature – e.g. a predetermined checklist of topics derived from the literature, which would have constrained the breadth of interview and emerging themes. The development of the DEMQOL also suffered from the use of relatively small field test samples. Moderate support overall has been reported for the validity and reliability of the DEMQOL with mild/moderate dementia, although results for the DEMQOL-Proxy are weaker (e.g. Banerjee et al., 2007; Smith et al., 2005). Results have been poor for people with severe dementia, although smaller subsamples mean not all tests could be conducted (e.g. factor analysis). There has been no support for the factor structure of either tool: five subscales have not been supported in factor analyses (Smith et al., 2005).

QUALIDEM (Ettema, Dröes, de Lange, Mellenbergh, & Ribbe, 2007)

The QUALIDEM (a dementia specific quality of life instrument) is based on ratings of observable behaviour by staff. It is based on an *adaptation-coping theoretical framework* of seven adaptive tasks seen as important domains of QoL, which is defined as: 'the multidimensional evaluation of the person-environment system of the individual, in terms of adaptation to the perceived consequences of the dementia'.

Two versions are available: a 37-item version suitable for people with mild to severe dementia, and an 18-item version suitable for people with very severe dementia. The full version contains nine domains describing observable behaviour; the smaller version uses just six of the nine domains.

Reliability has been shown to be weak to good. There is some evidence of validity, although content validity was assessed by experts rather than people with dementia (although users were involved at the outset of tool development). Samples used for psychometric testing were setting-specific and not generalisable. The instrument was developed in Dutch, and has been translated into German (see Dichter, 2011). There is potential for observer bias with such observational, proxy tools. This is its drawback, although this method can be useful with people who have severe dementia and those unable to assess their own QoL.

Quality of Life in Late-Stage Dementia (QUALID) (Weiner et al., 2000)

The QUALID is based on Lawton's (1994) further four-component division of QoL in dementia into objective

criteria (behavioural competence and aspects of external environment) and subjective criteria (perceived QoL and psychological well-being). It was developed by clinicians, from Albert et al.'s (1996) affect and activity measures, for use with people with late-stage dementia living in institutional settings. The developers referred to the challenge of people with dementia and their ability for self-assessment, which requires intact cognitive functioning. Due to this, they state that observer ratings are preferred for people with late-stage dementia.

Thus, QUALID is a proxy report scale, administered by interviewers to a family caregiver or professional care provider informant. The window of observation for each person is seven days. QUALID contains 11 items of positive and negative dimensions of concrete and observable mood and performance thought to be indicative of QoL in late-stage dementia, notably subjective, affective state while people with dementia are involved in daily life (smiling, sadness, crying, discomfort, irritability, calmness), and behavioural signs of comfort and engagement in very basic activities of life judged to be important by social norms (eating, engaging, interacting with others). The instrument focuses on basic activities to minimise the confounding effects of cognitive impairment, opportunity, income, culture, and education. Swedish, Norwegian, Dutch, and Spanish translations have been done and used.

QUALID provides both a rating of the overall quality of the interview, which includes the informant's ability to understand the items/responses and the effort the informant puts forth in answering questions, and the familiarity of the informant with the person with dementia. These items are not included in the score, but offer information about the validity and usefulness of the ratings.

Results for reliability and validity range from weak to good, although studies are based on small and selective samples (being intended for severe dementia only). Thus, the wider utility of the instrument is still to be convincingly demonstrated. The measure is both good in being brief and potentially limited also in effectively being a lesser version of another instrument, with a narrow conceptualisation of QoL.

Observational Dementia Care Mapping (DCM) ***(e.g. Ballard et al., 2001)***

DCM is a structured observational tool for use in residential settings. It is based on, e.g. Kitwood's (1997) psychosocial theories of dementia, and on four sentient states relevant to QoL in dementia: sense of personal growth, sense of agency, social confidence, and hope. The developers commented on difficulties of obtaining reliable subjective reports from individuals with dementia, leading to the development of this alternative observational method (with observations taking place at five minute intervals over at least five hours). Observed behaviours include conversation or creative expression and negative behaviours. Three additional behaviours are considered (sleeping, speaking, locomotion), focusing on well-being. A mean well-being score is calculated, though an additional

category of overall ill-being has also been created (<0) for a more sensitive measure of *poor* well-being.

The DCM has inconsistent results for reliability and validity, and inter-rater agreement is poor; DCM ratings are often based on small samples (e.g. Thornton, Hatton, & Tatham, 2004). The method is time-consuming with potential for bias (being a proxy measure).

Bath Assessment of Subjective Quality of Life in Dementia (BASQID) (Trigg, Skevington, & Jones, 2007)

The developers of the BASQID questioned the medical model of QoL that the more the symptoms present, the poorer the QoL. They referred to the medical model of QoL emphasising functional capacity, especially the ability to perform everyday tasks and fulfil pre-morbid social and occupational roles, and criticised the model as having an optimum, aspirational level of functioning, leading to people who are impaired or disabled achieving, by definition, a poor QoL. Thus, they argued that health, while important as a component of QoL, should be distinct.

They pointed to growing evidence that people with dementia can respond accurately to questions about their QoL. The BASQID was developed and tested for use with people with mild to moderate dementia (MMSE score 12+), and to be administered during interviews directly with the person with dementia.

QoL was conceptualised – based on qualitative interviews with 30 people with mild to moderate dementia – as the person's evaluation of multiple domains of QoL: health, function, leisure, sleep, energy, mobility, environment, mood, social interaction, as well as feelings of need fulfillment, identity, and affect. All these components of the conceptual framework were included in the initial item pool. The final, reduced 14-item version of the BASQID covered only the QoL domains of: health, social interaction, function, mobility, being occupied, energy, and psychological well-being.

The authors accepted that the BASQID does not include a comprehensive profile of QoL as only a narrow subset of the pool of items were included in the final version (notably adequacy of the person's environment and sleep, which were within the initial conceptual framework, were excluded). Thus, the measure is brief, and narrower than concepts of broader QoL. The measure was developed and tested on small samples. There was initial support for reliability and validity, though extensive testing is needed (i.e. with more and larger samples).

Cornell–Brown Scale (CBS) (Ready, Ott, Grace, & Fernandez, 2002)

The CBS is based on the concept that high QoL is indicated by positive affect, physical and psychological satisfaction, self-esteem, and a relative absence of negative affect and experiences – with cognition and functioning being excluded to prevent contamination of QoL with other disease features. The CBS has 19 bipolar items in four domains (not treated as separate subscales), which are rated by clinicians after *joint* patient and caregiver

(semi-structured) interviews, involving a time frame that covers the previous month.

The weakness of the scale is that it is based on clinical ratings, requiring joint interviews between clinicians, patients, and caregivers. Otherwise, there is some support for reliability and validity, but there are few studies (e.g. Ready & Ott, 2008), and results were based on small clinical samples and thus have limited generalisability.

Activity and Affect (A&A) rating scales (Albert et al., 1996)

This measures two dimensions: activity and affect. The activity component of the A&A rating scales was derived from Teri and Logsdon's Pleasant Events Schedule-AD (Teri & Logsdon, 1991). The affect component was derived from Lawton's Affect Rating Scale (Lawton, Van Haitsma, & Klapper, 1996). The measure contains 15 activity items (inside and outside the home) and 6 affect items (three concerning positive affect and three negative), with frequency coded over one or two weeks, respectively.

Two versions currently exist: (1) a proxy version for care providers to complete about the resident, which rates both activity and affect; and (2) a resident version, completed by the person with dementia, which rates activity only.

There is some support for reliability and validity, although proxy versions are inconsistent. The measure also has the advantage of being usable with a range of people with dementia (from severe to mild symptoms) and in a range of settings (institutional and home care). The main limitations are the restriction of two dimensions (three subscales), reflecting a very narrow conceptualisation of QoL, the potential for proxy bias in that instrument, and the relative lack of evidence of the instrument's qualities (from two studies conducted in the US – Albert et al., 1996; Albert et al., 1999).

Pleasant Events Schedule (PES-AD) (Teri & Logsdon, 1991)

Items for this QoL questionnaire were generated from interviews with caregivers, expert opinions, and literature reviews. The PES-AD contains a list of events that people sometimes enjoy. The full PES-AD is a 53-item checklist of events and activities for people with Alzheimer's disease, based on two earlier Pleasant Events Schedules. A short 20-item version is also available. It is a proxy measure with ratings of three elements (in four subscales): *frequency* of activity events in past month; *availability* of the events to the person with Alzheimer's disease; and enjoyment of events – *now* and in the *past*. The activity list is broad, and ranges from meeting someone new or making friends to looking at the stars or moon.

There is limited support for validity and reliability – but this comes from just one study with 42 people (i.e. evidence is limited and not generalisable) – see Logsdon and Teri (1997). As with other instruments, this is a proxy measure, so may be criticised on this basis.

Quality of Life Questionnaire for Dementia (QOL-D) (Terada et al., 2002)

The developers of QOL-D conceptualised QoL as multidimensional, encompassing social, psychological, and physical domains (both subjective and objective). Items for the QOL-D questionnaire were generated from interviews with caregivers, expert opinions, and literature reviews. The final version comprised 31 items grouped into six areas, with each item divided into a positive and a negative aspect of QoL.

The instrument was developed in Japanese. Results for psychometric properties range from weak to strong, but studies of it are few (i.e. Sloane et al., 2005; Terada et al., 2002). The measure is a proxy one (though a residents' version is also available) and the instrument was developed without input from people with dementia.

Quality of Life Assessment Schedule (QOLAS) (Selai, Trimble, Rosser, & Harvey, 2001)

The developers adapted a generic, *individualised*, person-centred QoL assessment technique, forming the QOLAS for use with people with dementia. They reported that people with dementia understood the interview and were able to describe their QoL both qualitatively and quantitatively. The QOLAS has five domains (physical, psychological, social/family, daily activities, cognitive), with ratings collected by the person with dementia and by the caregiver about them.

Internal consistency has been reported to be good, but agreement between the person with dementia QOLAS scores and scores on a generic measure of QoL ranged from poor to good, and agreement for caregiver-reported QoL ranged from poor to very good (caregivers rated people with dementia as having a worse QoL than the latter rated themselves on all subdomains of the QOLAS). There is just one study reporting on this measure (Selai et al., 2001), involving a very small sample, and hence further research is needed.

Observational OQOLD and OQOLDA (Edelman et al., 2007)

These are two related observational tools: Observing Quality of Life in Dementia (OQOLD) and Observing Quality of Life for Dementia Advanced (OQOLDA). Their development was based on qualitative and quantitative research.

Observations are recorded every five minutes for six hours for each resident/client. Codes relate to the state of pleasantness or unpleasantness in which the individual is observed most often: the most extreme state of pleasantness in which the individual is observed and the most extreme state of unpleasantness. Another coding system relates to 'whole-person wellness', with wellness dimensions of: physical, emotional, social, spiritual, intellectual, and vocational. These are used to describe the primary and secondary impacts of activities and programmes on people with dementia.

There is little evidence of the inter-rater reliability and validity of OQOLD and OQOLDA (reported by the developers – Edelman et al., 2007), but overall there is limited information on the measures' psychometric properties. The measure is also a proxy measure. Further research is needed on this instrument.

Progressive Deterioration Scale (PDS) (DeJong, Osterlund, & Roy, 1989)

PDS was generated from interviews with spouses/caregivers of people with Alzheimer's disease, designed to be completed by the caregiver (so a proxy measure). The final version of the PDS contains 27 items in 19 domains, based on a variety of activities/competences/interests. Results for reliability are inconsistent, though there is some support for validity. Inadequate information about the sample has been presented. The measure is based mainly on daily activities, thus limited mainly to *function*, though QoL is generally recognised to be broader than this. The authors cautioned that findings are suggestive and not conclusive. This requires further testing.

Psychological Well-Being in Cognitively Impaired Persons (PWB-CIP) (Burgener, Twigg, & Popovich, 2005)

The developers referred to Lawton's (1983, 1994, 1997) models of QoL as the enduring foundations for later definitions of QoL in dementia, encompassing psychological well-being (affect [anxiety, depression, agitation]); positive emotions; behavioural competence (physical health, functional ability, cognition, time use, social behaviour); objective environment (structured events, architecture of environment); and perceived QoL. They argued that *psychological* well-being is a key domain of QoL, justifying their scale. PWB is defined, based on the literature, as related to: positive and negative affect; relaxation; pleasure; meaningful interactions with environment, including activity and participation; and agitation-calmness. Burgener et al. (2005) stated that the PWB-CIP is consistent with these concepts with its inclusion of affective, behavioural, and interaction components.

The measure originally contained 16 items, which were reduced to 11 items following factor analysis. The caregiver version asks them to rate the items as they most closely reflect the behaviour of the person with dementia, and affect. The time frame used is the previous 24 hours.

Internal consistency has been shown to be good and construct validity was supported in the authors' longitudinal study, although their sample was relatively small. The limitation is that psychological well-being is only one domain of QoL. Furthermore, proxy assessments have potential for bias, and only one study has reported on this measure.

Comparisons across measures

Conceptual frameworks

The first issue to consider is the conceptual framework underlying the different measures. These are noted in

Table 1. It is questionable as to what extent most measures are truly based on a rigorous conceptual framework. The framework most frequently mentioned is that of Lawton. Lawton's (1983) earlier framework defined QoL as 'the good life', but he later changed this in relation to older age to include multidimensional evaluation, by the person and by social-normative criteria, of four domains: behavioural competence (ability to function in adaptive and socially appropriate ways), objective environment (everything that exists externally to the individual, including physical and interpersonal factors), psychological well-being (mental health and emotional state), and one's subjective satisfaction with the overall QoL (Lawton, 1991, 1994). Lawton (1997) expanded on his conceptualisation of QoL to include the multiple domains of affect (happiness, agitation, depression, affect state, emotional expression, spirituality); self-esteem (self-esteem, life satisfaction, morale); appraisal of physical functioning (self-care); social relationships (satisfaction with family and friends); social environment (social engagement, meaningful time use, physical safety, presence of amenities, privacy, stimulating quality, aesthetic quality, satisfaction with spare time and housing [institution] and healthcare; freedom from barriers); and health (behavioural symptoms, psychiatric symptoms).

Although investigators of the measurement of broader QoL in people with dementia sometimes refer to Lawton's conceptual model, few have attempted to develop the model or place it in the context of the broader literature on the topic. Some measures of QoL in dementia focus only on activity or events (A&A measures and QUALID – see Albert et al., 1996; Logsdon & Teri, 1997), or tap just part of it, and leave their measure underdeveloped (e.g. QOL-AD). Such measures may have limited applicability to those with severe conditions – for which other types of measure need to be developed.

Other conceptualisations of QoL in dementia are based on *health-related QoL* only (e.g. DEMQOL – Smith et al., 2005), with little reference to social (person with dementia) relevance. Still others are based upon specific elements of QoL, such as physical, psychological, and social well-being (QOLAS – Selai & Trimble, 1999), or broader models encompassing physical, mental, and social well-being and functioning, including daily and recreational activities, positive and negative affect, sense of aesthetics, and self-concept (e.g. DQOL – see Brod et al., 1999). While the BASQID (e.g. Trigg et al., 2007) was developed 'bottom-up' with the involvement of people with dementia and caregivers, this excludes some of the main themes that were emphasised by participants, and the studies underpinning it were small in size. Many measures are based on proxy assessments or observations of the person with dementia's QoL, rather than the latter's own ratings.

Psychometrics

Table 2 provides details of the psychometrics of the different measures. Clearly, the amount of evidence related to the measures depends in part on their popularity and

when they were developed. For some measures, there is little psychometric evidence (PES-AD, PDS, PWB-CIP, OQOLD, QOLAS, QOL-D, A&A, ADRQL, BASQID, CBS, DCM), while for others there is a growing body of evaluative work (DQOL, DEMQOL, QOL-AD, QUALID, and QALIDEM). Where psychometric data does exist, this tends to be focused on establishing reliability rather than validity, particularly internal consistency, and, to a lesser extent, test–retest reliability (few have details on inter-rater reliability). Among the measures that have greatest evidence for reliability are QOL-AD, DEMQOL, QALID, QOL-D, D-QOL, and CBS, whereas PES-AD, OQOLD, and A&A have scant evidence in this regard and therefore need to be treated with caution (since reliability is a necessary condition for validity).

Regarding the concept of validity, most measures can claim some evidence for content validity (though perhaps not PES-AD and OQOLD), as well as convergent validity, although relatively few studies (on any of the measures) have attempted to address other key validity concepts. It seems that the measures with the best evidence of overall validity are D-QOL, QOL-AD, QUALID, and QUALIDEM (with evidence existing on aspects such as known-group-differences and discriminant validity). However, the critical issue of responsiveness is almost untested for these measures (with little evidence, at best, for QUALID, DEMQOL, and BASQID). While factor analyses have been conducted on several of the measures, results have generally been equivocal, with resultant factor structures rarely supporting hypothesised subscales.

A further limitation of all measures (see particularly the table in supplementary web file #2 [refer to the ‘Supplemental data’ section available with the online version of this review]) is that they were tested on selective samples (ranging from people in the community to those attending hospital clinics, or subsamples/waves of existing population surveys), in a small number of sites/areas; therefore, their general and international applicability remains unknown. Predictive validity over time also remains largely untested for these measures (that is, the extent to which a measure’s score predicts scores on a valid criterion measure). We contend that it is possible to assess predictive ability in a progressive syndrome such as dementia: for example, QoL would be expected to decrease with decrease in cognitive functioning, up to the point where self-reports of QoL are no longer possible for the person. There thus remains a need for a broader QoL in dementia measurement, with full and rigorous psychometric testing.

Finally, it is important to note that many of the measures are based on proxy assessments, with questionable reliability and validity, and less often on observations that are time-consuming and expensive, or questioning of the person with dementia, which is possible with those with mild to moderate dementia. Of the latter, the more recently developed DEMQOL focuses only on health-related QoL in dementia (Smith et al., 2005), and the broader, but brief, BASQID did not include several of the areas prioritised by people with dementia/their caregivers (Trigg et al., 2007).

Discussion

Measuring QoL outcomes is a potentially important factor in ensuring that a person with dementia can ‘live well’ with dementia, and that their care and support up to death maintains this. QoL outcome assessment has important implications for cost-effective health and social care support services and pathways. Where a condition can affect life overall, broader QoL measurement is required, in addition to capturing elements specific to the caring circumstances. For policy outcomes to be relevant to people, measures of QoL need to have social, as well as policy, relevance, and conceptual strength. QoL is a subjective concept, and thus measures need to be socially relevant and require the participation of the population concerned in their development. Few investigators have developed their measures truly ‘bottom-up’ with the population of interest, and tend to focus on ‘expert opinions’. Thus, most measures have unknown social relevance, and there is no certainty about whether they are measuring the right things.

Moreover, QoL is a subjective concept, and assessments of a person’s QoL by clinicians and family and friends vary from those of the persons themselves (see review in Table SF1 in supplementary web file #2). It is a good research practice to obtain people’s self-reports where at all possible. Some existing QoL measures have proxy versions for use with staff or carers, although these generally have weaker levels of reliability and validity (see review in Table SF1 in supplementary web file #2).

It was earlier noted that many of the previous reviews of QoL in dementia were limited. The current review has identified 16 measures that have been reported, used, and researched in well over 100 articles, and is thus the most recent and comprehensive review of the topic. For example, this review has identified other measures that have been developed since Ready and Ott’s (2003) review, while the measures they previously identified have, in several (but not all) cases, been subjected to further research.

The current analysis has revealed that most measures are only loosely based on conceptual frameworks – most measure developers referring to the work of Lawton. As such, it is no surprise that the measures themselves possess a number of similarities, though they are largely notable for focusing on specific aspects of QoL (e.g. HRQOL), with the items and scales mainly being developed based upon researchers’ ideas rather than upon patient/client conceptualisations, and many measures being based upon proxy measurement by caregivers – which, though perhaps apt in cases of severe dementia, are of questionable validity for people with mild to moderate dementia. The latter issue is emphasised by the findings from various studies of certain measures that have shown discrepancies between caregiver and people with dementia ratings. And, finally, our analysis indicates the relative paucity of psychometric evidence for the different measures. Many measures have almost no evidence of their reliability/validity or utility, while even the best-studied measures (e.g. QOL-AD) are lacking in evidence for critical matters such as their responsiveness, discriminant validity, acceptability, and factor structure. The samples on which

measures have been tested have also tended to be limited in size.

So, what might an ideal measure be like? We suggest an ideal measure would reflect the views and priorities of the person with dementia. As there has been no large-scale, representative study to elicit the views of those with mild to moderate dementia, one cannot specify the domains in advance. However, previous research on generic QoL, with representative population samples of people aged 65+ living at home in the UK, reported that lay people have broader, more multidimensional perspectives of QoL than experts, and lay views cut across disciplinary boundaries (Bowling et al., 2003).

One other issue that is perhaps worth discussing is the practical utility of an ideal measure. A broader measure does not need to be overlong. Modern and classic psychometric techniques exist to examine and reduce the number of items in scales without significantly compromising their reliability and validity. As an example, Bowling and Stenner (2011) developed a long 35-item version of a broader QoL scale, which reflected the most frequently mentioned themes raised by a representative population sample of people aged 65+, and then reduced it to a short 13-item version, with excellent reliability and validity (Bowling, Hankins, Windle, Bilotta, & Grant, 2013). Moreover, older people reported that they enjoyed the baseline interviews (Bowling et al., 2003), from which questionnaire items were derived, despite the long length of the interview, because it gave them the rare opportunity to consider all aspects of their lives (Bowling, 2005). Broader QoL measurement is quite different from neuropsychological assessment.

As researchers, we accept the need to minimise respondent burden, especially with vulnerable people. Self-reported QoL is also realistic only with those with mild to moderate dementia, and those with severe dementia are excluded. In the cases of those with severe dementia, some existing QoL measures have proxy versions for use with staff or carers, although these have weak reliability and validity and are of questionable value (see review in Table SF1 in supplementary web file #2). The issue of the exclusion of those with severe dementia from self-reported questionnaires, and proxy measures being unsatisfactory, remains an unresolved issue.

With increasing interest in measuring QoL broadly, there is also recognition of the need for shorter measures among investigators, often because investigators' core questionnaires are already lengthy, or they wish to minimise respondent and research burden. There is an increasing trade-off in research between scale length and levels of psychometric acceptability.

Finally, we need to recognise certain limitations with this review. One limitation is the focus of this review on papers written in English (or at least having an English-language abstract). As noted throughout this paper, certain measures have been developed elsewhere, or translated from English and used in other languages. It is likely that some valuable information may therefore exist in foreign language publications, and the psychometric evidence of measure validity may be greater than reported here. A

second limitation concerns the relative rating of the different measures with respect to how well they have performed psychometrically (see Table 2). Our ratings are certainly subjective: a more rigorous rating scheme could ultimately be developed, though the utility of such a scheme would depend in part on a consistent reporting of psychometric data on relevant variables that we rarely found in the reviewed papers. Some of the validity concepts, for example, are difficult to clearly define, and hence we caution readers from imputing too great a value to our ratings.

In summary, it is clear that much more research is needed to verify the quality of the present measures before we can have complete confidence in their validity and utility, and before we can endorse them for evaluating service outcomes and intervention cost-effectiveness.

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Supplemental data

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Description of authors' roles

A. Bowling, J. Manthorpe, K. Samsi, and M. Crane conceived the idea for the research, designed the search criteria, key search terms, and sources, and with L. Joly oversaw its progress; S. Adams and P. Sands conducted the searches, and collated search numbers and papers retrieved, in collaboration with A. Bowling; A. Bowling analysed the results, and with G. Rowe finalised the checking; A. Bowling and G. Rowe wrote this paper, and all authors contributed to drafts of the paper.

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