Quality of Life Research (2005) 14: 675–686

A review of quality of life instruments used in dementia

Teake P. Ettema[1], Rose-Marie Dröes[2], Jacomine de Lange[3], Gideon J. Mellenbergh[4] & Miel W. Ribbe[1]
[1]*Institute for Extramural Medicine (EMGO), VU Medical Center, Amsterdam, The Netherlands (E-mail: t.ettema@vumc.nl);* [2]*Department of Psychiatry, Alzheimer Center, Institute for Extramural Medicine (EMGO), VU Medical Center, Amsterdam, The Netherlands;* [3]*Trimbos-Institute, Netherlands Institute of Mental Health and Addiction, Utrecht, The Netherlands;* [4]*Department of Psychological Methods, University of Amsterdam, The Netherlands*

Accepted in revised form 8 July 2004

Abstract

Objective: To provide an overview of QOL measures applicable for research in dementia, the scale content, method of data collection, and their psychometric properties. *Method*: Literature research. *Results*: Six dementia-specific QOL measures were identified, eight generic measures were used in a demented population, and three dementia-specific measures related to QOL are described as well. Measures vary considerably in scale content, and method of data collection. Reliability indexes were always available, support of instrument validity was often reported, but reports of responsiveness to change were found only for two dementia-specific QOL measures. *Conclusion*: When the interest is primarily on people with dementia, a dementia-specific instrument is to be preferred. Further clarification of the concept of QOL and particularly its relation to disease severity is required.

Key words: Dementia, Dementia-specific QOL, Measures, Quality of life (QOL)

Introduction

With the growing number of older people worldwide, the number of people suffering from dementia is increasing as well. It has been estimated that in the Netherlands the prevalence of dementia will rise from the present one in every 93 persons aged 65 or over, to one in every 81 in 2020, and even to one in every 44 in the year 2040 [1]. As it is currently not possible to cure people from the disease, the main focus in dementia care has become to promote well-being and maintain an optimal quality of life (QOL). Clark adequately expressed this as 'Adding life to years rather than years to life' [2]. Although behavioral and psychological symptoms in dementia (BPSD) are frequently used outcome measures in dementia research, the past decade QOL has gained in importance, and may well become the major outcome.

Assessment of QOL however is not a straightforward enterprise. The concept lacks a general accepted definition, and very often is not defined at all [3]. Critics, therefore, may maintain that a concept like QOL cannot be measured as its nature is unclear [4]. On the other hand many researchers agree that progress in the field has been made, and that a general consensus on some fundamental issues regarding QOL has emerged [5]. For instance, it is generally accepted that QOL is a multidimensional concept [6], encompassing several domains. Most authors also agree on the subjective nature of QOL, but adopt different positions in operationally defining the concept [7]. Some conclude that self report is the only viable option in assessing QOL [8], but others consider proxy reports to provide valid data as well [9, 10].

In the field of dementia self report in many cases is not possible, as the dementia affects the cognitive abilities, raising doubts about persons with

dementia being valid and reliable informants on their life quality. This problem complicates assessment of QOL even more, in comparison with other fields in health care.

In spite of the complexity of the concept, several measures have been developed specifically for Alzheimer's disease or related dementias. Some researchers have applied generic measures in order to assess QOL of people with dementia. Though generic measures cover a broad range of QOL domains and facilitate comparisons across different disease groups, disease specific instruments have the advantage that the items aim on the problems associated with that particular disease and are, therefore, more sensitive to change in QOL. The content validity of three generic QOL measures has been seriously questioned in relation to dementia [11], supporting the general preference for disease specific measures [12].

With the need for adequate QOL instruments evident, and with the growing number of instruments used, this review was conducted in order to

- identify currently available generic and disease specific QOL instruments applicable for research in people with dementia;
- provide an overview of the psychometric properties, the content, and research purposes of these instruments;
- make recommendations for the future development of QOL measures applicable in dementia.

Method

As the term well-being is sometimes used interchangeably with QOL, both terms were included in the searches to ensure a comprehensive result. We coupled the terms 'dementia' and 'Alzheimer's disease' separately with the other two terms, and searched the electronic databases of MEDLINE and PsychINFO. This was supplemented by cross-referencing with reference lists in identified papers. Limits were set to publications in English, Dutch or German between 1990 and April 2003.

Publications retained for the review needed to describe measures of QOL (or the development of those measures) specifically for dementia, or comment on the applicability of generic QOL measures used in dementia research. Studies applying any of those measures were selected when either comments on the utility of the instrument or its psychometric properties were reported in the article. Studies operationally defining QOL by negative indicators of BPSD were excluded, as a symptom in itself does not equate to a measure of QOL. Also excluded were studies measuring QOL by the use of one item.

The initial search resulted in 1225 publications referring to QOL or well-being in combination with dementia or Alzheimer's disease in the title, the abstract or the keywords. These were downloaded into a Procite database. Initial inspection of a random selection of abstracts, made it clear that QOL or well-being was mentioned, but often not used as a dependent variable in the paper. For instance, when in a study the aim of the intervention is to improve the activity level of patients, the authors may imply that QOL is enhanced as well, without support for this statement. Therefore, further screening was executed with a search of keywords on: QOL in combination with one of the following terms: measurement, reliability, validity, questionnaire, psychometrics, and instrument. This resulted in 311 abstracts that were hand searched. Application of the inclusion criteria resulted in 33 papers being retained for this review. Cross referencing the reference lists of these papers led to identification of another 5 papers, adding up to a total of 38 papers selected for further study.

The instruments traced in this search will be reviewed on relevant psychometric properties. The first is reliability, i.e., the precision of the estimation of the true score differences between persons of a population by the differences in their observed scores. In practice this means that results of two independent administrations of the same instrument to the same person are similar. Several estimates of reliability can be distinguished, e.g., internal consistency; agreement between observers (inter-rater reliability) or between occasions (reproducibility or test–retest reliability), but an extensive treatment of the subject is beyond the scope of this paper (see e.g., [13–15]). The second is validity, i.e., QOL is being measured rather than some other concept. One may come across various types of validity, like content, criterion, or construct validity, all addressing the issue of the degree of confidence we can place on the inferences we draw from scores on scales [13]. The third is

responsiveness, defined here as the ability to detect change in QOL due to interventions, but other definitions are used as well: the ability to detect changes in the true value of the underlying construct, or important changes over time [16]. On a conceptual level responsiveness is an aspect of validity [13], and some argue that there is no need for responsiveness as a separate instrument attribute [16]. We take the position that reports on responsiveness may be informative for researchers looking for an instrument.

The domains of QOL contained in the measure are a relevant indication of the content validity and will be reported on. In addition the way the measure is administered can be of importance to the purpose of the researcher, and may be linked to the level of dementia severity, as people with advanced dementia are often no longer reliable informants on their QOL. Therefore, the population of people with dementia the measure aimed at is mentioned, if possible by cut-off scores on the Mini-Mental State Examination (MMSE), otherwise referring to the description in the paper.

Results

Of the selected papers six described the development of a new dementia specific QOL measure, and another 13 reported their further development and application. Three papers described the development of dementia specific measures for pleasant events [17], discomfort [18], and positive responses [19]. These instruments can be considered to be related to QOL, and are for reasons of comprehensiveness included in this study. Four additional papers further reported on application and properties of these instruments, and were also included. Three papers adopted a battery approach, i.e., combining different measures of QOL related domains [20–22], including parts of instruments examined in this paper, and are therefore not included.

The remaining papers reported on the application of generic measures in dementia research, and are discussed separately.

Dementia specific QOL measures

The results of six identified dementia-specific QOL measures are summarized in Table 1. The first instrument, Dementia Care Mapping (DCM) [23], was in fact designed as an audit tool to evaluate the quality of care of facilities [24]. It uses a patient centered approach and combines the well or ill-being of patients with the level of activity. Observers are trained during 3 days in order to qualify as a basic user in DCM. The observers categorize activities (behavioral composites) that patients engage in (e.g., having a meal, sleeping, playing a game), and rate the level of well-ill-being, every 5 min during a 6 hour period. The number of activities coded may vary per patient. The method is very time intensive. DCM has been successfully used to examine and detect change in the QOL of people with dementia [25–29], and can, due to the observational character, be applied through all stages of the disease (Ballard et al. [28] reported a mean MMSE score of the sample of 8.7). Perrin [19], however, expressed her doubts about the applicability of DCM in severe dementia, as people with severe dementia are no longer able to build the more complex behavioral composites from the simple behavioral components, such as a smile, a gesture, or eye-contact.

Two other instruments rely on caregiver reports: the Alzheimer's Disease Related Quality of Life (ADRQL) [30] and the Quality of Life for Dementia [31], a Japanese measure. Both instruments are developed in order to determine efficacy of behavioral interventions, environmental settings and drug treatments. The ADRQL has been applied in a study on a long-term care unit [32], which provided additional data on the validity of the instrument. A recent follow-up [33] indicated that the ADRQL is sensitive to change. Data on the reliability were reported once [9]. The constructors used information from caregivers and Alzheimer's disease experts to shape the content of the instrument. The five subscales are calculated into separate scores, but can be summed to obtain one total score. The ADRQL requires a trained interviewer for data collection.

The Quality of Life for Dementia instrument [31] is an easily administered questionnaire that provides a profile of six scores on the domains that have been identified after a factor analysis. The process of item generation relied on review of the literature, supplemented by caregiver interviews and expert opinion.

The Quality of Life in Alzheimer's Disease (QOL-AD) [34] uses both patient and caregiver

Table 1. Dementia specific QOL measures identified

Measure	Data collection	Disease severity	Items	Domains	Reliability	Validity	Responsiveness to change
Dementia Care Mapping (DCM) [23]	Trained observers using systematic observation	All stages Mean MMSE in 1 study 8.7	See text	Observed behavioral categories (number varies per patient)	Inter-rater reliability (kappa's > 0.80)[27] Test–retest Spearman correlations from 0.58 to 0.33 on key indices [25]	Some evidence of concurrent validity [25]	Is responsive to change [24–29]
Alzheimer's Disease Related Quality of Life (ADRQL) [30]	Through interview by trained interviewer of caregiver	All stages	47	Social interaction Awareness of self Enjoyment of activities Feelings and mood Response to surrounding	Internal consistency for total scale (0.80) [9]; subscales n.a.	Supported by correlations with disease severity, depression, and behavior disorder [32]	Variation in change scores over a 2 year period detected [33]
Quality of Life for Dementia (QOL-D) [31]	Caregivers	Mild to severe (on Nishimura Mental State scale)	31	Positive affect Negative affect and action Ability of communication Restlessness Attachment with others Spontaneity and activity	Internal consistency (subscales varying from 0.79 to 0.91) Inter-rater (ICC's varying from 0.63 to 0.93)	Correlations with cognitive functioning and ADL scores. Moderate correlations between domains	n.a.
Quality of Life in Alzheimer's Disease (QOL-AD) [34]	Both patient self-report, and caregiver report through interview	Mild to moderate (community dwelling) MSSE > 10	13	Appraisal of: Physical condition Mood Interpersonal relations Ability to participate in meaningful activities Financial situation	Internal consistency (reports from 0.81 to 0.90 [34]; 0.83 to 0.90 [35]) Test–retest (ICC 0.76 for patients, 0.92 for carers) [34]. Patient-carer agreement: (r 0.40 [34]; ICC 0.19[a], 0.28[b] [35])	Supported by correlations with depression, day-to-day functioning, and pleasant events frequency	n.a.
Dementia Quality of Life instrument (D-QOL) [37]	Patient self-report through interview	Mild to moderate MMSE > 12	29	Self-esteem Positive affect Negative affect Feelings of belonging Sense of aesthetics	Internal consistency (subscales varying from 0.67 to 0.89) test–retest (0.64 to 0.90)	Evidence of discriminant validity between depressed and non-depressed patients	n.a.
The Cornell–Brown Scale for Quality of Life in Dementia [10]	Clinicist interviewing both patient and caregiver	Mild to moderate (tested in outpatients; mean MMSE 22.1)	19	Negative affect Positive affect Physical complaints Satisfactions (weight satisfaction; restful sleep)	Internal consistency for total scale (0.81) Inter-rater (ICC 0.90)	Correlations with visual analogue dysphoria scale	n.a.

Unless otherwise stated, data on reliability and validity derived from reference in the first column.
n.a.: not available: ICC = Intra Class Correlation, [a] ICC for absolute agreement, [b] ICC for consistency: r = Pearson correlation.

reports to assess QOL. The initially reported psychometric properties were reproduced in a larger sample [35], and the (American) instrument has been applied in a British sample as well [36]. Its application is limited to patient-carer dyads living in the community, and patients with MMSE score > 10. The QOL-AD is easy to administer.

The Dementia Quality of Life instrument (D-QOL) [8, 37] explicitly relies on self-report by patients. Brod et al. take the position that QOL is a strictly subjective individual experience, and, therefore, can only be assessed through patient information. They report reliable data obtained from patients with MMSE scores > 12. Brod et al. based the content of the instrument upon extensive literature research and the use of focus groups. The D-QOL provides a profile of scores on the subscales, and no overall score.

The Cornell–Brown Scale for Quality of Life in Dementia [10] is developed as a modification of an instrument to assess negative affect: the Cornell Scale for Depression in Dementia [38]. The original items, consisting of depression adjectives and symptoms, were supplemented with positive adjectives and satisfactions to add a positive pole. QOL is operationally defined as presence of positive affect, satisfactions, self-esteem, and the relative absence of negative affect. The scale is completed by a clinician, after a joint interview with patient and caregiver.

Dementia-specific measures related to QOL

Although the three identified instruments do not claim to assess QOL, relevant aspects of QOL can certainly be assessed with their use. Reports on responsiveness to change of any of these measures were not available. An overview is presented in Table 2.

The Pleasant Events Schedule – AD [17] consists of 53 items that are rated in three ways: the frequency of events in the last month, the availability of the event to the patient, and the enjoyment of the events. Logsdon and Teri later presented a shortened 20-item version [39] with the same satisfying psychometric properties.

The Discomfort Scale – Dementia of Alzheimer Type (DS-DAT) was specially developed for non communicative patients with advanced Alzheimer's Disease [18]. The patients showed MMSE

Table 2. Dementia specific instruments related to QOL

Measure	Data collection	Disease severity	Items	Domains	Reliability	Validity
Pleasant Events Schedule – AD [17]	Caregivers	Mild to moderate (tested in outpatiens) Short version: mean MMSE 18.4	53 (short version of 20 items)	Possible activities are rated on frequency, availability and enjoyability	Internal consistency (>0.86); Split-half (>0.78)	Correlations with cognitive functioning and depression
Discomfort Scale – Dementia of Alzheimer Type (DS-DAT) [18]	Trained observers	Severe dementia MMSE < 3	9	9 behavioral indicators	Internal consistency (from 0.86 to 0.89) [18] Inter-observer ICC 0.74, intra- observer ICC 0.97 [40]	Factor analysis reveals one construct; moderate association with acute illness
Positive Response Schedule [19]	Trained observers	Severe dementia	10	10 behavior categories	Inter-rater reliability of 80% overall agreement	Face validity

Unless otherwise stated, data on reliability and validity derived from reference in the first column.
ICC – Intra-Class Correlation.

scores from 0 to 2. Discomfort was defined as 'a negative emotional and/or physical state subject to variation in magnitude in response to internal or environmental conditions'. It consists of seven negative and two positive items, and is scored through systematic observation. Recently a Dutch version showed good inter-observer reliability [40], and to constitute one concept [41] in a sample with moderate to severe dementia.

Perrin [19] developed the Positive Response Schedule (PRS) as an instrument to assess the effect of short, individualized interventions on the well-being of people with advanced dementia. The method of Dementia Care Mapping proved unsatisfactory in this group of people. PRS uses a similar method of observation, but during a shorter period of time, and focuses on behavioral components (e.g., a smile or gesture) rather than behavioral composites (e.g., having a meal, sleeping or playing a game). Hadley et al. [42] concluded that the PRS is a labor-intensive measure that can be useful in circumstances which require a closer scrutiny.

Generic QOL instruments used in dementia research

Table 3 summarizes the results of the nine generic QOL measures used in dementia research. The cited references concern the use of the instruments in a demented population only: the instruments may have been (frequently) applied in other populations, but this is not relevant for the present review. In none of the publications data on responsiveness to change in QOL scores due to interventions were reported.

The QOLAS is recently developed for use in people with neurological disorders by Selai et al. [43]. It assesses QOL through an interview, in which the patient first recounts which 'constructs', elicited from five predetermined domains, are most important for his QOL (e.g., headaches for the physical domain). Next the patient rates how much of a problem each construct is now. Contrary to other neurological populations, not all patients with dementia were able to indicate 'how they would like to be' on a construct and this part was dropped from the interview. The economic/work domain was altered in daily activities, as this seemed more appropriate. In this study, patients not able to complete the interview had MMSE scores < 11. Although Selai et al. [43] provided no data on the duration of the interviews, the method appears labor intensive.

The Schedule for Evaluation of Individual Quality of Life (SEIQoL) is an individual measure of QOL [44, 45]. The subject first names the five most relevant domains for his QOL and then indicates on a visual analogue scale how well his life is on the domains. Next, 30 hypothetical profiles of the five domains are presented to the subject and he is asked to rate his overall QOL if the profile were his scores on the domains. From these results the relative weights of the domains are calculated. The method is laborious and complex; the average interview took 37 ± 11 min. The mean MMSE score of participants was 22.

The World Health Organization Quality of Life with 100 questions (WHOQOL 100), developed through international collaboration, is a long self-administered questionnaire (later abbreviated to 24 items [7]). This particular study was carried out in France [46]. For dementia patients having difficulties reading the test a medical student read the questions and filled in the form. All patients had MMSE scores > 15.

The other generic instruments have a focus on health more than on general QOL. Both the Health Status Questionnaire (HSQ-12) and the Short Form Health Survey (SF-12) are 12-item health questionnaires administered through an interview [47]. The study was performed in a large sample of community dwelling elderly, of whom 9.7 % suffered from dementia.

The Duke Health Profile (DHP) [48] and the Nottingham Health Profile (NHP) [49] were tested in French speaking populations of dementia patients. Both instruments are designed as self-administered questionnaires, but in both studies this population required assistance from an interviewer in more than 80% of the subjects. Mean MMSE in the DHP study was 15.6 and in the NHP study 13. Both profiles are presented by domain totals, without a general score. The DHP has also been used to asses patient and proxy agreement in a similar population [50], with similar results on internal consistency. The last five domains of the DHP (see Table 3) are derived from a recombination of the items of the preceding domains. The items of the DHP are Likert-type scales with three response options. The items of

Table 3. Generic QOL instruments used in dementia research

Measure	Data collection	Disease severity	Items	Domains	Reliability[a]	Validity[a]
Quality of Life Assessment Schedule (QOLAS) [43]	Self-report through interview	Mild to moderate MMSE > 10	10	Physical Psychological Social/ family Work Cognitive	Internal consistency (varying from 0.59 to 0.86)	Acceptable criterion validity and construct validity (with health status COOP charts)
Schedule for Evaluation of Individual Quality of Life (SEIQoL) [45]	Self-report through semi-structured interview	Mild to moderate Mean MMSE 22	30 hypothetical case profiles	Five domains (cues) named by the subject. Weights are assigned to cues through judgment analysis	Average internal reliability 0.74	Internal validity: (average $R^2 = 0.79$: proportion of variance in overall QOL accounted for by particular judgment policy)
World Health Organization Quality of Life 100 (WHOQOL 100) [46]	Self-report	Moderate dementia MMSE > 15	100	Activity in: Psychological function Physical state Autonomy Social relations Religion Environment	Test–retest reliability (0.70 in two domains, very poor in others)	Distinguishes between people with cancer and dementia
Health Status Questionnaire (HSQ) [47]	Self-report in interview	Unclear, All patients included lived at home	12	Health perception Physical functioning Mental health Role-Physical Role-Mental Social functioning Bodily pain Energy	n.a.	Distinguishes between people with and without dementia
Short Form Health Survey (SF-12) [47]	Self-report in interview	Unclear, All patients included lived at home	12	Mental component summary Physical component summary	n.a.	Not valid in dementia
Duke Health Profile (DHP) [48]	Self-report in interview	Mild to moderate Mean MMSE 15.6	17	Physical health Mental health Social health Perceived health Disability Self-esteem Anxiety Depression Pain General health	Internal consistency (varying from 0.23 to 0.76) Test–retest (ICC 0.45 to 0.80)	n.a.
Nottingham Health Profile (NHP) [49]	Self-report if possible (16%), else caregiver	Mild to severe Mean MMSE 13	38	Physical mobility Social isolation Emotional reactions Pain Sleep Energy	Internal consistency (varying from 0.54 to 0.85). Test–retest (ICC from 0.45 to 0.78)	n.a.
Health Utility Index 2 (HUI-2) [51, 52]	Caregiver	All stages	7	Sensation Mobility Emotion Cognition Self-care Pain Fertility	n.a.	Discriminates across AD stages
Health Utility Index 3 (HUI-3) [52]	Caregiver	All stages	8	Vision Hearing Speech Ambulation Dexterity Emotion Cognition Pain	n.a.	Discriminates across AD stages (but may yield substantially different results from HUI-2)

[a] Data on people with dementia derived from references in first column.
n.a. – not available; COOP – charts with response choices to questions offered as drawings; AD – Alzheimer's Disease; ICC – Intra Class Correlation.

the NHP are answered with 'yes' or 'no' and assigned a weight by the respondent.

The Health Utility Index is a family of generic, multi-attribute, preference-based health status classification systems. The versions Mark 2 (HUI-2) [51] and Mark 3 (HUI-3) [52] use caregiver reports and can be used to assess QOL in all stages of the disease. The attributes (domains in Table 3) are scored by levels of severity. Both generate a global index, as well as attribute indexes. Neumann et al. [51, 52] collected data in both studies through telephone interviews with caregivers.

Conclusion and discussion

As we set limits to the literature from 1990 onwards, there is no guarantee that the list of instruments used to asses QOL in dementia is exhaustive; however we are confident that after 1990 no older instruments have been applied. The results show that a variety of QOL measures for people with dementia are available to researchers and caregivers; generic as well as dementia-specific. The need for QOL measures in dementia is evident: from 1999 onwards five new dementia-specific measures have been published, and nine generic instruments have been used in a population of people with dementia. The measures vary in scale content, with a clear distinction between generic and dementia-specific measures. Methods of data collection also differ: from easily administered questionnaires to labor-intensive observation by specially trained observers.

The reliability reports on dementia-specific instruments are generally satisfying. Although Fossey et al. [25] conclude that test–retest reliability of the DCM is good, one may question their interpretation of the magnitude of the correlations (maximum value of r 0.58). The period between observations was 1 week. Bredin et al. [27], however, note that establishing test–retest reliability for DCM is problematic as the bounds of 'natural variation' of behavior needs to be ascertained.

The modest patient-rater agreement as a measure for reliability reported by Logsdon et al. [34, 35] is explained in part by the burden of care for patients that the (family) raters are confronted with. Carers systematically assess QOL lower than patients themselves. Similar results are reported by Novella et al. [50]. This phenomenon is often found in health related QOL research and referred to as the 'disability paradox' [53]. Clearly patient-rater agreement is a special case of inter-rater reliability, and it has to be established whether the results are due to unreliable self-reports or unreliable raters. Logsdon et al. [35] report better values of agreement in a group of patients less impaired by dementia, indicating that disease severity may also account for poor agreement.

Although self-report is often used as an argument in favor of assessing the subjective QOL, the choice between a self-report or proxy-report measure does not reflect a choice between subjective and objective QOL. It is a choice for a mode of measurement. And this choice is a matter of measurement accuracy: i.e., the instrument that provides the most reliable and valid scores in the population of study should be the first measure of choice. Here, the severity of the dementia will be the guiding factor. The researcher should be confident that self-report measures provide reliable and valid answers from the respondents. The authors of self-report measures claim that this is the case at least in part of the persons with dementia. For instance, Brod et al. [37] obtained adequate data with the D-QOL in 95 out of a sample of 99 people with mild to moderate dementia (MMSE $>$ 12). In another study 77.5% of 213 persons with dementia (MMSE $>$ 10) appeared to be 'interviewable' on the subject of QOL [54]. However, one may insist that providing an answer does not necessarily mean that the question has been understood. Brod et al. [37] reported that four patients with MMSE scores in the 17–21 range were not able to answer the questions. The cognitive deficit is not only a problem for self-report in advanced dementia, but also for some people with mild dementia.

The use of self-report measures clearly limits the group of people that can be investigated. In longitudinal research this can be a serious problem as the progress of the disease may lead to a high level of missing values on the second time of measurement. And even if the participants are still responding to the questions, it may be argued that they perceive the content of the questions differently compared to the first measurement, due to their deteriorated cognitive functioning. This

would be a serious threat to internal validity in the design of an experiment.

The reliability of the generic measures is not always reported. This is considered a serious shortcoming. Perhaps the reliability of the instruments in question has been reported in prior research, but this is not necessarily established in a demented population, where the reliability index may seriously differ from the one found in other populations. In the cases where reliability was reported, some of the subscales show insufficient reliability.

All dementia-specific instruments consider affect to be an essential domain of QOL, and in addition contain at least one of the following domains: self-esteem, activities, enjoyment and social interaction. The validity of most dementia-specific measures is supported by moderate correlations with depression or mood measures. Some find further support in correlations with measures of functioning in activities of daily living, and cognitive function. Without a gold standard for QOL these results are only a first step in the long process of establishing construct validity. QOL has been called an elusive concept [55], that plays a controversial role [56], and that lacks clarity and causes confusion [12]. The different conceptualizations support these statements. For instance, while some authors incorporate items on physical functioning in their instruments, others consider this to be a predictor of QOL, but not a part of the operational definition. Another example concerns the supposed multi-dimensionality of the concept, stressed by most authors, but remarkably, the D-QOL is the only dementia specific instrument to provide a QOL-profile of moderately correlated scores on the subscales, and not a total QOL score.

A large difference in conceptual approach is found between the generic and specific measures. Generic measures primarily focus on health domains. This is not only demonstrated by the domains contained in the instruments, but also by their ability to distinguish between diseases or stages of dementia, which is considered as an indication of instrument validity. This approach includes cognitive function in the operational definition, and implies that QOL in dementia will decrease automatically with disease progression. When, however, QOL is conceived as the evaluation of life and its circumstances, disease severity should be considered merely to be a predictor of QOL. When the purpose of research is to compare health-related QOL in different populations generic instruments may be a sensible choice. But when the interest is primarily on people with dementia, a specific measure should be preferred.

The ability to differentiate between different disease populations can be helpful in identifying items that are particularly relevant to dementia [46]. When the dementia group scores significantly higher on one item than another group, this result can be informative for modifying or developing dementia specific QOL measures.

Reports on responsiveness are only found for Dementia Care Mapping (DCM) and the Alzheimer's Disease Related Quality of Life (ADRQL). This is probably due to the recent application of most instruments. It takes more research to establish the responsiveness of the instruments.

The SEIQoL stands apart from the other instruments. It is the only measure for a genuine subjective assessment of QOL, with the patient deciding which domains of life constitute his life quality (to a lesser extent this applies for the QOLAS [43] too, but here the domains are predetermined). This property makes it a valuable instrument in the individual assessment of life quality of patients with sufficient cognitive abilities. Schölzel-Dorenbos [45] reported positively on its use with dementia patients, but serious doubts in this population have also been expressed [5]. However, in research investigating the QOL of a population, its use should be questioned, as the content of QOL would differ from subject to subject. The SEIQoL indexes would differ within and between the groups, and thus violate the fundamental assumption that the dependent variable is a reliable and valid quantification of one construct.

The three QOL related measures appear to be reliable instruments for detecting pleasant events in people with mild to moderate dementia, and positive responses or discomfort in advanced dementia. As the Positive Response Schedule (PRS) was developed in part because of the inadequacy of the DCM method for assessing well-being, the validity of DCM in advanced dementia may be questioned. The felt need, at least by some researchers, to develop an instrument for the group of people with severe dementia, makes clear that QOL or related

concepts, such as discomfort, may be differently conceived in the late stages of the disease. This calls for the question whether QOL can be assessed with one instrument in every stage of dementia. It has been done with the Health Utility Index (versions 2 and 3; HUI2 and HUI3) [52], with mixed results, and with the ADRQL [30] and the QOL-D [31]. In the last two instruments QOL was significantly correlated with cognitive impairment, indicating that QOL is lowered by the advance in severity of the dementia. This implies not that the concept changes as the disease progresses, but only the level of QOL. Whether this is truly the case on all aspects of life remains an open question and is still subject of debate.

Finally we can conclude that the field of QOL in dementia has made enormous progress in the last 5 years. A serious number of papers have been published discussing the pro's and con's of QOL measurement in dementia. A growing number of scientists and healthcare professionals endorse the view that even with a devastating disease, such as dementia, quality in life can be discovered. The development of dementia-specific QOL measures not only supports this statement, but also directs the care for people with dementia into the direction of positive aspects of life and person-orientation.

Nevertheless, the existing measures have their limitations. Much work on further clarifying the concept of QOL, and particularly its relation to disease severity, remains to be done.

Acknowledgements

This research was supported by grants from: ZonMw, Netherlands Organisation for Health Research and Development (ZonMw 1365.0003); Novartis; De Open Ankh; De Stichting tot Steun van Christelijke Verzorging van Geestes- en Zenuwzieken; Vereniging het Zonnehuis; and Stichting Cliënt en Kwaliteit.

References

1. Health Council of the Netherlands. Dementia. (report num: 2002/04). 2002. The Hague, Health Council of the Netherlands.
2. Clark PG. Quality of life, values, and teamwork in geriatric care: Do we communicate what we mean? Gerontologist 1995; 35(3): 402–411.
3. Lawton MP. Assessing quality of life in Alzheimer disease research. Alzheimer Dis Assoc Disord 1997; 11 (Suppl. 6): 91–99.
4. Hunt SM. The problem of quality of life. Qual Life Res 1997; 6(3): 205–212.
5. Selai C, Trimble MR. Assessing quality of life in dementia. Aging Ment Health 1999; 3(2): 101–111.
6. Lawton MP. A multidimensional view of quality of life in frail elders. In: Birren JE, Lubben JE, Rowe JC, Deutchman DE (eds), The Concept and Measurement of Quality of Life in the Frail Elderly, San Diego: Academic Press, Inc., 1991; 3–27.
7. The WHOQOL Group. Development of the World Health Organization WHOQOL-BREF quality of life assessment. Psychol Med 1998; 28(3): 551–558.
8. Brod M, Stewart AL, Sands L. Conceptualization of quality of life in dementia. J Ment Health Aging 1999; 5(1): 7–20.
9. Rabins PV. Measuring Quality of Life in persons with dementia. Int Psychogeriatr 2000; 12(suppl. 1): 47–49.
10. Ready RE, Ott BR, Grace J, Fernandez I. The cornell-brown scale for quality of life in dementia. Alzheimer Dis Assoc Disord 2002; 16(2): 109–115.
11. Silberfeld M, Rueda S, Krahn M, Naglie G. Content validity for dementia of three generic preference based health related quality of life instruments. Qual Life Res 2002; 11: 71–79.
12. Katschnig H. How useful is the concept of quality of life in psychiatry? Curr Opin Psychiatry 1997; 10(4): 337–345.
13. Streiner DL, Norman GR. Health Measurement Scales: A Practical Guide to Their Development and Use. 3rd edn. New York: Oxford University Press Inc., 2002.
14. McGraw KO, Wong SP. Forming Inferences About Some Intraclass Correlation Coefficients*1. Psychol Meth 1996; 1(1): 30–46.
15. Schuck P. Assessing reproducibility for interval data in health-related quality of life questionnaires: Which coefficient should be used? Qual Life Res 2004; 13(3): 571–585.
16. Terwee CB, Dekker FW, Wiersinga WM, Prummel MF, Bossuyt PMM. On assessing responsiveness of health-related quality of life instruments: Guidelines for instrument evaluation. Qual Life Res 2003; 12(4): 349–362.
17. Teri L, Logsdon RG. Identifying pleasant activities for Alzheimer's disease patients: The pleasant events schedule-AD. Gerontologist 1991; 31(1): 124–127.
18. Hurley AC, Volicer BJ, Hanrahan PA, Houde S, Volicer L. Assessment of discomfort in advanced Alzheimer patients. Res Nurs Health 1992; 15(5): 369–377.
19. Perrin T. The positive response schedule for severe dementia. Aging Ment Health 1997; 1: 184–197.
20. Albert SM, Del Castillo-Castaneda C, Sano M, et al. Quality of life in patients with Alzheimer's disease as reported by patient proxies. J Am Geriatr Soc 1996; 44(11): 1342–1347.
21. Zank S, Leipold B. The relationship between severity of dementia and subjective well-being. Aging Ment Health 2001; 5(2): 191–196.

22. Albert SM, Jacobs DM, Sano M, et al. Longitudinal study of quality of life in people with advanced Alzheimer's disease. Am J Geriatr Psychiatry 2001; 9(2): 160–168.
23. Kitwood T, Bredin K. A new approach to the evaluation of dementia care. J Adv Health Nurs Care 1992; 1(5): 41–60.
24. Brooker D, Foster N, Banner A, Payne M, Jackson L. The efficacy of Dementia Care Mapping as an audit tool: Report of a 3-year British NHS evaluation. Aging Ment Health 1998; 2(1): 60–70.
25. Fossey J, Lee L, Ballard C. Dementia care mapping as a research tool for measuring quality of life in care settings: Psychometric properties. Int J Geriatr Psychiatry 2002; 17(11): 1064–1070.
26. Brooker D, Duce L. Wellbeing and activity in dementia: A comparison of group reminiscence therapy, structured goal-directed group activity and unstructured time. Aging Ment Health 2000; 4(4): 354–358.
27. Bredin K, Kitwood T, Wattis J. Decline in quality of life for patients with severe dementia following a ward merger. Int J Geriatr Psychiatry 1995; 10(11): 973–976.
28. Ballard C, O'Brien J, James I, et al. Quality of life for people with dementia living in residential and nursing home care: The impact of performance on activities of daily living, behavioral and psychological symptoms, language skills, and psychotropic drugs. Int Psychogeriatr 2001; 13(1): 93–106.
29. Innes A, Surr C. Measuring the well-being of people with dementia living in formal care settings: The use of Dementia Care Mapping. Aging Ment Health 2001; 5(3): 258–268.
30. Rabins PV, Kasper JD, Kleinman L, Black BS, Patrick DL. Concepts and methods in the development of the ADRQL: An instrument for assessing health-related quality of life in persons with Alzheimer's disease. J Ment Health Aging 1999; 5(1): 33–48.
31. Terada S, Ishizu H, Fujisawa Y, et al. Development and evaluation of a health-related quality of life questionnaire for the elderly with dementia in Japan. Int J Geriatr Psychiatry 2002; 17(9): 851–858.
32. Gonzalez-Salvador T, Lyketsos CG, Baker A, et al. Quality of life in dementia patients in long-term care. Int J Geriatr Psychiatry 2000; 15(2): 181–189.
33. Lyketsos CG, Gonzales-Salvador T, Chin JJ, Baker A, Black B, Rabins P. A follow-up study of change in quality of life among persons with dementia residing in a long-term care facility. Int J Geriatr Psychiatry 2003; 18(4): 275–281.
34. Logsdon RG, Gibbons LE, McCurry SM, Teri L. Quality of life in Alzheimer's disease: Patient and caregiver reports. J Ment Health Aging 1999; 5(1): 21–32.
35. Logsdon RG, Gibbons LE, McCurry SM, Teri L. Assessing quality of life in older adults with cognitive impairment. Psychosom Med 2002; 64(3): 510–519.
36. Selai C, Vaughan A, Harvey RJ, Logsdon R. Using the QOL-AD in the UK. Int J Geriatr Psychiatry 2001; 16(5): 537–538.
37. Brod M, Stewart AL, Sands L, Walton P. Conceptualization and measurement of quality of life in dementia: The dementia quality of life instrument (DQoL). Gerontologist 1999; 39(1): 25–35.
38. Alexopoulos GS, Abrams RC, Young RC, Shamoian CA. Cornell Scale for Depression in Dementia. Biol Psychiatry 1988; 23: 271–284.
39. Logsdon RG, Teri L. The Pleasant Events Schedule-AD: Psychometric properties and relationship to depression and cognition in Alzheimer's disease patients. Gerontologist 1997; 37(1): 40–45.
40. Hoogendoorn LI, Kamp S, Mahomed CA, Ader HJ, Ooms ME, van der Steen JT. The role of observer for the reliability of Dutch version of the Discomfort Scale – Dementia of Alzheimer Type (DS-DAT). Tijdschr Gerontol Geriatr 2001; 32(3): 117–121.
41. Van der Steen JT, Ooms ME, van der Wal G, Ribbe MW. Measuring discomfort in patients with dementia. Validity of a Dutch version of the Discomfort Scale – dementia of Alzheimer type (DS-DAT). Tijdschr Gerontol Geriatr 2002; 33(6): 257–263.
42. Hadley C, Brown S, Smith A. Evaluating interventions for people with severe dementia: Using the positive Response Schedule. Aging Ment Health 1999; 3(3): 234–240.
43. Selai CE, Trimble MR, Rossor MN, Harvey RJ. Assessing quality of life in dementia: Preliminary psychometric testing of the Quality of Life Assessment Schedule (QOLAS). Neuropsychol Rehab 2001; 11(3–4): 219–243.
44. O'Boyle CA. The schedule for the evaluation of individual quality of life (SEIQoL). Int J Mental Health 1994; 23(3): 3–23.
45. Schölzel-Dorenbos CJ. Measurement of quality of life in patients with dementia of Alzheimer type and their caregivers: Schedule for the Evaluation of Individual Quality of Life (SEIQoL). Tijdschr Gerontol Geriatr 2000; 31(1): 23–26.
46. Struttmann T, Fabro M, Romieu G, et al. Quality-of-life assessment in the old using the WHOQOL 100: Differences between patients with senile dementia and patients with cancer. Int Psychogeriatr 1999; 11(3): 273–279.
47. Pettit T, Livingston G, Manela M, Kitchen G, Katona C, Bowling A. Validation and normative data of health status measures in older people: The Islington study. Int J Geriatr Psychiatry 2001; 16(11): 1061–1070.
48. Novella J, Ankri J, Morrone I, et al. Evaluation of the quality of life in dementia with a generic quality of life questionnaire: The Duke Health Profile. Dement Geriatr Cogn Disord 2001; 12(2): 158–166.
49. Bureau-Chalot F, Novella JL, Jolly D, Ankri J, Guillemin F, Blanchard F. Feasibility, acceptability and internal consistency reliability of the nottingham health profile in dementia patients. Gerontology 2002; 48(4): 220–225.
50. Novella JL, Jochum C, Jolly D, et al. Agreement between patients' and proxies' reports of quality of life in Alzheimer's disease. Qual Life Res 2001; 10(5): 443–452.
51. Neumann PJ, Kuntz KM, Leon J, et al. Health utilities in Alzheimer's disease: A cross-sectional study of patients and caregivers. Med Care 1999; 37(1): 27–32.
52. Neumann PJ, Sandberg EA, Araki SS, Kuntz KM, Feeny D, Weinstein MC. A comparison of HUI2 and HUI3 utility scores in Alzheimer's disease. Med Decis Making 2000; 20(4): 413–422.

53. Carr AJ, Higginson IJ. Are quality of life measures patient centred? Br Med J 2001; 322(7298): 1357–1360.
54. Mozley CG, Huxley P, Sutcliffe C, et al. 'Not knowing where I am doesn't mean I don't know what I like': Cognitive impairment and quality of life responses in elderly people. Int J Geriatr Psychiatry 1999; 14(9): 776–783.
55. Logsdon RG, Albert SM. Assessing quality of life in Alzheimer's disease: Conceptual and methodological issues. J Ment Health Aging 1999; 5(1): 3–6.
56. Jennings B. A life greater than the sum of its sensations: Ethics, dementia, and the quality of life. J Ment Health Aging 1999; 5(1): 95–106.

Address for correspondence: Teake P. Ettema, Department of Psychiatry, VU medisch centrum, Valeriusplein 9, 1075 BG Amsterdam, The Netherlands
Phone: +31-20-5736-517; Fax: +31-20-5736-687
E-mail: t.ettema@vumc.nl