

Review

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## Quality of Life measures for dementia

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### Abstract

Over the past 10 years, several instruments developed specifically for the assessment of Quality of Life (QOL) in dementia have been introduced. The goal of the current review is to present, compare, and critique existing QOL measures for dementia populations to assist investigators and clinicians in selecting the optimal inventory for their specific needs. Nine measures are reviewed with a focus on conceptualizations of QOL, psychometric data, targeted patient population, and administration and scoring procedures. Critical discussion and comparison of the instruments is presented after the scales are described individually. Differences in definitions of QOL, assessment procedures, and methods that were used to establish the validity of instruments are highlighted. An important direction for future research on QOL scales for dementia is to establish their responsiveness to change over time. It will also be important to identify factors that affect reports of QOL, determine the how perceived QOL affects decisions regarding the care of dementia patients, and evaluate interventions to increase patient QOL.

### Introduction

#### **Quality of Life measures for dementia**

Over the past 10 years, experts in the field of dementia have increasingly turned their attention to consideration of patient Quality of Life (QOL). The importance of measuring QOL outcomes in clinical trials and for the clinical management of dementia was debated and discussed among leaders in dementia research and treatment, the pharmaceutical industry, and government agencies [1,2]. Efforts to define, quantify, and systematically measure QOL in dementia resulted in the development of several new measures. These measures vary widely across several important domains but a unifying theme is the influence that Lawton's model of QOL in dementia [3–5] had on conceptualization of QOL. This paper will review existing measures of QOL developed specifically for dementia populations. Conceptualizations, psychometric data, and

administration and scoring procedures of the measures will be presented.

After the instruments are individually described and reviewed, they will be compared and critiqued. Discussion will focus on several critical dimensions that vary between QOL instruments. For example, some authors employ definitions of QOL that include a broad range of signs and symptoms that impact daily life, such as cognitive functioning, performance of activities of daily living (ADLs), and social and psychological factors, whereas other investigators designed scales to be much more narrow in focus. Instruments also differ as to the type and severity of dementia populations that were used in validation and reliability studies, and whether or not patients themselves or a proxy responds to items on the inventory.

Despite the introduction of several measures of QOL for dementia populations in recent years, there continues to be some confusion about what types of instruments should be considered QOL measures in dementia. For example, ADL and depression inventories have been classified as QOL measures [6,7]. Operational definitions of QOL in dementia are clearly needed to help clarify the boundaries between QOL measures and other outcome measures of dementia, such as neuropsychiatric symptoms and cognitive impairment. The goal of this review is to increase awareness of existing instruments and to highlight important distinctions among measures to help future investigators and clinicians select the most appropriate instrument for their purposes.

Measures included in this review have been developed for use with Alzheimer's disease (AD) patients or with mixed dementia populations. Instruments developed specifically for assessment of QOL in Parkinson's disease are excluded because they have been recently reviewed elsewhere (see references section [8]).

Generic and health-related QOL measures are beyond the scope of this review, although they have been adapted for use with dementia populations in some studies [9,10]. Generic measures are useful for comparative studies across different disease states and populations. However, they are not specifically tailored for dementia populations and thus may not fully capture unique and important aspects of dementia patients' experiences. For example, generic QOL measures may not assess enjoyment of activities, feelings and mood, or response to surroundings [11]. Furthermore, generic inventories assess many symptoms of physical illness that are unrelated to dementia. Thus, generic QOL scales are unlikely to be the most sensitive and specific measures of domains of QOL that are relevant to dementia patients.

## Method

### Literature Review

The literature on dementia and QOL was reviewed from 1966 to 2002. Medline and PsychINFO lit searches were conducted using the following key words in various combinations: quality of life, well-being, dementia, Alzheimer's disease, instrument, assessment, measurement, and questionnaire. Reference lists in publications that measured QOL in dementia populations also were included in the literature search. All articles that reported on the development and psychometric properties of an instrument that was designed to measure QOL in dementia were reviewed. As stated in the introduction, generic QOL measures and scales developed specifically for use with Parkinson's disease patients were excluded.

## Results

Fourteen articles regarding nine different dementia QOL scales were identified and reviewed. Characteristics of the QOL scales are reviewed in Table 1 (see Additional file: 1), which includes the following measures: Albert et al.'s Affect and Activity Ratings [12,13], Alzheimer Disease Related Quality of Life (ADRQL [11]), Cornell-Brown Scale for Quality of Life (CBS [14]), Dementia Care Mapping (DCM [15-17]), Dementia Quality of Life (DQoL [18]), Psychological Well-Being in Cognitively Impaired Persons (PWB-CIP [7,19]), Quality of Life in Late-Stage Dementia (QUALID) Scale [20], Quality of Life-Alzheimer's Disease (QOL-AD [21,22]), and the Quality of Life Assessment Schedule (QOLAS [23]). The instruments were developed between 1992 and 2002.

### Activity and Affect Indicators of QOL [12,13]

Albert et al. created a measure of QOL that incorporates assessment of patients' activity and affect. These domains were measured because they are observable, quantifiable, behavioral, and they were hypothesized to be indicators of subjective, internal states of patients [12]. A strength of this measure is that it is appropriate for use with a broad range of patients, from mild to severe stages of dementia severity. Furthermore, the measures can be used in both institutional and home-care settings. A potential drawback of this inventory is that it provides a fairly narrow measurement of QOL that is confined to two dimensions, activity and affect.

Fifteen activity items were selected from Teri and Logsdon's Pleasant Events Schedule-AD [24,25]. Activity items vary from simple to complex, and they occur both inside and outside of the home. Proxies rate the frequency for each activity within a 1-week time frame and these frequency counts are summed. For the affect measure, six affects were selected from Lawton's Affect Rating scale [26] to include both positive and negative affect and that could be easily recognized in body and facial expressions: pleasure, anger, anxiety, depression, interest, and contentment. Affects are coded for frequency during the past 2 weeks on a 5-point scale, ranging from never to greater than or equal to 3 times per day. Summary scores for positive and negative affect are calculated [13].

To assess the reliability and validity of the measure, telephone interviews were conducted with caregivers of 130 AD patients. One-week test-retest reliability ranged from .53 to .92 for the affect items ( $Mdn = .77$ ) and was above .60 for 12 of 15 activity frequency items. No systematic differences in QOL reports were found between family and institutional caregivers.

Validity of the scale was indicated by a significant correlation between activity and the modified Mini-Mental State

Examination (mMMS [27]) scores, indicating that activity decreased as dementia severity increased. Affect measures showed variable associations with dementia severity. An overall QOL composite was created by considering high activity frequency, high positive affect, and low negative affect as indicative of higher QOL [12].

#### **Alzheimer Disease Related Quality of Life (ADRQL) [11]**

The ADRQL was developed to assess domains that caregivers of AD patients and AD experts identified as important for health-related QOL in dementia. Scale development was guided by focus groups and expert panels. The scale measures both positive and negative behaviors across five domains: Social Interaction, Awareness of Self, Feelings and Mood, Enjoyment of Activities, and Response to Surroundings. The majority of items measure observable behaviors and actions, although some rely on assessment of subjective and internal states. Caregiver respondents are used for the ADRQL. Scores are calculated using a preference-based weighting approach, where weights for QOL indicators differ according to the importance of the domain. Weights were calculated from ratings of 61 caregivers, who were asked to rank each item as to its importance for QOL on a 1 to 10 scale. This scale promises to offer a comprehensive assessment of QOL across several important domains. However, at the current time, we are not aware of any published data regarding the psychometric characteristics of this scale. Furthermore, it is not clear if the scale is adaptable for use in both home-care and institutional settings, or for what level of dementia severity the scale was developed. Additional data are needed in order to accurately assess the strengths and weaknesses of this measure.

#### **The Cornell-Brown Scale for Quality of Life in Dementia (CBS) [14]**

The CBS provides a global assessment of QOL. The scale was developed based on the conceptualization that high QOL is indicated by the presence of positive affect, physical and psychological satisfactions, self-esteem and the relative absence of negative affect and experiences. Initial psychometric evidence has been obtained from patients in the mild to moderate stages of dementia severity, who are still living at home.

The CBS was developed by modifying the Cornell scale for Depression in Dementia in two ways [28,29]. First, to measure positive aspects of QOL, the Cornell scale items were broadened to include assessment of positive emotions, experiences, and satisfactions. Second, the rating scale for each item was altered to range from -2 (negative pole anchor) to +2 (positive pole anchor). Total CBS scores can range from -38 to +38. Negative scores indicate that negative ratings of mood, behavior, physical signs, ideational disturbance, and cyclic functions outweigh

positive ratings. Thus, the more negative the score, the poorer the QOL rating. Positive scores are obtained when positive ratings outweigh negative ratings and indicate higher QOL.

A strength of the CBS is that it incorporates patient and caregiver perspectives into one rating. The CBS is rated by a clinician after a joint interview with the patient and caregiver. Separate interviews and ratings can be made with patients and caregivers but initial psychometric data are based only on results of joint interviews. The interview is semi-structured and the time-frame covers the previous month.

Preliminary reliability and validity studies were conducted on data collected from joint interviews with 50 dementia patients and knowledgeable informants. All patients had an MMSE of 9 or greater. Results indicated that the scale has adequate interrater reliability (intraclass  $r = .90$ ) and internal consistency (Cronbach's  $\alpha = .81$ ). Criterion validity was indicated by a positive correlation between CBS scores and visual analogue positive mood ratings made by patients (Spearman  $\rho = .63$ ). QOL was negatively correlated with dementia severity as measured by the Clinical Dementia Rating scale ( $\rho = -.35$ ). Reliability and validity findings were similar for the more mildly and more severely impaired halves of the sample.

#### **Dementia Care Mapping (DCM) [15-17]**

DCM is a structured, observational assessment of dementia patient experiences that was introduced in 1992 [17]. DCM was developed for use in residential care settings with dementia patients who are unable to provide valid and reliable reports about their experiences [16]. Thus, it is most appropriate for use with moderate to severely impaired patients. Patient well-being and activities are coded with an emphasis on behaviors that are hypothesized to be related to QOL. Well-versus ill-being of patients is rated on a 6-point ordinal scale and ratings are based on signs from patients and on the behavior of staff towards the patient. There are 24 activity rating categories and indicators of social withdrawal also can be coded [15].

A strength of the DCM is that it is an intensive assessment method that typically requires observers to rate indicators of patients' QOL every five minutes over a 6-hour time frame, although differing time frames have been used [17]. For example, a one-hour assessment was significantly correlated ( $p < .05$ ) with the full-length assessment for activities ( $r = .68$ ) and well-ill being ( $r = .50$ ) [15]. This shorter observation period may be more practical for investigators who have limited time and funds.

In analyses of data collected from residential and nursing home facilities ( $N = 177$ ), results indicated that activity

and well-ill being scores were significantly correlated ( $r_s = .16$  to  $.63$ ,  $Mdn = .53$ ), indicating internal consistency of the measure [15]. One- to four-week test-retest reliability for 54 patients indicated good reliability for well-ill being scores ( $r = .55$ ) and moderate reliability for activities ( $r = .40$ ) and social withdrawal ( $r = .43$ ) [15].

Validity was indicated by agreement between DCM scores and quality assurance audit measures of residential nursing care [16]. Concurrent validity was indicated by a significant ( $p < .001$ ) correlation of well-ill being scores with a pencil and paper, generic measure of QOL [30] for a subset of 19 patients ( $r = .73$ ), but activities did not correlate significantly with the QOL measure ( $r = .29$ ). DCM has high face validity as indicated by a staff acceptability assessment [16].

#### **Dementia Quality of Life Instrument (DQoL) [18]**

The DQoL [18] was developed through an iterative conceptual and statistical process that included a literature review and consultation with expert panels composed of dementia patients, caregivers, and professional care providers. It is a 29-item scale, plus one global item ("Overall, how would you rate your quality of life?") that measures 5 domains of QOL: Positive Affect (6 items), Negative Affect (11 items), Feelings of Belonging (3 items), Self-esteem (4 items), and Sense of Aesthetics (5 items). The DQoL yields scores on 5 subscales but subscale scores are not summed to reach an overall or global measure of QOL.

The scale is unique because it is the only scale developed exclusively to be administered to patients. Item-stems were made as simple as possible and a 5-point visual scale is used to present multiple choice response choices to patients. All points on the response scale are associated with verbal descriptors. Screening questions ensure that patients understand questionnaire instructions and the response format for the scale. Because it relies solely on patient-input, the DQoL is appropriate for use with patients in the mild to moderate stages of dementia.

In a sample of 99 patients diagnosed with mild to moderate dementia (MMSE ranged from 12 to 21), only 4% of participants could not correctly answer the screening questions and thus were not administered the entire scale. For patients who completed the DQoL, internal consistency reliabilities for subscales were moderate to high (.67 to .89;  $Mdn = .80$ ). There were no significant differences between patient groups with mild (MMSE  $> 17$ ) and moderate (MMSE  $\leq 17$ ) dementia severity in terms of scale reliability. Two-week test-retest reliability for a subset of participants ( $n = 18$ ) ranged from .64 to .90 ( $Mdn = .72$ ). Convergent validity was indicated by correlations with scores on the Geriatric Depression Scale and 4 DQoL sub-

scales ( $r = -.48$  self-esteem,  $r = -.61$  positive affect,  $r = -.64$  absence of negative affect,  $r = -.42$  feelings of belonging) [18]. The instrument takes approximately 10 minutes to administer.

#### **Psychological Well-Being in Cognitively Impaired Persons (PWB-CIP) [7,19]**

The PWB-CIP measures aspects of QOL related to psychological well-being. It is an observer-rated, 11-item scale that measures positive and negative affective states and engagement behaviors [7]. It has been used with dementia patients in the mild to moderate stages of severity, who are being cared for at home. A strength of the scale is that some longitudinal data are available regarding its psychometric properties. Furthermore, it is an observer-rated scale and thus it is more appropriate for use with patients with greater dementia severity, relative to scales that rely on patient input. A drawback of the scale is that it is a relatively narrow measure of QOL, focusing only on affect and behavior.

Factor analysis on data gathered from 96 caregivers of dementia outpatients revealed three subscales: Frustrated/Agitated, Positive Interaction, and Discontent Expressions [19]. Internal consistency reliability for all three subscales was strong at baseline ( $\alpha = .79, .74, \text{ and } .66$ , respectively) and at an 18-month follow-up assessment ( $\alpha$ s =  $.75, .83, .68$ , respectively). Total scale internal reliability was .81 at baseline and .82 at the follow-up. Validity was indicated by significant ( $p < .01$ ) correlations between total PWB-CIP scores and measures of depression, personality, social behavior, functional ability, problem solving, and task orientation at baseline and 18-month follow-up.

#### **The Quality of Life in Late-Stage Dementia (QUALID) Scale [20]**

The QUALID was created by selecting a subset of items from Albert et al.'s affect and activity measures [12] to be used specifically with late-stage dementia patients in institutional settings. A strength of the scale is its brevity. It is a proxy-report instrument that measures 11 observable behaviors indicating activity and emotional states. Ratings are made for observations made over the preceding 7 days. The scale was developed to be administered by a technician to nursing home personnel. Items are rated on a 5-point Likert scale and it takes 5 minutes of administration time.

The scale was evaluated in 42 residents of a dementia special care unit. Respondents were required to have 30 or more hours of exposure to patients during preceding week. Internal consistency reliability was reported as good to excellent (Cronbach's  $\alpha = .77$ ). Inter-item correlations were positive and ranged from .17 to .70. For 19 residents, 2- to 3-day test-retest reliability was .81. Interrater

reliability was .83 for 23 of the residents. Validity was assessed by examining correlations between QUALID scores and several other measures of dementia. There were no significant correlations between the QUALID and the MMSE or a measure of basic ADLs, but moderate and significant correlations were found with a measure of depressive symptoms ( $r = .36$ ) and neuropsychiatric symptoms ( $r = .40$ ).

#### **Quality of Life-Alzheimer's Disease (QOL-AD) [21,22]**

Items for the QOL-AD were selected to reflect domains of QOL in older adults based on a literature review of QOL in geriatric populations. Face validity and comprehensiveness was ensured by having AD patients, caregivers, nondemented older adults, and dementia experts review potential items. The final scale is composed of 13-items that measure the domains of physical condition, mood, memory, functional abilities, interpersonal relationships, ability to participate in meaningful activities, financial situation, and global assessments of self as a whole and QOL as a whole. Response options are 4-point multiple choice options (1 = poor, 4 = excellent). Scale scores range from 13 to 52, with higher scores indicating greater QOL. Strengths of this scale are its brevity and that it relies on reports from patients, caregivers, or both. A drawback is that it relies on a conceptualization of QOL that may be regarded by some investigators as somewhat broad because it includes items about memory and functional abilities.

Patients and caregivers typically complete the QOL-AD separately. Patients are interviewed and caregivers respond to the QOL-AD items on a questionnaire. Composite scores that combine reports from patients and caregivers are weighted to favor patient self-report. The patients' score is multiplied by 2, added to the caregiver score, and the composite is divided by 3. The scale takes an average of 10 minutes to administer to patients and caregivers take less than 10 minutes to complete the questionnaire [22].

Psychometric properties of the QOL-AD were initially evaluated in a group of 77 AD outpatients and their caregivers [21]. A follow-up study with a larger sample of 177 AD patients was recently published [22]. For both studies, QOL-AD was rated separately by caregivers and patients. In the larger study, 155 of the 177 patients interviewed were able to complete the QOL-AD. Mean MMSE for non-completers was 4.1 compared to 18.1 for completers (range 4 - 29), and all patients with MMSE scores above 11 were able to complete the QOL-AD. In addition to greater cognitive impairment, noncompleters also had significantly more impairment in basic and instrumental ADLs.

Internal consistency reliability (Cronbach's alpha) ranges from .84 to .88 for patients and caregivers [21,22]. Patient-caregiver agreement for the total score was significant in the initial validity study ( $r = .40$ ,  $p < .01$ ) and individual item agreement ranged from .04 (ability to do chores) to .45 (energy) with a median value of .24 [21]. Agreement was lower in the second study ( $ICC = .19$ ; [22]). One-week test-retest reliability for 30 patients was acceptable ( $ICC = .76$  for patients and .92 for caregivers [21]). Moderate levels of cognitive impairment do not appear to adversely affect internal consistency reliability and patient-caregiver agreement [21,22].

Validity was indicated by low to moderate correlations between QOL scores and the MMSE and reports of instrumental activities of daily living, depression, and engagement in pleasant events [21]. Validity of patient scores in the second study was indicated by correlations between QOL-AD scores and several measures of domains hypothesized to be associated with QOL: behavioral competence, psychological status, physical function, and interpersonal environment. There were stronger associations between caregiver-reported QOL and measures of these other domains [22].

#### **Quality of Life Assessment Schedule (QOLAS) [23]**

A strength of the QOLAS is that it is the only dementia QOL instrument that is tailored to individual patients and employs both qualitative and quantitative measurement approaches. Patients are interviewed and asked to identify what is important for their QOL and two issues from each of the following domains are identified: Physical, Psychological, Social/family, Usual activities, and Cognitive functioning. Patients then rate how much of a problem s/he is currently experiencing with regard to each of the 10 issues on a 6-point scale (0 = no problem; 5 = it could not be worse). Scores range from 0 to 50 with higher scores reflecting poorer QOL.

A drawback of the QOLAS is that psychometric properties have been evaluated in a small sample of patients, to date. Data were collected from 22 dementia patient-carer dyads who participated in psychometric evaluation of the QOLAS. Carers and patients were interviewed separately. Internal consistency reliability as measured by coefficient alpha was .78 for patients and caregivers. Construct validity was indicated by significantly ( $p < .05$ ) higher patient-reported QOL for a subgroup of patients with less disability in ADLs as compared to patients with more disability. Agreement between patient-reported QOL scores and scores on a generic measure of QOL ranged from poor to good (kappa ranged .09 to .67,  $Mdn = .45$ ). For caregiver-reported QOL, kappa values ranged from poor to very good (range .09 to .82,  $Mdn = .47$ ).

## Discussion

Several instruments designed specifically to measure QOL in dementia were introduced within the past 10 years. These measures vary widely in scale content, type of respondent, method of administration, and population for which they were developed. The greatest similarity among the instruments is that their development was strongly influenced by Lawton's model of QOL. The greatest differences appear to stem from differences in how this model is implemented.

### **Differences in Conceptualization of QOL in Dementia**

Lawton's model of QOL has undoubtedly been the most pervasive influence on conceptualizations of QOL in dementia and subsequently on the development of QOL instruments. Lawton argued that QOL assessment should include consideration of subjective and objective factors [4]. He identified four overarching dimensions that contribute to QOL: (1) psychologic well-being (e.g., positive and negative affect), (2) behavioral competence (e.g., cognitive and functional abilities), (3) objective environment (e.g., caretakers and living situation), and (4) perceived QOL [3].

Authors of dementia QOL scales have used different methods to implement the model. Some investigators have interpreted these four factors as defining features of QOL (e.g., [21]), whereas others have viewed some factors as predictors of QOL and others as indicators of QOL (e.g., [14,18]). For example, some instruments incorporate items about functional and cognitive impairment in the scale, whereas others see these factors as potential predictors of QOL, but not as defining features. Some authors noted that including items about cognition and physical functioning in QOL measures is problematic because these domains inevitably decline with advancing dementia. Thus, including items about cognition and functioning in a QOL scale means that QOL also will inevitably decline with greater dementia severity [11]. Instruments that are the most broad and incorporate objective and subjective indicators of QOL are the QOL-AD and the QOLAS. The other QOL instruments focus more narrowly on two or more of the following dimensions: affect, activity, enjoyment, self-esteem, and social interactions.

### **Type of Respondent**

Another critical dimension along which dementia QOL instruments vary is whether or not patients participate in the assessment. This is a critical factor because of the highly subjective nature of QOL assessments. As indicated in Table 1, authors of four QOL scales made efforts to incorporate patients' input in their QOL ratings [14,18,21,31]. Three of these scales [18] also incorporates caregiver input, but two scales weight patients' responses more than caregivers in creating a composite measure of QOL [21].

The remaining five scales rely solely on proxy reports to assess QOL.

The two central issues that authors considered in deciding whether or not to incorporate patients' input into rating their QOL were cognitive impairment and lack of awareness, both of which are common in dementia. Cognitive impairment is a diagnostic criteria for dementia [32] and increases in severity as dementia progresses. Patients eventually lose the ability to communicate effectively. Thus, measures of QOL for patients in the moderate to severe stages of the disease must inevitably rely more on proxy reports than on patient self-report. However, for patients in the mild to moderate stages of dementia, evidence from several studies indicates that they can provide QOL ratings that demonstrate adequate reliability and validity [14,18,21,23]. The most important requirement for obtaining reliable data from elderly individuals with cognitive impairment may not be overall level of cognitive impairment but rather orientation, attention, and language skills [33].

Some investigators recognize the limitations of conducting assessments with dementia patients and have deliberately designed questionnaires to accommodate this unique population. For example, Brod et al. developed a brief questionnaire, with simple items, and a visually-mediated response scale [18] and Selai et al. incorporated time to establish good rapport with patients before assessing their QOL [23].

Loss of insight and awareness is common in dementia [34–36], and this fact raises concerns about the validity of data that is provided by individuals diagnosed with dementia. However, there is evidence to suggest that awareness of impairments varies across modalities in dementia [37]. Brod et al. argue that since loss of awareness is not a unitary phenomena in dementia, it is possible that awareness of cognitive impairment may be distinct from awareness of one's own feeling states. Thus, patients may be able to report reliably on their QOL, even when they have poor insight into the severity of their dementia.

### **Establishing the Validity of QOL Measures**

Establishing the validity of QOL measures is perhaps the most challenging aspect of scale development. Investigators approached the issue in different ways that are revealing about their conceptualizations of QOL in dementia. For example, some authors used indicators of disease severity to validate QOL scores [12], implying that QOL should decrease with increasing dementia severity.

Depression and mood measures were often used to validate QOL scores [14,18], but other factors included activities of daily living [23] and generic QOL measures

[16,23]. Several authors used combinations of many factors to establish the validity of their instrument [19–21]. Without a gold standard against which to compare QOL assessments, a multimodal approach is probably the best strategy to establish construct validity of new instruments.

#### **Future Directions**

An important issue to address is whether dementia QOL measures are sensitive to change over time. A measure's sensitivity to change is critical to evaluating response to treatment and to determine the effects of disease progression on QOL. Alert et al. reported that one of their motivations for developing a dementia QOL measure was to develop an instrument that might be sensitive to changes in severe and late-stage dementia, when scores on measures of dementia severity have bottomed-out [12]. Thus, future longitudinal studies will need to evaluate whether or not QOL measures are sensitive to clinically meaningful change over time.

More research is needed to identify characteristics of patients, caregivers, and staff that may affect QOL reports about patients. For example, patients with more severe cognitive and functional impairment had more difficulty reporting on their QOL than patients who were somewhat higher functioning [22]. Another factor that may interfere with self-reports is lack of insight, which is common in dementia and increases with dementia severity [36,38,39]. However, little is known about if and when lack of insight may compromise the validity and reliability of patient self-reports. In addition, there are several caregiver factors, such as depression and burden that may affect their reports of patient QOL. In a longitudinal study, Burgener and Twigg (2002) found that caregiver depression and burden were correlated with caregiver-reported QOL [7]. It is not clear if caregiver factors caused lower patient QOL, are simply correlated with patient QOL, or may have biased their reports of patient QOL. Logsdon et al. (2002) also reported that caregiver burden was correlated more strongly with caregiver-reported QOL relative to patient-reports [22]. More research is needed to address factors that may threaten the validity and reliability of data provided by patients, caregivers, and healthcare professionals.

More research is also needed regarding the impact of perceived QOL on decisions regarding the care of persons with dementia. For example, a better understanding of how caregiver reports of patient QOL determine decisions for residential care planning and use of formal and informal respite services is needed. The impact of differences between caregiver and patient perceptions regarding patient QOL in decision-making also is needed to determine the degree to which patient perceptions enter into the decision-making process.

Finally, as measurement of QOL advances, investigators will be in a better position to develop and evaluate interventions to maintain and enhance QOL for persons with dementia. Data regarding the effectiveness of medical, social, behavioral, and environmental interventions for maximizing patient QOL are needed to help guide resource allocation for the optimal care of dementia patients.

#### **Conclusion**

The importance of considering QOL in dementia can not be overstated. It is of the utmost importance to patients and their families [40]. Furthermore, for patients diagnosed with chronic neurodegenerative disease, healthcare professionals might have a better ability to intervene to improve QOL than to change other aspects of the disease [18]. Assessment of QOL also has the important effect of calling attention to positive states and 'personhood' in dementia, in contrast to most other measures of dementia that focus on deficits and pathology [3].

Great strides have been made in recent years to conceptualize, define, and systematically measure QOL in dementia. A range of instruments with promising preliminary psychometric data are now available for dementia patients with a range of disease severity. Important directions for future research on QOL in dementia are to establish if measures are responsive to change over time, identify factors that affect reports of QOL, determine the effect of QOL perceptions on decisions regarding the care of dementia patients, and evaluate interventions to increase patient QOL.

#### **Authors' Contributions**

RER conducted the literature review, wrote summaries of the QOL instruments, and contributed to the comparison and critique of the instruments.

BRO contributed the preparation of the manuscript for publication and participated in the description, comparison and critique of instruments.

Both authors read and approved the final manuscript.

## Additional material

### Additional file 1

#### Table 1

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[<http://www.biomedcentral.com/content/supplementary/1477-7525-1-11-S1.doc>]

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