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Direct assessment of quality of life (QoL) of persons with dementia has largely been ignored due to logistical, conceptual and practical issues. This article presents a disease-specific conceptual framework of QoL for dementia. Based on this conceptualization, a 29-item instrument designed to assess QoL by direct interview with dementia patients was developed and tested on 99 participants. The data show that the instrument is reliable and shows evidence of validity. Nearly all participants (96%) were able to respond to questions appropriately. Thus, persons with mild to moderate dementia can be considered good informants of their own subjective states, paving the way to consider patient responses rather than proxy measures as the gold standard for assessing QoL for persons with dementia.

Key Words: Cognitive impairment, Disease-specific domains, Patient perceptions, Alzheimer's

Conceptualization and Measurement of Quality of Life in Dementia: The Dementia Quality of Life Instrument (DQoL)

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Quality of life (QoL) is a multidimensional concept encompassing social, psychological, and physical domains (Birren, Lubben, & Rowe, 1991). For individuals with dementia, as for most chronic degenerative diseases, the ability of health care providers to intervene and affect QoL is far greater than to affect the course of the disease. Unfortunately, the measurement of QoL in dementia patients, although recently receiving more acknowledgment, has been largely ignored as a result of conceptual, logistical, and measurement difficulties inherent in accurately assessing QoL directly from this population. As a result, proxy measures, tapping limited domains of QoL, have been used primarily, and it is unclear whether QoL is being measured accurately. QoL in dementia needs to be conceptualized as a complex, comprehensive construct if researchers are to understand fully the impact of dementing illness. QoL remains a key consideration in: (a) evaluating service programs; (b) testing the efficacy of new drug treatments; (c) the ethical debate regarding health care resource utilization; (d) end-of-life decision making; and (e) developing clinical guidelines.

The concept of QoL has been defined and applied in a variety of ways over the past two decades. In the purest sense, the term implies an evaluation or subjective rating by the individual. Thus, the term has been used to refer to people's overall evaluation of their lives in general (e.g., how satisfied they are, all things considered, with their current lives) or of various components of life such as social life, financial situation, work, or living situation (Andrews & Withey, 1976; Campbell, Converse, & Rodgers, 1976). Some conceptual frameworks of QoL for older people are available (George & Bearon, 1980; Lawton, 1994; Stewart & King, 1994); however, they are often quite similar to those for people of younger ages.

The concept of health-related QoL (HRQoL) refers to aspects of QoL that are most likely to be affected by various diseases. For people suffering from dementia, the unique characteristics of the disease lead to sometimes subtle and sometimes obvious differences in the importance and definition of specific QoL domains and subdomains. It is only by appreciating these differences that an accurate, comprehensive, disease-specific conceptualization of QoL can be developed for dementia. Additional impetus for a disease-specific instrument is found in the need to evaluate new therapies. Many studies have shown that the effects of any therapeutic intervention to improve QoL are best measured with sensitivity by disease-specific instruments that focus on the domains most relevant to the disease under investigation and on the characteristics of patients in whom the condition is present (Epstein et al., 1992; Hammond & Aoki, 1992; Meenan, Mason, Anderson, Guccione, & Kazis, 1992; Testa & Simonson, 1996). Disease-specific instruments target appropriate domains and have an increased likelihood of capturing change over time (Guyatt, Berman, Townsend, Pugsley, & Chambers, 1987; Howard & Rockwood, 1995).

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A comprehensive evaluation of QoL should consist of both objective and subjective domains. Because subjective states can be difficult to measure in dementia patients, investigators often bypass these personal evaluations and infer QoL through knowledge of things about persons that are more observable or objective (Albert et al., 1996), or by use of proxy measures. Although the objective dimensions of health are important in assessing the clinical course of illness, as Testa and Simonson (1996) state, "the patients' subjective perceptions and expectations translate that objective assessment into the actual quality of life experienced." Inferring subjective quality or well-being from external circumstances or from more objective domains (e.g., functioning) does not take fully into account the values, needs, and adaptabilities of individuals to various life circumstances (Flanagan, 1982; Sanifort, Becker, & Diamond, 1996).

Direct respondent assessment in cognitively impaired populations is seldom done due to the presumed logistical and methodological issues, notably concerns about comprehension and reliability (Stewart, Sherbourne, & Brod, 1996). Thus, proxy measures are the most common methodology employed to collect data about persons with dementia. The use of proxies to measure QoL in dementia patients may decrease nonresponse, but it creates an additional set of difficulties. Characteristics of the proxy such as the nature of the relationship and time spent with the patient, the degree of objectiveness of the questions, and the level of impairment of the patient may influence the degree of correspondence between patient and proxy responses (Magaziner, Simonsick, & Kashner, 1988; Zimmerman & Magaziner, 1994). Additionally, concordance between patient and proxy report is likely to be greater for objective than for subjective domains (Sanifort et al., 1996).

There is a widely held belief that lack of concordance in responses to similar questions between persons with dementia and their proxies is attributable to the inability of the demented person to respond accurately. However, there is a growing body of evidence suggesting that many, if not most, early and moderate stage dementia patients are able to comprehend and answer questions about themselves and their situation (Grut et al., 1993; Kiyak, Teri, & Borson, 1994). Teri and Wagner (1991) found that the degree of concordance between persons with dementia and caregivers was not dependent upon the level of dementia. Further, similar lack of concordance has been found when comparing caregivers' and health professionals' ratings, providing further evidence that poor correlations cannot be entirely attributed to patients' cognitive impairment (Lukovits & McDaniel, 1992; Teri & Wagner, 1991).

Recent studies have also demonstrated success in directly assessing patients. Parmelee, Katz, and Lawton (1989) found no significant differences in either patient or proxy ratings, or in one-year test-retest reliability on the Geriatric Depression Scale, between cognitively impaired and intact individuals. McHorney (1996) found that although cognitively impaired patients took twice as long to complete a 245-item, self-administered survey as cognitively intact respondents did and had a higher proportion of missing data, with few exceptions results from psychometric tests for scaling success, internal-consistency, and construct validity were comparable between impaired and intact individuals. Logsdon and colleagues also found acceptable reliability and validity for their patient-administered measure of QoL for Alzheimer's disease (Logsdon, Whitehouse, & Teri, 1996). Further evidence that persons with dementia are able to report on their situations comes from the growing number and acceptability of support groups for persons with early stage dementia. An observer at one of these groups' meetings will be immediately struck by the participants' ability to report and discuss their deficits and the emotional consequences of their disease.

Most studies that have looked at dementia patients' ability to report on their own conditions, as well as studies of concordance between patients and proxies, have not paid attention to the issue of questionnaire formatting, administration methodology, or comprehension factors. Thus, it is unclear whether dementia patients are poor reporters or if proxy measures themselves are biased. The lack of concordance may be the result of lack of insight or ability to report accurately on the part of the demented patient, or may be due to inappropriate instrumentation for this population. Regardless, if researchers wish to capture patients' perceptions of their own QoL, rather than a proxy's perspective, then it is necessary to query the patient directly. This is especially relevant for the more subjective domains where personal interpretation is the critical factor. The evidence discussed so far suggests that the quality of data obtained from persons with dementia can be improved by paying more attention to issues such as item clarity and simplicity, formatting, limited attention span, and respondent burden.

This study was designed to address these conceptual and measurement issues by: (a) conceptualizing the domains of QoL appropriate for persons with dementia; (b) developing an instrument based on this conceptualization which could be interviewer-administered to the person with dementia (referred to as patient-administered); and (c) determining the psychometric properties of the instrument, and the feasibility of its administration.

Methods

The study was conducted in two phases: Phase I, the refinement of the concept of QoL for dementia populations, and Phase II, the development, pilot testing, and field testing of the Dementia Quality of Life instrument (DQoL), a patient-administered, disease-specific QoL instrument.

Phase I : Conceptual Framework

Three focus groups were held in order to develop a comprehensive, dementia-specific definition of QoL that would include domains truly meaningful to mildly to moderately demented persons. Focus groups have been effectively applied to QoL research where they have been used to generate ideas related to the design of scales or tests, and to examine priorities among varying QoL indicators (Brod, 1998; Krueger, 1996). Focus groups allow data from several people to be collected simultaneously and can aid the understanding of personal experiences and provide knowledge and explanations for behavior (Kitzinger, 1994). Three focus groups were held: one consisted of caregivers, one of health care providers, and one of persons with dementia. The caregiver focus group consisted of five live-in caregivers of dementia patients with varying degrees of impairment. The provider group consisted of six persons, who were (by profession), the director, a social worker, and a program assistant of an Alzheimer's adult day health program; a representative from the Alzheimer's Association; the coordinator of a geriatric assessment program; and a nurse from a nursing home special care dementia unit. The dementia focus group consisted of six persons with early stage dementia who regularly participated in an early diagnosis support group. All groups met for approximately 1.5 hours and were facilitated by the first author. A discussion guide was developed for each group to identify the appropriate QoL domains in dementia and how dementia affects the life of the afflicted person. The information gathered from the three groups, along with the current literature on QoL in dementia, formed the basis for the conceptual framework of QoL in dementia populations.

Phase 2: Instrument Development

The process of developing the instrument proceeded through several steps, as follows:

1. Develop questions based on a literature review and focus groups, corresponding to the conceptual framework.
2. Design questionnaire, pilot test questions on persons with dementia, and revise questions.
3. Administer questionnaires to a large sample (field test).
4. Examine variability and reliability to enable construction of preliminary scales (item distributions, scale internal-consistency reliability, item test-retest reliability, scale test-retest reliability).
5. Explore construct validity of preliminary scales (scale-scale intercorrelations, correlations of scales with the Geriatric Depression Scale).
6. Finalize scales depending on the results of steps 1–5.

1. *Develop Questions.*—Based on the findings of Phase I, an item pool of 96 questions was developed to measure all relevant domains. Items were written that were believed to tap the domains and subdomains identified by the focus groups and prior measures of QoL. Disease specificity was implied by choosing domains and subdomains that were identified as relevant to persons with dementia. This was done intentionally so that respondents would not be required to complete the sometimes difficult cognitive task of attributing problems to dementia.

2. *Design Questionnaire, Pilot Test and Revise.*—Three iterations of the instrument were required during the pilot phase. In the first version, in order to address the logistical and methodological concerns of assessing patients with cognitive impairment (impaired comprehension, shortened attention span, and impaired memory), several decisions were made regarding formatting and item construction. We believed that the item stems needed to be as simple as possible, the number of response choices reduced, and no specific time frame used as a reference for an item. For the initial questionnaire, item stems were kept simple and no more than two response options were provided for most questions. To further differentiate levels of response, we used response trees in which additional questions followed each initial question. The initial instrument was pilot tested on 10 persons with dementia. The first pilot test found that response trees required an expense of time that was not acceptable. Additionally, respondents were able to answer multiple-choice questions without apparent difficulty.

In the second iteration, piloted on 17 respondents, multiple-response choices were presented on a 5-point visual scale that had both endpoints and the midpoint labeled with a descriptor appropriate to the question. In order to assess comprehension of the response format, screening questions were added to the beginning of the instrument. Several versions of the screening questions were developed before the final set of questions was finalized. Screening questions used hypothetical situations that had a clear correct answer and were as concrete as possible. We found that respondents were able to abstract to a hypothetical situation as long as they were being asked to imagine a situation different from what they were currently experiencing. For example, subjects were not able to respond correctly to the question, "If you were feeling bad today, which choice would you pick to describe how you felt?" Instead of "bad," patients often said, "But, I feel fine today," and picked the choices labeled "good" or "excellent." However, when asked, "If you just received some very good news, which choice would you pick to describe how you felt?," patients were able to answer correctly.

For the purpose of this second iteration, all individuals were administered the questionnaire regardless of their ability to answer the screening questions correctly. This was done to ensure that the respondents' ability to answer the test questions accurately predicted their ability to comprehend the instrument itself. The second iteration revealed that respondents had some difficulty with the unlabeled points on the scale. Therefore, in the third and final iteration, all points on the scale were given descriptors.

3. *Sampling.*—Subjects were recruited from an existing database of participants from previous studies of dementia, from the local chapter of the Alzheimer's Association, and through requests for volunteers in local newsletters. Prospective participants were sent a letter describing the study and then screened by phone to determine eligibility. In order to be enrolled, individuals had to meet the following inclusion

criteria: (a) have a diagnosis of a dementia (Alzheimer's disease, vascular dementia, Parkinson's dementia, Lewy Body disease, or Pick's disease); (b) be English speaking; and (c) have a spouse or related caregiver who either lived with them or visited at least three times per week. Written consent was obtained from each participant's caregiver, and the participant where appropriate, just prior to beginning the interview.

4. *Methods of Administration.*—The total pool of 96 items, including the 15-item Geriatric Depression Scale (GDS; Yesavage, Brink, & Rose, 1983), was administered to our main study sample ($N = 99$). Respondents were seen either in the research clinic office, the respondent's home, or in the adult day health center that the person attended; the choice was made by the respondent or caregiver. The interview began with an explanation that the respondent was going to be asked some questions about his or her life. The respondent was instructed to choose answers from one of several 5-point response set scales placed in front of the respondent on a card (e.g., level of satisfaction, difficulty). Questions were grouped according to response set and each new response set was described immediately prior to use. The respondent was told the general category of questions which were to follow, such as "Now I am going to ask you how often you have felt certain things recently." The interviewer then pointed out the anchor points of the scale while reading these choices aloud, for example, "This scale goes from never to very often." The respondent was allowed either to pick a choice verbally or point to the answer. If he or she answered conversationally, or forgot to use the response scale, he or she was reminded to pick one of the choices. If the respondent was unable to pick a choice, the question was left unanswered and the interviewer moved on to the next item. The questionnaire contained eight different sets of response choices.

Eight items were randomly selected, one from *each of several hypothesized scales, as immediate re*test items and repeated at the end of the questionnaire. For two-week scale test-retest, a subsample of 18 subjects (9 mild and 9 moderate) were readministered the entire questionnaire (without retest items) two weeks after the first administration.

5. *Examine Missing Data, Variability, Reliability, Scaling Adequacy.*—Data from the 96 items were first combined across respondents with mild to moderate dementia to determine the proportion of missing data, item distributions, variability, reliability of the items and scales, and the adequacy of the hypothesized scales. The percentage of missing data on each item was considered an indicator of item difficulty. Variability was determined through examination of the frequency distributions of the items and hypothesized scales, the range of observed scores compared to the possible range, and the nature of the distributions.

Three types of reliability were examined: (a) item test-retest, (b) internal-consistency reliability for multi-item scales, and (c) two-week scale test-retest reliability. For test-retest reliability, the appropriate coefficient was selected based on the scale distribution. We used the Pearson product-moment coefficients for multi-item scales and scales with five or more observed scale levels (e.g., continuous measures); Phi for dichotomous scales; and Kendall's tau for scales with 3–4 observed scale levels. Same-time item retest correlations were based on the readministration of a subset of items at the end of the interview. For multi-item scales, internal-consistency reliability was examined using Cronbach's coefficient alpha (Cronbach & Meehl, 1955).

The scaling adequacy of the hypothesized scales was tested by examining interitem correlations of the items within a hypothesized scale, the item-scale correlations, and the reliability coefficients for the scale (Stewart, Hays, & Ware, 1992). Development of scales was iterative, that is, we developed hypothesized scales and revised them or deleted items based on results of the previous analyses. Thus, the process yielded a subset of measures that met at least minimum criteria for scale adequacy.

In addition, information from the interviewers regarding difficulties that patients had with various items and comments made by the patients were used to identify potential areas of confusion of wording, particularly when a scale was not meeting our psychometric criteria.

6. *Explore Construct Validity.*—We explored the construct validity of measures in two ways. First, we tested the hypothesis that the well-being scales would be substantially correlated with GDS, and that among these, the negative affect scale would be most highly correlated with the GDS. To assure the validity of the GDS in this population, we also tested the psychometric adequacy of the GDS according to the same criteria set for the QoL scales. Second, we examined correlations among the scales within each domain.

7. *Develop Final Scales.*—In order to produce a shortened, easily administered instrument and reduce *respondent burden, scales formed from the 96 items* were retained if they met all of the following criteria: had adequate psychometric properties (i.e., percent missing scale score < 10, nearly full range of scale scores endorsed, test-retest correlations $> .50$, internal consistency reliability $> .70$), were conceptually clear, were not redundant, and reflected the subjective experience of the person with dementia.

Results

Conceptualization of QoL in Dementia

All participants in the expert panels confirmed that dementia affects all traditional domains of QoL, confirming our belief that the impact is multidimensional. This impact was disease specific, that is directly related to cognitive, behavioral, and social changes accompanying disease progression. Thus, although the domains affected were similar to those of other more generic conceptualizations of QoL, the definition of each domain was shaped by the presence of the dementia. The conceptual framework is presented in Table 1.

Table 1. Conceptual Framework of QoL Domains for Cognitively Impaired Individuals

Domain	Subdomain
Physical Functioning: Ability to perform basic physical activities of daily life	Physical functioning (e.g., walking, going up and down stairs, reaching, bending)
Daily Activities: ADLs and IADLs	Self-care activities Instrumental activities: (e.g., shopping, cooking, handling finances)
Discretionary Activities: Performance of discretionary activities	Hobbies, recreational activities, vacations Work/productivity Being active
Mobility: Ability to travel out of the house	Travel in neighborhood and outside of neighborhood Public transportation
Social Interaction: Social relationships	Intimacy, happiness with family Social participation
Interaction Capacity: Ability to interact with the environment	Communication difficulties Ability to comprehend Confusion
Bodily Well-Being: Symptoms and bodily states reflecting physical comfort, discomfort	Fatigue Sleep
Sense of Well-Being: Positive and negative emotional/affective states and perceptions of self	Self-esteem Embarrassment, self-consciousness Sense of control Depressed mood, sadness Feeling loved and wanted Anxiety/worry Loneliness/isolation Fears Anger/irritability Frustration Boredom Feelings of belonging Feeling useful, valuable to others, helpful Calm, peaceful Happiness, cheerfulness Sense of humor
Sense of Aesthetics: Sensory awareness	Enjoyment/appreciation of beauty/nature Creativity/artistic expression and appreciation Awareness and appreciation of surroundings
Overall Perceptions: Summary ratings and evaluations about one's health and overall life situation	Self-rated health Life satisfaction

Two new domains were found to be important to persons with dementia, domains we have labeled Aesthetics and Interaction Capacity. Aesthetics is defined as the experience of appreciation and pleasure obtained from sensory awareness on either a verbal or nonverbal level, such as viewing or creating art, the sights and sounds of nature, and listening to music. Both health care professionals and participants with dementia commented on the obvious pleasure that persons with dementia received from these activities, even in the later stages of their disease.

The domain of Interaction Capacity reflects a disease-specific influence for persons with dementia. This domain includes communication difficulties as well as difficulty in social interactions. Word-finding difficulties and memory problems inherent in the disease may interact to make basic conversation difficult for persons with dementia. Social interaction between persons with dementia and others is often strained due to a lack of understanding of dementia on the part of others and embarrassment on the part of the demented person. We believe difficulty in these subdomains impedes interactions between the person with dementia and his or her environment, thus the domain label of Interaction Capacity.

Sample Description and Completion Rates

The sample had a mean age of 78.7 years (*SD* = 7.43 years), was predominantly female (59%), Caucasian (76%), married (57 %), and living with their spouse (51%). The majority had at least an eighth grade education (79%). The sample is described in Table 2.

Ninety-nine persons with dementia were interviewed. Four subjects (4%) were unable to answer two out of three screening questions correctly and thus would not be considered assessable according to our screening criteria. However, for study purposes, the entire instrument was administered to these subjects. The Mini-Mental State Examination (MMSE) scores for these four were all in the 17–21 range. It was found that subjects who were not able to answer two of the three screening questions correctly were also unable to answer questions in the remainder of the instrument. Conversely, not one of the respondents who answered two of the three test questions correctly was unable to complete the interview. The data presented include only those 95 respondents who passed the screening questions. Forty-five of these participants had mild dementia (MMSE > 19), and 50 had moderate dementia (MMSE 19–13).

The mean length of time to complete the original 96-item interview was 34 ± 12 minutes (range 13–65 minutes). This translates into approximately three items per minute. However, it is important to note that, in a subsequent study using the DQoL, we found that *it was unnecessary to precede each group of questions* with a description of the corresponding response scale. Instead, for the first question of each group, subjects were simply asked the question and then read the choices. The remaining questions were asked without repeating the choices unless the subject became distracted or forgot to use the scale. This adaptation in administration reduced overall time by approximately 10 minutes. Assessments were done by three interviewers, all of whom were trained by the first author according to a prescribed set of administration guidelines.

Final Scales

From the original item pool, 56 items forming 17 scales met our criteria for psychometric adequacy. Of these 56 items, 29 items, forming 5 scales, also met the remaining criteria for selection (conceptual clarity, lack of redundancy, and subjective in nature). Table 3 presents a brief definition of each of the retained measures, notes the response set (RS) used for the questions, indicates the number of items in the final scale, and presents descriptive statistics for the respondents (percent missing, mean, standard deviation, possible and observed range). Three estimates of reliability are shown: item test-retest for items administered at the same time at the end of the interview, two-week scale test-retest on a subsample of 18 respondents, and internal-consistency reliability of scales for the total sample.

Results of Missing Data, Variability, and Reliability Examination

Table 3 presents descriptive statistics for the five scales computed from the final subset of 29 items.

Table 2. Patient Characteristics (*N* = 95)

Characteristics	Percentages
Gender	
Male	41
Female	59
Age (years)	
55–65	7
66–75	23
76–85	53
over 85	17
Ethnicity	
Caucasian	84
African American	7
Asian	4
Native American	1
Other	3
Education[a]	
1st–7th grade	11
8th–12th grade	43
College	27
Graduate school	19
Marital Status	
Single	1
Married	57
Widowed	32
Divorced	8
Separated	2
MMSE	
12–14	13
15–17	17
18–20	24
21–23	22
24+	23
Occupation	
Unemployed	1
Professional	38
Housewife	26
Nonprofessional	11
Semiprofessional	15
Other	7
Religion	
Protestant	48
Catholic	20
Other Christian	7
Jewish	10
Mormon	1
Buddhist	1
None	7
Other	6
Income	
<$4,999	4
to $10,000	6
to $20,000	19
to $30,000	26
to $40,000	25
>$40,000	21
Living Situation	
Lives alone	9
Lives with spouse only	51
Lives with spouse & others	2
Lives w/other relative	26
Lives w/nonrelative	3
Lives in health care facility	6
Other	3

[a] Highest grade completed.

Table 3. Quality of Life Measures for Dementia Patients: Descriptive Statistics and Reliability Coefficients of Retained Items ($N = 95$)

Measure: Definition and Response Set (RS)[a]	No. of Items	% Missing	Mean[b] (*SD*)	Possible Range	Observed Range	Item Test-Retest (Same Time)	2-Week Test-Retest[c] ($N = 18$)	Internal Consistency Reliability[d]
Self Esteem: Thoughts and feelings about themselves (frequency feels confident, satisfied with self, accomplished something, makes own decisions) (RS 1)	4	7.4	3.66 (.73)	1–5	1.25–5	—	.68	.80
Positive Affect/Humor: Frequency felt happy, cheerful, content, hopeful, found something that made them laugh, jokes and laughs with others (RS 1)	6	4.2	3.55 (.73)	1–5	1.83–5	.54 Content	.90	.83
Negative Affect: Frequency felt afraid, lonely, frustrated, embarrassed, angry, worried, depressed, nervous, sad, irritated, anxious (RS 1)	11	6.3	3.86 (.69)	1–5	2–5	.62 Lonely	.64	.89
Feelings of Belonging: Frequency felt useful, felt people liked you, felt lovable (RS 1)	3	8.4	3.66 (.74)	1–5	1.33–5	—	.74	.67
Sense of Aesthetics: Extent to which obtained pleasure from sensory awareness, appreciation of beauty (extent of enjoyment listening to music, listening to sounds of nature, watching animals or birds, looking at colorful things, watching clouds or sky) (RS 2)	5	6.3	3.99 (.74)	1–5	1–5	.75 Listening to music	.72	.77

[a] Response scales are as follows: RS 1—Frequency: 1 = never, 2 = seldom, 3 = sometimes, 4 = often, 5 = very often; and RS 2—Enjoyed: 1 = not at all, 2 = a little, 3 = somewhat, 4 = mostly, 5 = very.

[b] All measures scored so that a high score indicates better QoL.

[c] Pearson correlation.

[d] Standardized alpha.

Participants' scores for each of the scales were computed by averaging the participants' responses to the items that comprise the scale. For example, a respondent's score for the Self-Esteem scale is the nonweighted average of the participant's responses to the four items that comprise the scale. If the subject had missing data on one of the four items within the scale, then the Self-Esteem scale score would be computed using the three items in the scale that the participant answered. If the respondent answered only two of the four questions in the scale, the scale score was not computed and considered missing. Similarly, we computed scale scores for no less than four of the six items in the Positive Affect/Humor scale; no less than nine of the eleven items for the Negative Affect scale; no less than two of the three items for the Feelings of Belonging scale; and no less four of the five items in the Aesthetics scale. The percentage missing on any final scale score ranged from 4.2–8.4. The higher percentage of missing data occurred for the Self-Esteem and Feelings of Belonging scales because a scale score for any subject with more than one missing item on either of these scales was not computed and therefore was considered missing.

The variability of most scores was adequate, with a good range of scale levels being represented in each of the five scales. The mean of the scale scores for the entire sample fell above the midpoint of the scale, but was within one standard deviation of the midpoint for all but the Aesthetics scale.

The internal-consistency reliability ranged from .67 to .89 (median .80). Thus, all were above the .50 criterion set by Nunnally (1978) for group comparisons which is appropriate for a new instrument. Four of the five scales had internal-consistency reliabilities of .70 or greater, a more stringent criterion often set for measures for which there is more experience. Two-week test-retest coefficients ranged from .64 to .90 (median .72). The three single-item test-retest coefficients (tested at the same time, at the end of the interview) ranged from .54 to .75 (median .62). Thus, all were above the .50 criterion. There were no significant differences between groups with mild (MMSE > 17) and moderate levels of dementia (MMSE <= 17) in scale reliabilities (Self-Esteem $p = .271$; Feelings of Belonging $p = .147$; Aesthetics $p = .113$; Positive Affect/Humor $p = .393$; Negative Affect $p = .575$).

Results of Validity Analyses

Correlations among the five sense of well-being scales ranged from .09 to .67 (median .36), with the highest being between Self-Esteem and Positive Affect (see Table 4).

The correlations of the sense of well-being scales with the GDS (which had an internal-consistency reliability of .83 and a two-week test-retest coefficient of .76) are as follows: Self-Esteem $r = -.48$; Positive Affect/Sense of Humor $r = -.61$; absence of Negative Affect $r = -.64$; and Feelings of Belonging $r = -.42$. Thus, our hypothesis that the GDS would correlate most highly with the Negative Affect scale was confirmed.

We separated the sample into two groups based upon the GDS criteria for possible depression. Of the 94 respondents with GDS scores, 15 met the criteria for possible depression by reporting six or more symptoms. The other 79 reported five or fewer symptoms. We found significantly higher mean scale scores for the nondepressed group compared with the "possibly depressed" group for the following scales: Sense of Belonging ($p = <.001$), Negative Affect ($p = <.001$), Positive Affect ($p = <.001$), and Self Esteem ($p = <.001$). There was no significant difference between the two groups on the Aesthetics scale ($p = .087$), although the mean score for the nondepressed group was higher than for the depressed group.

Discussion

The focus group members unanimously believed that the discussion of QoL for persons with dementia is of significant value. Persons with dementia, caregivers, and health care professionals discussed how dementia affects QoL and, more importantly, how QoL changes as the disease progresses. It is clear from the discussions that a broad range of domains are affected by the disease. To measure QoL as a unidimensional construct would do a serious injustice to researchers' understanding of the dementia-specific influence on QoL. Additionally, without an appreciation for this multidimensionality, the clinical understanding of disease progression and impact, development of appropriate interventions, and measurement of treatment effects would be seriously compromised.

With the exception of the Aesthetics and Interaction Capacity domains, the domains identified are similar to those traditionally considered when measuring QoL. The definitions of the subdomains within each major domain, however, were different than for other diseases or for healthy populations, thus strengthening the argument for a disease-specific conceptualization and measurement of QoL in this population. For example, sense of well-being is not defined solely in terms of mood states, but also in terms of embarrassment, self-consciousness, and feelings of being useful.

The Aesthetics domain appears to be of particular importance to dementia patients, as it is an area that offers promise for interventions and appears to be one domain that can remain pleasurable into the more advanced stages of the disease. We agree with Russell (1996) who "challenges us to go beyond the narrow idea of dementia as a contraction of life to a new and more complex vision of a unique and creative world . . . in which people with dementia may actually have a more personal, unique and individual experience because of their dementia" (p. 1401).

The domain of Interaction Capacity reflects the disease-specific influence by specifically tapping areas of difficulty which persons with dementia have in interacting with the environment. Difficulties in carrying on a conversation and expressing oneself greatly hinder social interactions. Problems with comprehending written material leave a person at a great disadvantage in interacting with the world, a world which relies on the written word to communicate.

It cannot be overly stressed that QoL is a subjective, individual experience (Callahan, 1992), and as Whitehouse and Rabins (1992) state, "ultimately, it is up to each individual to evaluate and assess his or her own quality of life, based on the degree of importance that he or she gives to each component" (p. 135). Individuals with similar diseases or conditions may have very different QoL because of their individual attitudes, beliefs, and circumstances. Dementia patients are no different. Emotional well-being and satisfaction with life are shaped by many forces beside levels of cognitive functioning. Other health factors, family and social interactions, economic status, and religious beliefs are only some of the additional factors that contribute to QoL. Dementia does not by definition strip an individual of these influences. Many dementia patients and their spouses have described how the illness has improved their relationship or how they have never loved their spouse more than at this time. The additional time, patience, and vigilance required to measure self-reported QoL accurately in demented persons is essential if we are to truly measure this subjective experience.

There are two fundamental issues in considering

Table 4. Interscale Correlations

	Self-Esteem	Positive Affect/ Humor	Negative Affect	Feelings of Belonging	Sense of Aesthetics
Self-Esteem	1.0				
Positive Affect/Humor	.67	1.0			
Negative Affect	.37	.35	1.0		
Feelings of Belonging	.57	.63	.33	1.0	
Sense of Aesthetics	.18	.38	.09	.29	1.0

the validity of subjective states in dementia: (a) the respondent's ability to comprehend the question being asked, and (b) the respondent's awareness of his or her internal subjective states.

It is the opinion of the interviewers that, overall, respondents were able to comprehend the questions and respond appropriately. The test questions at the beginning of the instrument served as the primary method of assessing the respondent's ability to comprehend questions and to use the Likert scales to express an appropriate response. There were 4 persons out of 99 who scored above 12 on the MMSE who were not able to comprehend the test questions. Although questionnaire administration was attempted with these four respondents, none of them were able to complete the interview. For instance, some of these persons were not able to comprehend the concept "how often." When asked how often they felt certain things, they would describe a typical situation that produces that feeling, or report the last time they felt that way.

Much of the initial restructuring of the instrument was based on respondent observations of the ambiguity of some of the questions. The following examples illustrate the level of comprehension respondents possessed. When faced with an ambiguous question, respondents would typically request more information. For instance, when asked, "How comfortable do you feel in social situations?," respondents often asked, "What type of social situations?," or "Do you mean with people I know or don't know?"

The precision of a respondent's thinking and response was also often surprising. For example, when asked, "How happy are you with your family life?," some participants wanted to know just who was to be considered one's family, and sometimes proceeded to report how satisfied they were with *each member* of their family. Similarly, in response to the question "Do you spend enough time with your family?," some patients replied "According to who?" Such observations and clarifications came from both mildly and moderately demented patients.

Finally, the depth of response that some questions elicited clearly indicated that the respondent possessed a firm grasp on what was being asked and demonstrated his or her ability to answer appropriately. When asked about feelings of self-worth and usefulness, some participants expressed the desire to be of more service to their community and family, and expressed pain at not having an opportunity to contribute something of worth to others and in feeling themselves to be a burden to others. Responses such as these reveal not only comprehension, but an awareness of self and concern about the impact one has on others. (It is interesting to note that although some respondents presented this awareness, they often attributed their difficulties to age or other circumstances rather than to the disease process.)

Of all methodological and conceptual difficulties in assessing subjective states in dementia, perhaps the most difficult is the issue of the degree of a person's self-awareness. Although the accuracy of the self-report of subjective states is impossible to determine objectively in any situation, this matter is of particular concern in assessing persons with dementia given the evidence that dementia may distort self-awareness. Studies have focused primarily on anosognosia, or unawareness of deficit, in Alzheimer's patients, who form the majority of age-related dementia cases. Reports of the prevalence of anosognosia in Alzheimer's disease range from 12% to 25% (Reed, Jagust, & Coulter, 1993; Sevush & Leve, 1993). The incidence of anosognosia in vascular dementia has been rated lower than that in Alzheimer's disease, and Mahendra (1984) reports that insight in vascular dementia may be relatively well preserved.

Awareness of *deficit* has most often been studied as the awareness of *cognitive* deficit or the processing of external cues (Allender & Kaszniak, 1989; Anderson & Tranel, 1989). Numerous studies have demonstrated that persons with Alzheimer's disease typically underestimate their level of cognitive impairment as compared to caregiver reports and actual test performance (McGlynn & Kaszniak, 1991; Ott et al., 1996; Schacter & Glisky, 1986). However, there is considerable argument over whether awareness is a global or modality-specific phenomenon. We would like to suggest that the awareness of cognitive deficit is conceptually distinct from awareness of one's own feeling states, and that awareness of feeling states may be preserved even in instances where awareness of cognitive deficits is impaired. Feeling states do not require an awareness of *loss,* a memory of one's previous functioning, awareness of current functioning, or the ability to compare the two. Feeling states only require an awareness of *being,* of how and who one is.

Several studies support this hypothesis that persons with Alzheimer's disease vary in their degree of unawareness across different modalities. Logsdon, Whitehouse, and Teri (1996) report good patient/caregiver correlations of measures of patient mood, energy, physical health and sense of self, although they found agreement on items most affected by the dementia state, such as memory and the ability to do chores, to be lower. Similarly, Seltzer, Vasterling, Hale, and Khurana (1995) found the greatest disagreements in caregiver and patient ratings for memory and self-care items, moderate disagreements in ratings of anxiety and irritability, and minor disagreements in assessment of depression and heath status. Reisberg, Ferris, and Franssen (1985) reported that persons with Alzheimer's disease who show marked unawareness of cognitive functioning maintained a preserved awareness of their ability to communicate with their spouse.

Some studies have shown that awareness of deficit declines in relation to disease severity as measured by the MMSE (Lopez, Becker, Somsak, Dew, & Dekosky, 1994; McGlynn & Kaszniak, 1991; Seltzer, Vasterling, Hale, & Khurana, 1995), suggesting that direct assessment of QoL in persons with dementia may be more reliable in the earlier stages of illness. In contrast, others have shown no correlation between severity and anosognosia (Auchus, Goldstein, Green, & Green, 1994; Ott et al., 1996). Of importance to this debate is our finding of no difference in the reliabilities of moderately and mildly demented patients.

The data show that persons with dementia can be considered good informants of their own subjective states. All of the scales had at least moderate reliability, and preliminary evidence of validity was found. Thus, we consider the items that exhibited problems to be due to our inability to design adequate measures. Nearly all dementia participants were able to respond to test questions appropriately, indicating that comprehension was not an issue.

The finding of significant differences on the mean QoL scores between depressed and nondepressed respondents on all four sense of well-being scales provides evidence of the discriminant validity of the instrument. The fact that these mean scores were all within the three to four point range lends support to the focus group findings that "reasonable" QoL for this population is a reality. Further interventions to reduce levels of depression may result in improved QoL for this group. Studies conducted in different settings are necessary to shed more light on the relationship between depression and QoL in dementia and to assess whether these observed means are generalizable.

The DQoL has been tested on persons with dementia with an MMSE score of 12 or above. Future research is needed to determine if it is also valid with slightly more demented persons (i.e., MMSE >10). However, there remains a group of patients with severe dementia for which the instrument is not intended. Instruments such as the Apparent Affect Rating Scale (Lawton, van Haitsma, & Klapper, 1996), which employ observational ratings to assess subjective states, offer a promising methodology for capturing QoL for the severely demented.

Persons with dementia who had no caregivers were represented in the focus group and thus were considered in developing the conceptual framework. However, a limitation of this study is that only individuals with a caregiver who interacted regularly with the person were eligible. Thus, it is unclear whether persons without caregivers would respond differently either to direct assessment or to specific domains measured.

The DQoL represents a promising alternative to proxy measures by directly measuring QoL of persons with dementia. We agree with McHorney (1996) that we are better served by obtaining self-report data from cognitively impaired persons on a fewer number of domains than by not obtaining any data at all. Given the good reliability and promising validity of direct assessment of subjective domains, there is little reason not to use direct assessment in these domains. In order to reduce respondent burden and administration time, to accommodate a reduced attention span, and address the concerns that dementia patients may be poor raters of their own cognitive and functional limitations, we suggest that the more objective aspects of domains (e.g., number of social interactions) be assessed via proxy. As it is not our intention to recreate what has been well done by other researchers in measuring more objective QoL domains, we suggest that other well-tested measures be used where appropriate. Figure 1 suggests an assessment strategy for measuring a comprehensive conceptualization of QoL in dementia that optimizes the positive contributions of various data sources and existing measures.

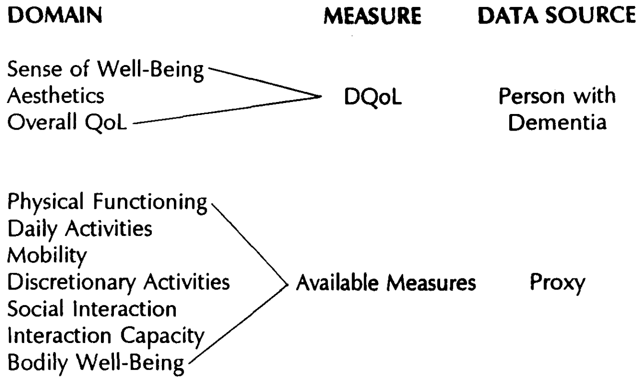

Figure 1. Assessment strategy.

This strategy produced the 29-item DQoL instrument comprising five scales assessing the subjective experience of dementia. Additionally, we suggest that an overall QoL item such as "Overall, how would you rate your quality of life?" also be asked along with the DQoL. By doing so, the relationship between global QoL and its component parts can be further explored. This optional overall item has been added to the instrument. The test questions used to assess comprehension have been changed in the final version so that the response choices of the test questions match the response choices of the first set of DQoL items. We estimate the DQoL will take approximately 10 minutes to complete. This should greatly reduce respondent burden and facilitate the use of the DQoL in multiple settings such as clinical drug trials, clinical practice and service settings. Inclusion of the DQoL will provide patients and their families with important information with which to compare new drug treatments, many of which have equivalent or modest clinical efficacy (Hollister & Gruber, 1996). The information can also be used to evaluate outcomes of social and service interventions that are specifically designed to improve QoL. The DQoL Instrument is available upon request from the first author.

Conclusion

Assessing QoL by proxy, especially the subjective domains, has long been a less than adequate solution for cognitively impaired populations. This study has paved the way for more serious consideration of direct measurement of QoL from the persons with dementia themselves. We believe that our findings strongly indicate that, with patient administration, it is feasible to assess directly QoL from most dementia patients with a MMSE score greater than 12. By doing so, we allow for the individuals' perceptions to become the gold standard by which to assess their QoL. Additionally, we can begin to include the large numbers of individuals who do not have an appropriate proxy in our assessment of QoL for this population.

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