

Can people with mild to moderate dementia provide reliable answers about their Quality of Life?

Richard Trigg¹, Roy W Jones² & Suzanne M Skevington¹

¹ Department of Psychology, WHO Centre for the Study of Quality of Life, University of Bath

² Research Institute for the Care of the Elderly, Bath

Contact Details

Correspondence to:

Dr Richard Trigg
Division of Psychology
Nottingham Trent University
Nottingham NG1 4BU
England
Tel: +44 (0) 115 8485603
Email: Richard.trigg@ntu.ac.uk

Professor Roy Jones
Research Institute for the Care of the Elderly
St Martin's Hospital
Bath
BA2 5RP
Tel: +44 (0) 1225 835866
Email: r.w.jones@bath.ac.uk

Professor Suzanne Skevington
Department of Psychology
University of Bath
Bath
BA1 4NG
Tel: +44 (0) 1225 386830
Email: s.m.skevington@bath.ac.uk

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Key Points

- Subjective accounts of quality of life (QoL) are necessary to better understand the experience of people with dementia
- Cognitive impairment and reduced insight have previously been viewed as barriers to completion of self-report QoL assessments in dementia
- Data presented here adds to a growing body of evidence suggesting that people with mild to moderate dementia can complete standardised self-report QoL assessments
- Reliability coefficients indicate that it is feasible and appropriate to obtain QoL ratings across a range of domains, from people with MMSE scores of >11
- Further work is needed to determine the minimum cognitive requirements needed to complete self-report QoL assessments

Background – Cognitive limitations and a lack of insight have been seen as a barrier to self report in quality of life (QoL) assessment of people with dementia. However growing evidence suggests that people with mild to moderate dementia may be able to complete standardised questionnaire items and articulate feelings, providing reliable evaluations of their health and QoL.

Objective – To examine the reliability of the item pool of a new measure of self-report QoL, the Bath Assessment of Subjective Quality of Life in Dementia (BASQID)

Subjects – Sixty people with mild to moderate dementia, recruited from a memory clinic.

Methods – Participants completed 44 items from an initial draft of the BASQID and 30 completed the items on a second occasion, two weeks later. Item analytic criteria, including item facility, score distributions, tests of internal consistency and reproducibility, were used to reduce the item pool, and the reliability of the reduced pool was examined.

Results – Twenty items were removed from the item pool. All retained items had at least moderate test-retest reliability ($\kappa > 0.41$), with 13 items displaying good to very good reliability ($\kappa > 0.61$). These 24 items were internally consistent ($\alpha = 0.91$), and the total score had good two-week test-retest reliability with an intraclass correlation coefficient of 0.82 (0.66 - 0.91).

Conclusions – Participants were able to complete items relating to feelings and evaluations of a range of QoL domains. The consistency of responses over a two-week period suggests that self-report QoL assessments are feasible and appropriate for people with mild to moderate dementia.

Introduction

Subjective evaluations of QoL by people with dementia may be influenced by their cognitive limitations and may reflect reduced insight, however they represent the best way of understanding the experience of life with dementia. Medical models of QoL have traditionally assumed that the more symptoms present, and the more advanced the disease, the poorer the QoL. However people with chronically limiting conditions often report a high quality of life [1]. Woods [2] suggests that there is an implicit assumption in many studies that increased independent function must be associated with a better QoL. He concludes that if well-being is to be increased through efforts to improve independent function, then there needs to be a better understanding of how the person with dementia cognitively processes these changes. Therefore, an understanding of people's perceptions, behaviours and experiences is needed if the concept of subjective QoL is to be adequately described.

People with dementia may have a range of cognitive and behavioural symptoms that can interfere with their ability to answer QoL questions. Communication, attention, memory and judgement are necessary skills to answer survey questions [3] and these are all cognitive areas that may be impaired in people with dementia. Similarly, altered psychological states such as depression, may impact on QoL assessment particularly when this involves reports about subjective well-being. Katschnig et al. [4] highlight the role of momentary affective states, reality distortion, and poor cognition in the distortion of responses to questions about functioning in social roles, and about material and social living conditions.

A further challenge for the direct assessment of QoL in people with dementia is the apparent lack of insight demonstrated by many individuals. This deficit can relate to awareness of specific memory/cognitive deficits, awareness of global memory/cognitive deficits, awareness of the impact of memory problems/dementia, or awareness of dementia as a whole [5, 6]. Insight varies across domains such as self-care, memory, health status and language abilities [7, 8]. However Brod et al. [9] suggest that “awareness of feelings may be preserved, even in instances where awareness of cognitive deficits is impaired” (p33). They cite evidence (e.g. [10]) that reports good correlations between patient and proxy measures, such as mood, energy, health and sense of self, alongside poor agreement on measures of memory and functional ability.

There is growing evidence to suggest that people with dementia can respond accurately to questions about QoL [9, 11-16]. Although investigations of cognitively impaired individuals show that proxies consistently rate QoL lower for the patient than they would rate themselves [17, 18], this lack of agreement is not entirely attributable to the level of patient cognitive impairment [19, 20]. Case studies [11] and research [12-15] suggest that mild to moderately cognitively impaired individuals can articulate feelings, concerns and preferences, and provide evaluations of their health and QoL.

More recently, direct assessment of QoL in people with mild to moderate levels of cognitive impairment has been carried out using assessments specifically designed for this purpose. Logsdon et al. [16] administered a 13-item QoL measure (QoL-AD) to 177 people with Alzheimer’s disease and showed that the assessment was valid and

reliable for people with mild to moderate levels of cognitive impairment. Of 177 respondents, 155 could complete the assessment. All of those who were unable to complete the QoL-AD had Mini Mental State Examination scores of 10 or below (MMSE; [21]). Similarly the DQoL is a QoL measure [9] that is administered directly to the person with dementia, and contains 29 questions relating to their self-esteem, positive and negative affect, feelings of belonging, and sense of aesthetics.

Administering the measure to 99 patients with mild to moderate stage dementia (MMSE>11), Brod et al. found that 95% were able to complete the DQoL and they concluded that “it is feasible to assess directly QoL from most dementia patients with a MMSE score greater than 12” (p34).

This paper reports on the preliminary stages of the development of the Bath Assessment of Subjective Quality of Life in Dementia (BASQID), which is a new measure of self-report QoL designed for use by people with mild to moderate dementia. The properties of the final BASQID measure, including validity and responsiveness to changes in QOL, have been reported elsewhere [22]. This paper focuses on the process of item reduction, where issues of item reliability were explored.

Method

Design

A cross-sectional design with a single follow-up was employed. Item-reduction was conducted through field-testing the item pool and application of standard psychometric criteria [23-26].

Participants

Sixty people with a diagnosis of dementia according to DSM-IV [27], and a MMSE score of 12 or above, were recruited as consecutive admissions to a memory clinic (see Table 1). Participants were excluded from the study if English was not their first language. A sample size of 60 was sufficient for item analysis, allowing detection of significant correlations (>0.3) between BASQID items. Thirty participants were reassessed two weeks later, to assess temporal stability of BASQID items, as 30 would allow the detection of significant correlations (>0.7) between the two administrations of the measure. This sub-sample was obtained through quota sampling, whereby consecutive participants recruited to the study were invited to undergo a second assessment. This process continued until 30 had been recruited to the retest.

Insert Table 1 here

Materials

BASQID Item Pool

Through previous in-depth interviews with people with mild to moderate-stage dementia ($n=45$), a conceptual framework for subjective QoL in dementia was developed which contained nine domains of QoL, reflecting recurrent themes in the interview data (see Table 2). An initial item pool was written so as to include all of the dimensions (facets) of QoL contained within these domains. These items were standardised to conform to two types of question stem and response scale (satisfaction

and capacity/intensity). Each response scale contained five response options, scored 0-4 where high scores represented good QoL. Questions beginning with the stem 'how satisfied are you...' were given a response scale 'not at all satisfied, a little satisfied, satisfied, very satisfied, extremely satisfied'; items beginning with 'to what extent...' were given a response scale 'not at all, a little, a moderate amount, quite a lot, a great deal'. Each item was written on an individual card 18cm x 6cm, in a large sans serif font (Arial 26pt), and response scales on cards 30cm x 10 cm with the same font. Response scales were set out horizontally, with vertical lines separating scalar points. The scale contained only the words defining each point on the scale, not the scores associated with each response. This item pool was pre-tested, using a simplified version of an item-by-item probing technique [28], on 15 participants in order to investigate problems with language, and item format. Revisions resulted, and a second draft of 44 items was written.

Insert Table 2 here

For the field test, an additional item was added to the item pool so that it could be used in analysis of the validity of BASQID items. This global item asked, "How would you rate your overall quality of life?" and was scored on a five-point response scale (very poor/poor/ fair/ good/ very good).

Procedure

Written informed consent was obtained from all participants. The BASQID item pool was administered to participants either at home or in the memory clinic, depending on the participant's preference. Administration began with the presentation and explanation of the response scale; respondents were asked if they could see the

response scale clearly, and if they were able read all points on the scale. Questions were then laid one at a time underneath the appropriate response scale, in front of the respondent, and read aloud by the interviewer. The respondent was asked to select an appropriate response, and this was recorded on a standardised interviewer score sheet. Where a respondent encountered difficulties, the interviewer provided limited assistance but did not suggest an appropriate response to a question. The forms of assistance available for use included repetition of questions and response options, clarification of words and phrases (where standardised prompts were available) and provision of reassurance that respondents should answer questions to reflect their own feelings and opinions. Thirty participants were reassessed using the same procedure.

Analysis

The first analysis phase involved examining the properties of individual items. Response distributions were examined for frequency of endorsement, such that items with two or more adjacent scale points showing an average of less than 10% of the responses were deemed to have frequency problems [25]. Item facility indices were calculated, and a value within one point of the scale anchor values indicated a skewed distribution. Item discrimination was assessed by examining item-total correlations. Item validity was examined through the correlation between each item, and the global QoL question. Spearman's correlations were used throughout, due to the ordinal nature of the data. A correlation coefficient of 0.3 or above, between individual items and total score is evidence of internal consistency [26], and is also a suitable criterion for examining the correlation between individual items and the global rating of QoL. Finally, weighted kappa (κ) was used to assess the test-retest reliability of each item across two-weeks. The strength of agreement between the responses using κ was

defined as poor (<0.2), fair (0.21-0.4), moderate (0.41-0.6), good (0.61-0.8), and very good (0.81-1.0) [23].

Items were flagged for possible deletion from the item pool where they had either: an item-total correlation of < 0.30; an item-global QoL correlation of < 0.30; test-retest weighted κ of 0.4 or less; or κ of 0.41-0.60 in conjunction with a poor response distribution (characterised by a failure to meet both the item facility and the response endorsement criteria). Internal consistency of the remaining items was calculated using Cronbach's alpha and item-total correlations, in order to identify whether the items formed a cohesive scale. An intraclass correlation coefficient explored the test-retest reliability of summed item scores.

Results

All except one of the participants were able to complete the 44-item pool. Missing data was minimal: question (Q) 20 had the highest level (6.7%), whereas Q25 and Q39 had missing data in 5% of cases. The retest was completed by 29 of the 30 participants.

Item analysis of the BASQID item pool highlighted problems with 20 of the 44 items (shaded rows in Table 3). These items were rejected from the item pool as none of the problems associated with these questions could be corrected through minor alterations to wording, and there were no obvious outliers in the data that may explain their poor performance. Thirteen of these items displayed poor validity, with correlations of

< 0.3 with the global QoL question, while five rejected items displayed poor association with other items ($r < 0.3$). Only one item (Q40) from the entire pool displayed poor test-retest reliability ($\kappa < 0.4$). Nineteen of the 44 items displayed good test-retest reliability with values of κ ranging from 0.61-0.85. Moderate test-retest reliability in conjunction with poor response distributions accounted for the rejection of nine items.

Insert Table 3 here

The internal consistency of the reduced item pool (24 items) was excellent, with a Cronbach's coefficient alpha of 0.91 ($n=55$). All corrected item-total correlations were > 0.3 , and alpha could not be improved by omitting any single item. A total score for the scale (0-96) was calculated by summing the scores on individual items. The mean for the total score was 66.52 (s.d. = 12.91, range = 35-91, $n = 55$). Values for 25% and 75% quartiles were 58 and 76 respectively. Analysis of the test-retest reliability of the 24-item scale produced an intraclass correlation coefficient of 0.82 ($n=29$; 95% CI = 0.66 - 0.91), indicating good agreement between responses over two weeks. The mean score for Time 1 assessments was 67.75 (s.d. = 11.36, $n=29$), and Time 2 was 69.35 (s.d. = 8.80, $n=29$). The mean difference in scores over two weeks (Time 1 – Time 2) was 1.60 (s.d. = 5.97) with values ranging from -18 to 7. Eight participants obtained the same score on both occasions.

Discussion

The initial BASQID item pool contained items drawn from nine different domains of QoL incorporating questions on health, social interaction, function, being occupied,

energy, sleep, psychological well-being and environment. Questions not only included assessment of 'feelings', as in the DQoL [9], but also included an appraisal of different QoL areas. Framing appraisal items in terms of respondent satisfaction gives an indication as to how changes in function are cognitively processed by individuals [2]. This allows for the possibility that respondents may report higher levels of satisfaction in areas of poor performance, due to a low perceived importance of a QoL domain or the successful use of coping and adaptation [22]. In this way the BASQID differs from measures such as the QoL-AD [16] which typically ask the respondent to rate actual performance. That respondents were able to complete the item pool with minimal missing data supports previous research that suggests people with mild to moderate dementia are able to respond appropriately to QoL questions [14], and express these responses using a standardised response scale [9, 16, 29]. Moreover, the level of test-retest reliability at both item and scale levels over a two week period supports the view that people in the earlier stages of dementia are able to respond consistently to such items [15].

Item analysis of the BASQID item pool reduced the number of items from 44 to 24. Items were rejected from the pool according to several criteria including item facility, item discrimination, response distribution, construct validity, and repeatability. The remaining 24 items form an internally consistent scale with good test-retest reliability over two-weeks. All items within the final item pool display moderate to very good test retest reliability, with 13 items displaying weighted kappa coefficients over 0.6.

Although the group data suggests that standardised QoL assessments can be used in this population, care must be taken when evaluating responses at an individual level. The Scientific Advisory Committee of the Medical Outcomes Trust [24] suggests that

for group comparisons a minimum reliability coefficient (reproducibility and internal consistency) of 0.7 is required. As with existing self report measures of QoL in dementia [9, 16, 29] the BASQID items when taken together fulfil this criterion. However to use a measure for individual comparisons, a higher reliability coefficient of 0.9-0.95 is ideal. Reliability coefficients less than 0.9 lead to the potential for wide confidence intervals in relation to an individual's score. Therefore care must be taken with the interpretation and use of individual scores, until more is known about those factors that predict the ability of individuals to reliably complete such measures. Further work is needed to determine the minimum cognitive requirements needed to complete self-report QoL assessments.

However the inevitability of unreliability in certain individual cases should not be used as an argument against self-report in dementia. The data presented here illustrates that self-report measures of QoL such as the BASQID can provide valid, reliable and useful information at the group level, which allows exploration of the subjective experiences of people with dementia. Measurement in all fields is an imprecise science, and error may be introduced through a wide variety of sources, such as position effects, and satisficing strategies [3, 30], and yet none prohibit measurement in other conditions or situations. As long as developers seek ways of reducing these potential sources of measurement error through careful attention to the wording and format of questionnaires, the cognitive limitations and reduced insight of respondents should not be used as justification for ignoring the perspective of the person with dementia on QoL issues.

Conflicts of Interest

None

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Ethical Approval

The study was approved by the Bath Local Research Ethics Committee (ref

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Table 1: Sample characteristics

		Total Sample (n=60)	Test-retest subsample (n=30)
Probable diagnosis	Alzheimer's / Mixed	49 (82%)	26 (87%)
	Vascular	8 (13%)	3 (10%)
	Frontotemporal	3 (5%)	1 (3%)
Cognitive ability	MMSE mean (s.d.)	18.44 (4.07)	19.07 (3.43)
	MMSE median (range)	18.00 (12-26)	19.50 (12-26)
Living arrangement	Living alone	8 (13%)	3 (10%)
	Living with spouse	45 (75%)	24 (80%)
	Living with relative/other	5 (8%)	2 (7%)
	Residential accommodation	2 (3%)	1 (3%)
Sex	Male	28 (47%)	13 (43%)
	Female	32 (53%)	17 (57%)
Age	<65	7 (12%)	3 (10%)
	65-74	24 (40%)	13 (43%)
	75-84	19 (32%)	8 (27%)
	>85	10 (16%)	6 (20%)

Table 2: Quality of Life Domains and Facets

QoL Domain	QoL Facet
Health	Satisfaction with physical health Satisfaction with mental health Feelings of pain or discomfort Feeling unwell
Social interaction	Satisfaction with relationships Ability to interact Opportunity to interact Social confidence Satisfaction with treatment by others Appearance to others Satisfaction with role
Function	Satisfaction with self care performance Satisfaction with ADL & IADL performance Satisfaction with level of independence Confidence in ability Frustration with ability
Mobility	Satisfaction with mobility around the home Satisfaction with community mobility Availability of transport Satisfaction with ability to get out of the home Feelings of restriction
Being occupied	Satisfaction with leisure Opportunity for leisure Meaningful time use Boredom
Energy	Bothered by feelings of fatigue Satisfaction with motivation / enthusiasm Satisfaction with activity levels Satisfaction with energy levels
Sleep	Satisfaction with amount of sleep Bothered by sleep disturbance
Psychological	Contentment and happiness Depression Anxiety Feeling important Feeling useful Feeling in control
Environment	Adequacy of home Adequacy of possessions Satisfaction with financial status Availability of support Satisfaction with support Privacy Feelings of comfort Feelings of security

Table 3: Criteria for reduction of BASQID item pool

No.	Item	Valid n	Facility index	Range	Item-total r n=53	Item-global r	Weighted Kappa (S.E.) n=29
Q1	How satisfied are you with your health?	60	2.83	1-4 ¹	.71**	.46**	.72 (.13)
Q2	How satisfied are you with your memory?	60	1.72	0-3	.51**	.33**	.85 (.12)
Q3	How satisfied are you with your concentration?	59	2.25	1-4	.15	.11	.52 (.13)
Q4	How satisfied are you with your thinking processes?	60	2.00	0-4	.30*	.27*	.61 (.11)
Q5	How satisfied are you with your ability to look after yourself?	60	2.50	0-4	.50**	.29*	.73 (.11)
Q6	How satisfied are you with your ability to carry out daily activities in the home?	60	2.45	0-4 ¹	.45**	.12	.71 (.13)
Q7	How satisfied are you with your level of energy?	60	2.73	0-4 ¹	.67**	.40**	.41 (.13)
Q8	How satisfied are you with your enthusiasm for doing things?	60	2.45	0-4 ¹	.54**	.48**	.55 (.11)
Q9	How satisfied are you with your sleep?	60	3.02	0-4 ¹	.31*	.05	.66 (.13)
Q10	How satisfied are you with your ability to move around all areas of your home?	60	3.18	0-4¹	.60**	.50**	.58 (.14)
Q11	How satisfied are you with your ability to get out of your home?	59	2.91	0-4	.74**	.41*	.47 (.12)
Q12	How satisfied are you with your ability to move around your local community?	59	3.11	0-4 ¹	.66**	.27*	.52 (.13)
Q13	How satisfied are you with your ability to travel to places outside of your local community?	59	2.58	0-4	.39**	-.02	.45 (.12)
Q14	How satisfied are you with the way you usually spend your day?	59	2.76	1-4 ¹	.58**	.48**	.72 (.12)
Q15	How satisfied are you with your level of independence?	59	2.39	0-4	.67**	.35**	.47 (.11)
Q16	How satisfied are you with your relationships with people who are close to you?	59	3.27	2-4 ¹	.33*	.28*	.61 (.18)

Q17	How satisfied are you with your ability to talk to other people?	59	2.93	0-4	.57**	.27*	.57 (.11)
Q18	How satisfied are you with the way other people treat you?	59	3.10	1-4¹	.48**	.36**	.50 (.13)
Q19	How satisfied are you with the support you receive from other people?	58	3.2	2-4¹	-.11	-.20	.59 (.15)
Q20	How satisfied are you with the support you receive from medical and social services?	56	3.21	2-4¹	.28*	.03	.42 (.13)
Q21	How satisfied are you with the place where you live?	59	3.49	2-4 ¹	.27*	.03	.71 (.15)
Q22	How satisfied are you with your financial situation?	59	3.08	1-4 ¹	.47**	.19	.70 (.15)
Q23	To what extent do you suffer from physical discomfort?	59	3.02	0-4 ¹	.32*	.31*	.64 (.12)
Q24	To what extent do you feel unwell?	59	3.39	1-4 ¹	.44**	.33**	.71 (.12)
Q25	To what extent are you able to do all the activities that you want to?	57	2.67	0-4	.55**	.52**	.50 (.11)
Q26	To what extent do you have confidence in your ability to do things?	59	3.08	1-4¹	.44**	.31*	.53 (.13)
Q27	To what extent do you feel frustrated with your ability to do things?	59	2.88	0-4	.43**	.29*	.61 (.12)
Q28	To what extent do you feel anxious about your ability to do things?	59	3.05	0-4¹	.49**	.37	.51 (.13)
Q29	To what extent are you bothered by feelings of tiredness and fatigue?	59	2.98	1-4	.42**	.32*	.71 (.12)
Q30	To what extent are you able to go to the places that you want to?	58	2.53	0-4	.35*	.10	.64 (.11)
Q31	To what extent are you able to do things that you enjoy?	59	2.76	0-4 ¹	.64**	.60**	.75 (.12)
Q32	To what extent do you enjoy life?	59	3.39	0-4¹	.60**	.51	.59 (.15)
Q33	To what extent do you feel bored?	59	3.05	0-4	.53**	.35**	.72 (.12)
Q34	To what extent do you feel you are in control of your life?	58	2.62	0-4 ¹	.60**	.38**	.59 (.13)
Q35	To what extent do you feel you have the choice to do the things that you want to	58	2.60	0-4	.53**	.51**	.45 (.12)

	do?						
Q36	To what extent do you have the opportunity to meet other people?	58	2.57	1-4	.23	.18	.68 (.12)
Q37	To what extent do you have confidence when meeting other people?	59	2.86	0-4 ¹	.44**	.19	.49 (.12)
Q38	To what extent do you feel useful?	59	2.46	0-4	.55**	.38**	.54 (.12)
Q39	To what extent do you feel that other people take notice of your opinions?	57	2.18	0-4	.44**	.16	.53 (.12)
Q40	To what extent do you feel there are people you can call on if you need help with anything?	58	2.91	1-4 ¹	.43**	.10	.33 (.11)
Q41	To what extent do you feel happy?	58	2.87	2-4 ¹	.49**	.52**	.54 (.13)
Q42	To what extent do you feel unhappy?	58	3.26	1-4¹	.42**	.43**	.58 (.12)
Q43	To what extent do you feel anxious?	59	2.88	1-4	.35*	.51**	.78 (.13)
Q44	To what extent do you have the goods and possessions to meet your needs?	58	3.21	2-4¹	.64**	.36**	.57 (.13)

* Significant at $p < 0.05$

** Significant at $p < 0.01$

¹ Two or more adjacent scale points showing <10% of the responses

Shaded items flagged for deletion from item pool

Figures in bold indicate main reasons for item deletion