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How can we best assess the quality of life of people with dementia? The Bath Assessment of Subjective Quality of Life in Dementia (BASQID)

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Purpose of the Study - The study aim was to develop a measure of self-reported QoL for people with mild to moderate dementia based on their views - the Bath Assessment of Subjective Quality of Life in Dementia (BASQID).

Design and Methods - The measure was developed through multiple stages. Two field tests of the measure (n=60 & n=150) enrolled people with dementia from a memory clinic and the data were used to analyse the psychometric properties of the scale. Nested within this was a longitudinal investigation of 36 Alzheimer's disease patients prescribed with acetylcholinesterase inhibitors.

Results - The BASQID contains 14 items assessing a range of QoL issues. Results show that the BASQID satisfies the criteria of a valid, reliable, and acceptable assessment of subjective QoL. Scores were responsive to changes in QoL, over 3-months. Low association between the BASQID and Mini Mental State Examination indicates that cognitive function may influence QoL, but is an indirect measure of the QoL experienced during dementia.

Implications – The BASQID provides a means of better understanding the experiences, perceptions, and beliefs of people with dementia. It does this through acknowledgement of the many influences on QoL, over and above health status. The BASQID can be used alongside objective assessments of dementia to provide a complete appraisal of a person's QoL.

Key words: Psychometrics, Self-report, Alzheimer's disease, Outcome assessment, Well-being

Introduction

With no cure available, one of the main goals for pharmacological, behavioural, social and environmental interventions in dementia must be the maintenance or improvement of the patient's quality of life (QoL). Quality of life is a multidimensional construct that should include not only objective (observable) indices of well-being judged against socio-normative criteria, but also the individual's own subjective perception of their position in life (Lawton, 1991). Global concerns of patients in relation to their own values and expectations must be considered if an acceptable standard of care is to be provided for people with dementia. With the increasing trend towards patients presenting at earlier stages of the disease, and being involved in decisions about their care and treatment, it is important that clinicians have accurate information about the overall impact on well-being of both the disease, and any potential intervention (Schneider, 2001).

Measuring Quality of Life in Dementia

In dementia, there has been a long unchallenged assumption in research and practice that people with dementia are unable to give a reliable account of their own QoL (Cotrell & Schulz, 1993). Measurement has therefore focused on observable aspects of QoL, such as symptom severity and function, with only fleeting reference to the person's subjective perceptions (Stewart, Sherbourne & Brod, 1996). Consequently, many QoL measures risk being little more than health status assessments that replicate much of the information that can be obtained from many other disability and disease burden measures (Gill & Feinstein, 1994; Leplege & Hunt, 1997). There is also the danger that by conceptualising QoL for those with dementia in terms of negative constructs such as loss and disability, QoL research will focus on minimising negative outcomes, to the exclusion of maximising the potential for positive life

experiences.

The medical model of QoL places most emphasis on functional capacity, stressing the ability to perform everyday tasks and fulfil premorbid social and occupational roles (Leplege & Hunt, 1997). Implicit within the medical model is the notion that there is an optimum level of functioning, to which all people should aspire, whereby those who are impaired or disabled have, by definition, a poorer QoL. This leads to the questionable assumption that positive QoL cannot be achieved in the presence of physical deficits. Similarly, whilst health is undoubtedly an important component of QoL, the two terms should remain distinct (Hunt, 1997), as evidence suggests that it is possible for people in poor health to report a good QoL (Albrecht & Devleiger, 1999). In developing QoL measures, care must be taken to differentiate between causal variables (e.g. symptoms and reduced function) that affect QoL, and outcome variables that reflect QoL (Fayers & Machin, 2000). By weighting QoL assessments heavily towards the presence or absence of symptoms like memory loss and disability, the possibility is excluded that some people may be able to adapt or adjust to their health problems, so maintaining or even improving their QoL (Ettema, Droes, de Lange, Mellenbergh & Ribbe, 2005). Indeed, evidence indicates that there is little or no association between QoL and severity of cognitive impairment for people with mild to moderate-stage dementia (Hoe, Katona, Roch & Livingston, 2005; Logsdon, Gibbons, McCurry & Teri, 1999; Ready, Ott, Grace & Fernandez, 2002; Thorgrimson et al., 2003). Just because an individual's cognition worsens, we cannot assume that this inevitably leads to a worsening of QoL.

It has been argued that QoL can only be adequately measured by determining the opinions of patients, rather than relying on the views of 'experts' e.g. clinicians, or

carers (Gill & Feinstein, 1994) which may be reliable for observable aspects of behaviour and ability, but are unsuitable for inferring subjective experience and feelings (Berkowitz, Du, Kazis & Lewis, 1995). Recent research suggests that with careful attention to the wording, structure and format of questions, self-reported QoL is possible using standardised measures (Brod, Stewart, Sands & Walton., 1999; Logsden, Gibbons, McCurry & Teri, 2002). Moreover, it provides consistent and reliable information regarding QoL issues (Feinburg & Whitlatch, 2001; Mozley et al, 1999).

Reviews of QoL measures that could be used in dementia highlight a variety of suitable tools (Ettema et al., 2005; Ready & Ott, 2003) but few have been developed specifically for dementia, and even fewer are designed to gather information directly from the person with the condition. The Dementia Quality of Life Instrument (DQoL) (Brod et al., 1999) is a measure designed solely for patient-administration; it assesses a person's 'sense of well-being' and 'aesthetics'. Common indicators of QoL such as social interaction, mobility and activity performance were excluded with the aim of minimising respondent burden and because these domains are seen as more suited to objective assessment. The DQOL therefore focuses primarily on feeling states and mood. However Jennings (1999) suggested that QoL judgements based on feelings such as happiness are too simplistic; it is not plausible to say that a person's QoL is good just because pleasurable sensations outnumber the unpleasant ones. An evaluation of life areas such as satisfaction is central to the concept and assessment of QoL (Lawton, 1997). The QoL-AD (Logsdon et al., 1999) is a brief measure designed for both patient and proxy completion, with respondents asked to rate general life areas such as physical health, energy, mood, living situation, memory, family, marriage, friends, chores, fun, money, self and life as a whole on a scale from poor to

excellent. However one might argue that this approach differs from an evaluation of satisfaction in that it does not allow for the possibility that the person may rate his/her performance in a particular life domain as poor but report higher levels of satisfaction due to a low perceived importance of that domain, or the successful use of coping and adaptation.

There is therefore a need to develop a new measure of QoL for use by people with mild to moderate-stage dementia, to subjectively assess a range of QoL domains particularly relevant to this population; including positive and negative feeling states, and with judgement or evaluation of various life areas. The measure should avoid inclusion of causal variables such as symptom severity that do not necessarily reflect QoL status *per se*, and should promote the assessment of positive constructs, such as feelings of self-worth and life satisfaction.

Development of the Bath Assessment of Subjective Quality of Life in Dementia (BASQID)

The BASQID was developed from the perspective of the person with dementia and this philosophy remained central to each stage of development. These stages had previously included the qualitative development of a conceptual framework, generated from in-depth interviews, with thirty people with mild to moderate-stage dementia, exploring in their own language and ideas, those issues that were relevant and important to their QoL, and the ways in which dementia impacted on these areas. Further, structured interviews with people with dementia examined understanding, and the relative importance, of the emergent QoL domains, and provided an opportunity to explore the potential format of questions, and response choices. Results indicated that presenting questions and response scales both visually and

orally may be beneficial in helping the respondent attend to questions, and respond to choices. An initial pool of 44 items was produced, based on the domain and facet structure from the conceptual framework.

The conceptual framework and details of item reduction are presented elsewhere (Trigg, Jones & Skevington, 2007). This paper reports on the psychometric properties of the final BASQID measure, including the relationship of BASQID scores to other clinical indicators, such as cognition.

Method

Design

The field-testing of the BASQID item pool was split into two stages, so that the initial pool of items could be reduced before large numbers of people were assessed on the measure within a memory clinic setting. The main purpose of the first field test (Stage 1) was to carry out item reduction analyses along standard psychometric procedures, and applying criteria provided by the Scientific Advisory Committee of the Medical Outcomes Trust (2002). At Stage 1, the 44-item version of the BASQID was administered with the15-item Geriatric Depression Scale (GDS-15) (Sheikh & Yesavage, 1986). The WHOQOL-BREF (The WHOQOL Group, 1998a) was also completed by the spouse/caregiver and not the patient, as the burden on participants was of primary concern at this stage of development. It was felt that the addition of a further assessment such as the WHOQOL on top of the 44-item BASQID and GDS would be excessive.

A second field test (Stage 2) followed, when a shortened version of the BASQID (21 items) was administered, with the Mini Mental State Examination (MMSE) (Folstein,

Folstein & McHugh, 1975). This information was used to produce the final BASQID instrument, and explore the contended relationship between QoL and cognition.

Nested within the Stage 2 sample was a modest longitudinal study of 36 participants who were beginning treatment on one of the three available acetylcholinesterase inhibitors for mild-moderate Alzheimer's disease (AD) (Sample 2a). They were tested twice, at 3-month intervals, to provide information on validity and responsiveness of the BASQID scores to changes in clinical condition.

Participants

Sixty people with dementia (Sample 1) were included in the Stage 1 field test as 60 was calculated as being sufficient to detect significant correlations (>0.3) between questionnaire items, and between measures for the purpose of construct validity testing. Thirty of these were re-assessed two weeks later, and the scores used to examine test-retest reliability, as 30 would allow the detection of significant correlations (>0.7) between the two administrations of the measure, albeit with large standard errors. For Sample 2, 150 patients were recruited, as this was sufficient to allow detailed analysis of the structure and scaling properties of the BASQID using factor analytic techniques. MacCallum, Widman, Zhang & Hong (1999) indicate that between 100-200 cases is adequate when there are few factors, and variables have communalities (common variance) of > 0.5. Nested within Sample 2 was a subgroup of 36 participants who were beginning treatment on one of the three available acetylcholinesterase inhibitors for mild-moderate AD. They were assessed on the first occasion that these drugs were prescribed, and then again, three months later.

Participants were consecutive admissions to a memory clinic during a 15-month period, who satisfied the inclusion criteria of a positive diagnosis of dementia, according to DSM-IV (American Psychiatric Association, 1994), and a MMSE score of 12 or above, signifying a mild to moderate stage (National Institute of Clinical Excellence, 2001). Previous research shows this to be the level at which patients are able to directly report on QoL issues (Logsdon et al., 1999; Mozley et al., 1999). Exceptionally, some patients with scores below 12 were recruited if the clinical staff judged that they might be able to complete the assessment, and if their low MMSE score was due to poor sight or hearing. Participants were excluded if they had already participated in the BASQID development, or did not have English as their first language. At Stage 1, the participation of a spouse or caregiver of the person (where available) was requested to complete proxy assessments on behalf of the patient for validation purposes.

Materials

Bath Assessment of Subjective QoL in Dementia (BASQID)

The number of items contained within the measure was different for the two field tests: 44 items for Stage 1, into which the 21 items tested at Stage 2 were embedded. The items were administered via interview, with the interviewer presenting each question visually and orally to the person with dementia. Each item is printed on an individual card in large sans serif font. Response scales are printed on individual cards (same font size) and are set out horizontally, with vertical lines separating the five scalar points. Two response scales are used within the BASQID; ‘not at all satisfied, a little satisfied, satisfied, very satisfied, extremely satisfied’ and ‘not at all, a little, a moderate amount, quite a lot, a great deal’. Only words define each point on the scale, not the scores associated with each response. All items are scored 0-4, so

that low scores indicate poor QoL.

Geriatric Depression Scale (15-item version)

The 15-item GDS (Sheikh & Yesavage, 1986) demonstrates acceptable reliability as a screening instrument (alpha = 0.81) for depression. It has advantages over shorter versions in that the total score can be used as a measure of the severity of the depressive episode (Almeida & Almeida, 1999).

WHOQOL-BREF

The WHOQOL-BREF is a 26-item short form version of the WHOQOL-100 (WHOQOL Group, 1998b). It is a generic assessment of QoL across four domains: Physical health, Psychological, Social relationships, and Environment (Skevington, Lofty & O'Connell, 2004). Internal consistency reliability has been demonstrated by Cronbach's alpha values of between 0.66-0.88 for the four domains, in an international sample of well and sick people. The WHOQOL-BREF was found to be comparable to the WHOQOL-100 in terms of discriminating between the QoL of ill and well respondents.

Mini Mental State Examination

The MMSE (Folstein et al., 1975) is a widely used measure of cognitive function. The MMSE has a maximum score of 30 points. It assesses aspects of orientation to time and place, registration, attention, calculation, recall, language and visual construction. The MMSE scores validly discriminate between people with dementia, depression, or cognitive impairment with depression (Folstein et al., 1975). Test-retest reliability was measured at 0.89, with inter-rater reliability at 0.83. Validation of the measure is reported (Tombaugh & McIntryre, 1992) however it must also be noted that the

MMSE has been criticised for its dependency on education and age (Tombaugh & McIntryre, 1992) and on race, ethnicity and language (Ramirez et al., 2006).

Clinician Global Change Rating (CGCR) Forms

A Clinician Global Change Rating (CGCR) of QoL was completed for each participant in Sample 2a as part of the assessment of responsiveness. Responsiveness testing requires the comparison of measure changes to an accepted indication of change as the external standard (Husted, Cook, Farewell & Gladman, 2000). However for QoL measurement, no such gold-standard measure exists. Terwee, Dekker, Wiersinga, Prummel & Bossuyt (2003) suggest that in such cases, global ratings of change by clinicians might be appropriate. While admittedly an imperfect measure, because a physician saw all participants, this was seen as the most appropriate form of proxy QoL rating in the current study. The CGCR consisted of a transitional question in which the physician used a 5-point scale to rate whether the participant's QoL was: a lot worse, a little worse, the same, a little better or a lot better, compared to three months previously.

Procedure

At Stage 1, interviews were conducted in the participants' home or at the memory clinic, depending on the preference of patient and carer. Informed consent was obtained from both parties. The carer completed the WHOQOL-BREF on behalf of the patient. The BASQID and then the GDS-15 were administered via interview to the patient. Thirty respondents were revisited two weeks after the initial administration when patients completed the BASQID alone, to provide data for calculation of test-retest reliability statistics.

All assessments at Stage 2 were conducted in the memory clinic as part of the

patients' scheduled visit. Routine cognitive assessments and evaluations completed by memory clinic staff included administration of the MMSE. The researcher was then introduced to the patient and explained the purpose of the QoL assessment. Informed consent was obtained from the participant, and the BASQID administered.

For participants in Sample 2a, the procedure above was completed twice. The first assessment was administered prior to the participant being prescribed an acetylcholinesterase inhibitor for the treatment of AD. The second assessment was at their three-month follow-up appointment where the effectiveness of the drug was evaluated by the physician supervising the prescription of the intervention, using the CGCR form.

Statistical Analysis

Data from Stage 1 was revisited once the final BASQID scales had been produced, as part of construct validity and test-retest reliability analysis. The relationship between BASQID scores, the GDS and the four subscales of the WHOQOL-BREF was examined using Pearson correlation coefficients. Intraclass correlation coefficients were used to explore the temporal stability of the BASQID.

Data from Stage 2 was used to develop the final BASQID instrument retaining only the items and subscales that demonstrated sound psychometric properties. The dimensionality of BASQID items was explored using Principal Components Analysis (PCA) with a Varimax, orthogonal rotation. In an iterative process, factors were retained if eigenvalues exceed 1.0. Items that failed to load at least 0.4 on any factor or that cross-loaded on more than one factor (at above 0.4) were considered for possible rejection from the measure. Once items had been eliminated, the best-fit model was re-run. It is noted that these analyses are exploratory, and that other

models, e.g. a bifactor (Gibbons et al., 2007) or a random intercept model (Maydeu-Olivares & Coffman, 2006) should be examined in future analyses. The latter model is appropriate when item wording may affect item response, and the bifactor model is informative with respect to the presence of a general factor in addition to two subfactors that capture residual covariation.

Internal consistency of the resultant scales were examined using Cronbach's coefficient alpha. Secondary analysis was conducted to investigate the effect of participant cognitive status on internal consistency. Sample 2 was divided into tertiles according to MMSE scores (<16, 16-20, >20) and Cronbach's alpha recalculated for the BASQID scales within each tertile (Logsdon et al., 2002).

Responsiveness of the scales was assessed through calculation of effect size statistics (change score for the instrument divided by the standard deviation of the baseline scores; Kazis, Anderson & Meenan, 1989). These effect sizes were compared to the CGCR to assess whether the BASQID was able to detect clinically important observed changes in patients' QoL. Spearman's correlations examined agreement between the effect sizes recorded on the BASQID, and changes in QoL as rated on the CGCR form. Secondary analysis involved splitting the sample into three groups according to clinician judgements about improved QoL, a worse QoL or the same QoL, compared to three months ago, and comparing effect sizes across the groups.

The construct validity of the BASQID was explored thorough examination of Pearson's correlations between BASQID scores and participant cognitive status, age, GDS-15 and the carers' proxy judgement using the WHOQOL-BREF. An independent samples t-test explored differences in BASQID scores for males and

females. It was hypothesised that BASQID scores would show low-moderate significant correlations with proxy ratings of QoL on the WHOQOL-BREF. As there is a strong relationship between self-reported QoL and mood (Logsdon et al., 2002; Thorgrimson et al., 2003), McDowell and Newell (1996) suggest that the correlation between QoL and depression may be as high as 0.6, so a moderate correlation was expected between BASQID scales and GDS-15. In line with results from other self-report QoL instruments, significant correlations were not expected between BASQID scales and participant MMSE scores (Logsdon et al., 1999; Ready et al., 2002; Thorgrimson et al., 2003), or between BASQID scores and participant age or sex. One-way analysis of variance was used to explore differences in BASQID score across age and MMSE tertiles.

Results

The properties of the BASQID outlined below are based on data from Stages 1 and 2, but data from these two stages was analysed separately. Table 1 displays the characteristics of the samples used. In Sample 2, 11 participants had MMSE scores of less than 12.

In Stage 1, seven participants were unable to complete all 44 items. Of these, five provided answers for at least 42 of the items. In Stage 2, seven people out of 150 were unable to complete the 21-item measure. All except one had MMSE scores of 12 or below. Reasons for non-completion of items included fatigue, confusion, poor attention, and poor language skills.

The item reduction procedure is published elsewhere (Trigg et al., 2007) and the analysis in this paper is conducted on the 14 extracted items that were found to be the

'best' items out of 44 in psychometric terms, and form the final measure.

Insert Table 1 here

BASQID Scales

The BASQID measure contains 14 items. In Stage 1, the level of missing data for these items was minimal, with any one question having no more than three missing values (5%). For Stage 2 the level of missing data within the 14 items was no more than 4.66% (7/150). Listwise deletion of cases was employed where there was missing data in the variables used for analyses.

A total score for the 14-item scale (BASQID), from 0-100, is derived by multiplying the sum score by 100/(*m* x (*k*-1)) where *m* represents the number of items in the scale and *k* represents the number of response choices. The distribution of scores on the BASQID had a mean of 61.47 (SD = 14.25, range = 23.21–89.29).

Insert Figure 1 here

A PCA was used to explore the dimensionality of the 14 items, using data (n=143) from Stage 2. The Kaiser-Meyer-Olkin statistic had a value of .90, indicating an excellent level of sampling adequacy. Bartlett's test of sphericity was significant, indicating that PCA was appropriate. Both the Kaiser criterion, of retaining factors with an eigenvalue of greater than one, and the scree test (see Figure 1) suggest that the items within the BASQID may be organised according to two orthogonal dimensions. Although the test of scree suggests an essentially unidimensional result (a ratio of 4 to 1 of the first to the second eigenvalue, with the second only slightly over

1), the presence of two components cannot be ruled out without further confirmatory analyses with a cross-validation sample and other models. The content of the items within each dimension suggest that Component 1 (eigenvalue = 5.90) represents a Life Satisfaction (LS) subscale and Component 2 (eigenvalue = 1.36) represents a Feelings of Positive QoL (FPQ) subscale. The content of these items and loadings on the two components are displayed in Table 2.

Insert Table 2 here

Subscale scores were calculated in the same manner as those for the BASQID. The distribution of scores for the two subscales (n=143) were distributed around a mean of 58.69 for LS (SD = 14.92, range = 6.25–90.63) and 65.18 for the FPQ (SD = 16.85, range = 0–95.83).

Reliability

Internal Consistency

The internal consistency of the BASQID was calculated using data from Stage 2. Cronbach's alpha for the BASQID was 0.89, whilst alphas for LS and FPQ subscales were 0.84 and 0.83 respectively (n=143), indicating acceptably high internal consistency. When Sample 2 was divided into tertiles on the basis of MMSE scores, internal consistency was acceptable for each of the three groups, with the lowest at 0.78 for the LS scale in the MMSE<16 group (n=47).

Reproducibility

Using Sample 1 data, test-retest reliability for the BASQID (n=29) demonstrated a non-significant difference between the two administrations (Time 1 – Time 2) of 0.65 (s.d. = 3.89, t = -0.85, p > 0.05) with an intraclass correlation coefficient of 0.85 (95%

CI = 0.70–0.93). For the LS subscale there was a non-significant difference in mean scores between the two administrations of -2.58 (s.d. = 8.43, t = 1.65, p > 0.05) with an intraclass correlation coefficient of 0.79 (95% CI = 0.59-0.89). Difference in mean scores for the FPQ subscale was -0.30 (s.d. = 8.48, t = 0.18, p > 0.05) with an intraclass correlation coefficient of 0.85 (95% CI = 0.70–0.93).

Validity

Content Validity

The content of the BASQID is based on a framework derived from qualitative work, that conceptualised subjective QoL as the person's evaluation of multiple QoL domains of health, function, leisure, sleep, energy, mobility, environment, mood, and social interaction, as well as feelings of need fulfilment, identity and affect, and all components of this framework were included as items in the initial pool (Trigg et al, 2007). The 14 items in the BASQID relate to the QoL domains; health, social interaction, function, mobility, being occupied, energy and psychological well-being.

Construct Validity

As expected, scores on the BASQID show moderate correlation with the GDS-15, and low to moderate association with the proxy-completed WHOQOL-BREF (Table 3). The social subscale of the WHOQOL-BREF, and the GDS-15 displayed the highest level of association with BASQID scales.

Insert Table 3 here

Discriminant validity was supported as the BASQID failed to display significant correlations (n=143) with either participant age, or scores on the MMSE. This lack of

association was confirmed by splitting the sample into MMSE tertiles (<16, 16-20, >20) and comparing scores on the BASQID across the groups. No significant differences in scores were found for the BASQID ($F(2, 140) = 0.41$, $p > 0.05$), for LS subscale ($F(2, 140) = 0.12$, $p > 0.05$) or FPQ subscale ($F(2, 140) = 0.75$, $p > 0.05$). Similarly the sample was split into age tertiles (<77, 77-81, >81) and BASQID scores compared across the three groups. No significant differences were found for the BASQID ($F(2, 140) = 0.58$, $p > 0.05$), for LS ($F(2, 140) = 0.26$, $p > 0.05$) or FPQ ($F(2, 140) = 0.86$, $p > 0.05$). An independent t-test explored differences between BASQID scores for men (n=58) and women (n=85) in Sample 2, and found no significant difference for the BASQID ($t = 0.19$. $p >0.05$), LS ($t = -0.26$, $p > 0.05$) or FPQ ($t = 0.70$, $p > 0.05$).

Responsiveness

Ten of the 36 people in Sample 2a, were judged by clinicians to have an improved QoL after three months, 23 remained the same, and three deteriorated. Effect size statistics were calculated for the BASQID and the two subscales (see Table 4), and significant correlations found between clinician global ratings of QoL change effect size statistics (for BASQID, $r = .50$, $p < 0.01$; for LS, $r = 0.49$, $p < 0.01$; for FPQ, $r = 0.33$, $p < 0.05$).

Insert Table 4 here

Participants were grouped according to the CGCRs of QoL so that effect sizes for those who had better, same or worse QoL could be compared (Table 5) and there is a trend in the data. Small/medium negative effect sizes were found on the BASQID, LS and FPQ for the three people deemed to have a worse QoL; negligible effect sizes for

the 23 people who remained stable; and small/medium positive effect sizes for the 10 people considered to have improved QoL. Small samples in two groups meant that these differences did not reach statistical significance and confidence intervals were wide.

Discussion

The primary aim of this research was to develop a measure of QoL that was appropriate for self-report by people with dementia. Examination of the properties of the BASQID suggests that this has been achieved. The BASQID is brief and easy to administer and is well received by respondents, with positive wording used throughout items. The visual presentation of questions and responses is an important factor in minimising the burden of response. A parsimonious approach was taken with regard to the inclusion of items within the BASQID. The BASQID is a disease-specific measure for people with mild to moderate dementia, insomuch as it focuses on domains of QoL particularly relevant for this population. The fact that only a relatively narrow subset of items has been chosen for inclusion within the measure does have implications for how scores are interpreted. It would be wrong to suggest that the BASQID provides a comprehensive profile of QoL, as domains that were part of the initial conceptual framework, such as the adequacy of the person's environment and sleep, are not included. Rather, it assesses a subset of QoL items that appear to be useful in discriminating between individuals with dementia and exploring changes in QoL over time in response to disease change or intervention. If a comprehensive assessment of QoL is required, then further research should address the question as to whether existing generic profiles of QoL are appropriate for this population.

The internal consistency of the 14-items indicates that the BASQID may be used as a single scale of QoL. However preliminary results from the PCA suggests that the 14 BASQID items may contain two independent subscales; LS and FPQ. It must be acknowledged that the separation of items into a satisfaction component alongside a component relating to feelings and mood may be an artefact induced by the item stems, as spurious factors can be induced by wording, e.g., positively and negatively worded and ordering of items (see Marsh, 1996). However this separation of constructs is supported by existing conceptualisations of QoL (Brod et al., 1999; Ferrans & Powers, 1992; Jennings, 1999; Lawton, 1997) and may allow a more detailed investigation of QoL in people with dementia. Further evaluation of the dimensionality of the BASQID using confirmatory analyses is warranted, with larger samples and other models, to confirm the independence of these subscales.

Overall, the BASQID displays strong psychometric properties is brief and acceptable to patients. The BASQID displays high internal consistency and acceptable test-retest reliability, in line with other measures such as the QoL-AD and DQoL. As with the DQoL and QoL-AD, the BASQID does not show any association with MMSE scores, but does display a strong association with depression. Construct validity was supported through significant correlations with proxy ratings of QoL. Although significant, these correlations were low to moderate in size, which concurs with the literature (Novella et al., 2001). As with any new measure, ongoing validation with large samples is needed in order to determine the usefulness of the measure in different settings with different groups of individuals. The samples used in the development of the BASQID were recruited from a memory clinic and therefore will have included people more likely to be receiving support and intervention from health and social services and accustomed to undergoing formal assessment. The participants

were English-speaking, mainly Caucasian, individuals and therefore there is the possibility that QoL issues important to other ethnic groups are not represented.

Although sensitive to the effects of dementia, it would seem that the BASQID is not simply reflecting the effects of worsening symptoms or changes in disease. Whilst changes in cognition and function may influence QoL, they should not be taken as a direct measure of QoL. There is a low level of association between the BASQID and the physical domain on the WHOQOL-BREF, but perhaps more significantly there is a lack of association between the BASQID and MMSE scores. This concurs with current research evidence (Hoe et al., 2005; Logsdon et al., 1999; Ready et al., 2002; Thorgrimson et al., 2003) and adds weight to the argument that cognitive ability is not necessarily a predictor of subjective QoL. Indeed, the work of Kitwood (1995) has demonstrated that it is possible that the person with dementia can experience positive long-term changes.

The responsiveness of BASQID scores to changes in QoL over a three-month period experienced by people receiving an acetylcholinesterase inhibitor for the treatment of AD was explored. Effect sizes for the BASQID showed significant associations with the QoL change ratings of clinicians. Data from this study is strongly indicative that the BASQID is responsive to changes in QoL, but is somewhat limited due to the relatively small sample size employed in this study and the use of physician ratings of QoL as the external standard of QOL change. Further work on responsiveness is needed, with longer follow up periods to chart changes in QoL brought about through changes in other variables, such as lifestyle, living arrangements, care provision and non-pharmacological therapeutic interventions. Studies such as this should combine quantitative and qualitative methodologies in order to assess how changes in

BASQID scores relate to accounts of significant life events reported by patients and carers.

As a self-report measure, the BASQID should complement existing objective measures of health, disability and QoL, giving a more complete appraisal of the QoL of people with dementia. The BASQID has been developed to provide a means of better understanding the experiences, perceptions, and beliefs of people with dementia. It does this through acknowledgement of the many influences on QoL, over and above health status. By adopting a biopsychosocial framework, the BASQID allows people to report QoL levels that might differ from that suggested by objective indices of health and disability. This subjective viewpoint on issues of life satisfaction and feelings of positive QoL may provide caregivers and researchers an important insight into treatments and therapies that have personal benefits for the person with dementia. With the availability of measures such as the BASQID, there is no longer a reason to ignore the perspective of the person with dementia when evaluating approaches to dementia care.

Declaration of Interest

None

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Table 1

Sample characteristics from BASQID field tests

		Sample 1	Sample 2	
			Whole sample	Sub-sample 2a
		(n=60)	(n=150)	(n=36)
Probable diagnosis	Alzheimer's / Mixed	49 (82%)	123 (82%)	36
	Vascular	8 (13%)	19 (13%)	
	Frontotemporal	3 (5%)	8 (5%)	
Cognitive ability	MMSE mean (s.d.)	18.44 (4.07)	18.06 (4.63)	18.38 (3.83)
	MMSE median (range)	18 (12-26)	18 (5-28)	18 (11-26)
Living arrangement	Living alone	8 (13%)	25 (17%)	4 (11%)
	Living with spouse	45 (75%)	93 (62%)	25 (69%)
	Living with relative/other	5 (8%)	21 (14%)	4 (11%)
	Residential accommodation	2 (3%)	11 (7%)	3 (8%)
Sex	Male	28 (47%)	62 (41%)	15 (42%)
	Female	32 (53%)	88 (59%)	21 (58%)
Age	<65	7 (12%)	8 (5%)	1 (3%)
	65-74	24 (40%)	29 (19%)	6 (17%)
	75-84	19 (32%)	85 (57%)	21 (58%)
	>85	10 (16%)	28 (19%)	8 (22%)

Figure 1

Scree test plot of component eigenvalues

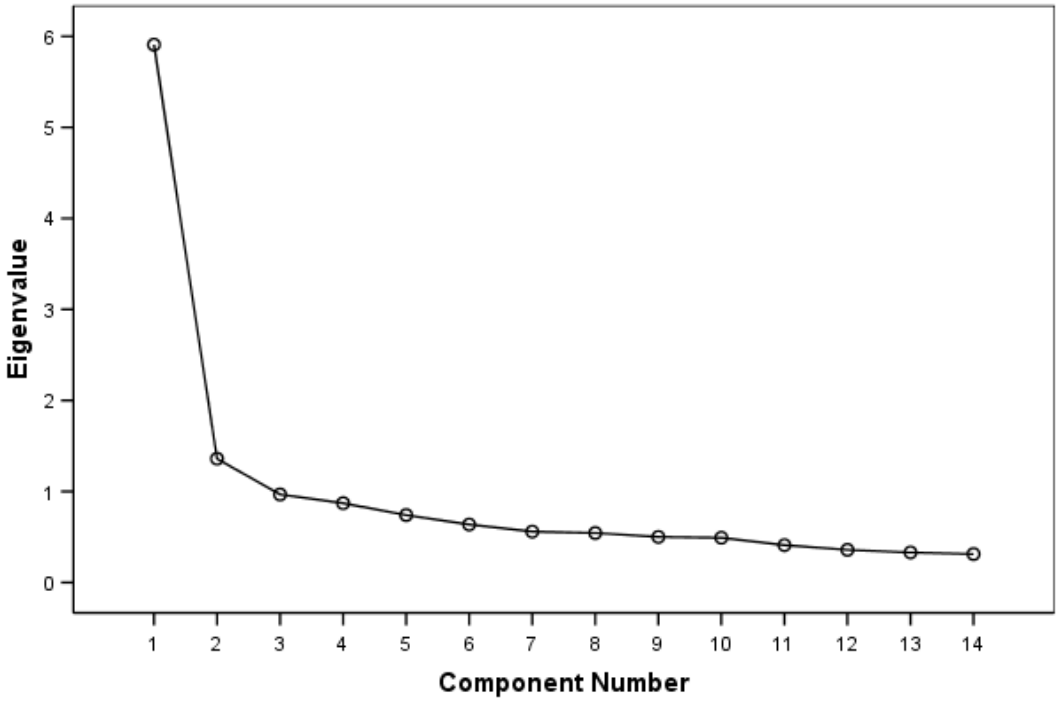

Table 2

Two-factor structure of BASQID items (n=143)

	Question Content	Component 1 LS	Component 2 FPQ
Q1	How satisfied are you with your health?	.647	.167
Q2	How satisfied are you with your ability to look after yourself?	.655	.178
Q3	How satisfied are you with your level of energy?	.664	.272
Q4	How satisfied are you with your enthusiasm for doing things?	.731	.162
Q5	How satisfied are you with the way you usually spend your day?	.651	.289
Q6	How satisfied are you with your level of independence?	.671	.364
Q7	How satisfied are you with your personal relationships?	.577	.328
Q8	How satisfied are you with your ability to talk to other people?	.565	.092
Q9	To what extent are you able to move around your local community?	.257	.685
Q10	To what extent are you able to do all the activities that you want to?	.328	.688
Q11	To what extent are you able to things that you enjoy?	.302	.761
Q12	To what extent do you feel you have the	.136	.771

	choice to do the things that you want to do?		
Q13	To what extent do you feel useful?	.103	.682
Q14	To what extent do you feel happy?	.332	.605

Shaded areas reflect factor loadings>0.4

Table 3

Correlations between the BASQID scales and the WHOQOL-BREF, GDS-15, MMSE and participant age

	Scale		
	BASQID (n)	LS (n)	FPQ (n)
WHOQOL- BREF - Physical	.32* (41)	.23 (44)	.36* (41)
WHOQOL- BREF - Psychological	.39* (41)	.37* (44)	.37* (41)
WHOQOL- BREF - Social	.59** (30)	.61** (33)	.50** (30)
WHOQOL- BREF - Environmental	.34* (41)	.27 (44)	.39* (41)
GDS-15	.58** (47)	.50** (50)	.54** (47)
MMSE	-.08 (143)	-.07 (143)	-.09 (143)
Age	-.12 (143)	.09 (143)	.12 (143)

* Significance level of $p<0.05$

** Significance level of $p<0.01$

Table 4

BASQID Change scores and effect sizes for Sub-sample A, grouped according to Clinician Global Change Ratings

Clinician Global Change Rating	Scale	Mean change in scores	Mean Effect Size	Effect Size 95% Confidence Interval
Worse QoL	BASQID	-5.00	-.67	-1.34 to .00
(n=3)	LS	-2.33	-.55	-1.22 to .12
	FPQ	-2.66	-.63	-1.30 to .04
Same QoL	BASQID	-.04	.00	-.25 to .25
(n=23)	LS	-.17	-.04	-.47 to .39
	FPQ	.13	.03	-.22 to .28
Better QoL	BASQID	3.20	.43	.13 to .73
(n=10)	LS	2.30	.54	.14 to .93
	FPQ	.90	.22	-.07 to .50