

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

Manual: Instructions for Administrators and Scale Properties

The BASQID is a measure of dementia-sensitive quality of life that has been developed and validated for use with mild to moderate dementia (identified by a Mini Mental State Exam score of 12 or above). The measure should be interview administered directly with the person with dementia. Questions should be presented visually and orally to the person. Each question should be printed on an individual card (approximately 18 x 6 cm) in large sans serif font (Arial 26pt or equivalent is recommended). The three response scales should be printed on individual cards (approximately 30 x 10 cm) in a similar font size to the questions. The response scale should be set out horizontally with vertical lines separating points on the scale. The scale should contain only the words defining each point on the scale and **not** the scores associated with each response. This file contains the manual for the BASQID, including instructions for administrators and a summary of BASQID properties. Files containing an interviewer score sheet and templates for the question and response cards are also available and can be obtained from the author on request, or downloaded from http://www.rice.org.uk/research_BASQID.php

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1. Background and description

With no cure available, one of the main goals for pharmacological, behavioural, social and environmental interventions in dementia must be the maintenance or even improvement of the patient's quality of life (QoL) (Conrad, 1990; Kane, 1999). Quality of life is a multidimensional construct incorporating many different life areas. It is a construct that should ideally 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). The subjective element of QoL is exactly the reason why QoL is valuable as an indicator of the effectiveness of treatments, interventions and systems of care (Ben-Shlomo, 1999; Whitehouse et al, 1997). The global concerns of patients in relation to their own values and expectations must be considered if we are to provide an acceptable standard of care for people with dementia. With patients presenting at earlier stages of the disease and being involved in decisions about their care and treatment, it is important that we are able to provide them with accurate information about the impact on their overall well-being of both disease and any potential intervention (Clancy & Cooper, 1999). This is especially significant now that a range of drug interventions is available to people with dementia. For people with dementia and their carers "the benefits of these drugs will be determined by their ability to improve everyday functioning and QoL" (Kelly et al, 1997).

Disorders of memory, attention, communication, insight, judgement and a variety of behavioural and non-cognitive symptoms such as delusions, depression or agitation, all limit the ability of a person with dementia to report on QoL issues. Because of this, there has been a long unchallenged assumption that people with dementia are unable to give a reliable account of their own QoL (Cotrell & Schulz, 1993). Measurement has therefore focused on observable and more objective aspects of QoL such as symptom severity and function, with only brief reference to the subjective perceptions of the person (Stewart et al, 1996). As a result, many measures of QoL run the risk of being little more than health status assessments that replicate much of the information that can be obtained from other measures of disability and disease burden (Gill & Feinstein, 1994; Leplege & Hunt, 1997)

One method of gaining an accurate insight into the subjective experience of the person with dementia, and how they feel about their QoL, is to question the person directly. Research has demonstrated that people with mild to moderate-stage dementia are able to provide consistent and reliable information regarding QoL issues (Feinburg & Whitlatch, 2001; Mozley et al, 1999). Although many of the traditional domains associated with QoL such as daily activities, physical status, mobility, social interaction and relationships, environment, emotional well-being are relevant for people with dementia, research suggests that there may be important disease specific issues relating to the impact of dementia within each of these areas (Brod et al, 1999)

Brief, simple measures that place a low cognitive burden on the respondent are needed. The content and language of questions should be developed from information gained directly from the people who live with this debilitating condition.

QoL measures that claim to be 'subjective' are often developed without input from those people who have experience of living with dementia. Such measures run the risk of asking patients to answer questions that are important to clinicians and other third parties, rather than answering questions that truly reflect their concerns (Leplege & Hunt, 1997; Muldoon et al 1998; Russel, 1996). Only through an accurate understanding of the QoL issues valued by the patients themselves can systems of care be developed that are effective in satisfying the needs of people with dementia.

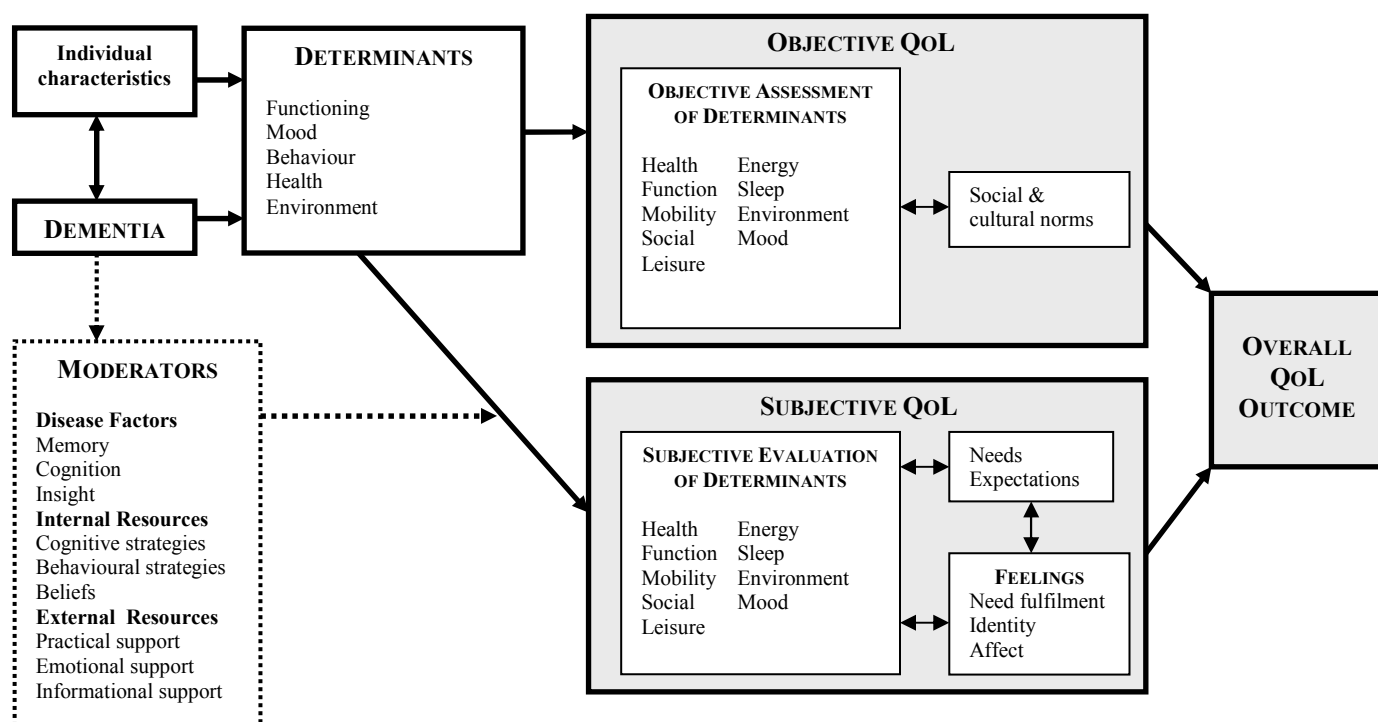
There is therefore a need for a new measure that can be used with people with mild to moderate-stage dementia, to assess the subjective evaluation of a complete range of QoL domains. This measure could then be used alongside more objective instruments, based on observation by others, to provide a comprehensive assessment of patient QoL.

The Bath Assessment of Subjective Quality of Life in Dementia (BASQID) has been designed to allow assessment of QoL issues by direct interview with people with dementia. The content of the BASQID has been developed from qualitative data derived from extensive interviews with people with dementia (n=45) recruited from The Research Institute for the Care of the Elderly (RICE) in Bath, UK. Data from these interviews was used to develop a conceptual framework for QoL in dementia (Figure 1).

QoL is a multidimensional construct encompassing physical, psychological, social and environmental issues (Guyatt et al., 1989). Judgements of QoL should incorporate both a subjective evaluation by the individual as well as a more objective appraisal judged against social norms (Muldoon et al, 1998). This second point is well illustrated by the World Health Organisation definition of QoL which states that QoL is "an individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns" (The WHOQOL Group, 1995). Similarly, Lawton (1991) has described QoL as "a multidimensional evaluation by both intrapersonal and social-normative criteria, of the person-environment system of the individual". The model shown in Figure 1 illustrates these two points. Dementia can impact on life areas relating to a person's functioning, mood, behaviour, health and environment (determinants). The effect of dementia on these determinants can be assessed both objectively and subjectively by assessing the person's health, function, mobility, social interaction, leisure activities, energy, sleep, mood, home and financial environment.

Objective indicators of QoL are those that one might find in assessments based on a medical model of dementia care where emphasis is on curing or alleviating symptoms of disease, or a consequences model where the aim of care is to compensate for impairments, disabilities or handicaps. At this level assessments are very much concerned with the presence or severity of symptoms, the level of ability or disability displayed by an individual and the frequency with which they are able to perform various activities. The person's performance is judged against standards derived from social and cultural norms.

Figure 1: Conceptual framework for QoL in dementia



Alternatively, QoL may be judged according to the subjective evaluation of the person with dementia. This evaluation will be influenced by a range of moderator variables including internal resources, such as the use of coping strategies and changing expectations, values and preferences. Moderators of subjective QoL may also include external resources such as formal and informal support, and disease related factors such as the individual's level of insight and cognitive function. Assessments that are based at this level should include questions based on an individual's feelings such as satisfaction, enjoyment, competence and confidence and should allow for the possible influence of moderator variables. At the subjective level, the person's evaluation of his/her QoL will be influenced by that person's needs and expectations. People will use their own subjective evaluations of different QoL domains to determine the extent to which they feel their needs are being met. This process of self-examination will also have important consequences not just in terms of perceived need fulfilment but also in terms of the person's feelings about themselves and their abilities and their emotional state.

It is not possible, at this stage, to be definite about the direction and strength of association between different areas of the model. This is very much an initial conceptualisation based on qualitative data. The availability of measures such as the BASQID, that allow assessment of subjective QoL issues such as satisfaction, need fulfilment and identity, will allow further testing of this model.

Referring to the conceptual model, the BASQID concentrates on the assessment of subjective QoL. The content of the BASQID covers those areas that relate to the individuals evaluation and experience of multiple life domains, their need fulfilment and their feelings about themselves and their identity. The questions are framed in such a way as to allow the influence of moderator variables. For example, rather than ask the person to rate their ability to perform various activities, respondents are

asked about their level of satisfaction with their ability and the extent to which they are able to perform the activities they want to do. It is hoped that by taking this approach, QoL can be conceptualised in a way that is relevant for all people with dementia, including those with severe problems and limitations. People with dementia may be severely restricted in terms of what they can do and where they can go. If one looks objectively at their performance across multiple domains of QoL they will undoubtedly perform very poorly and a negative QoL will be inferred. However some people with dementia may have successfully adjusted to life with the illness and accepted that they face an inevitable decline. Through coping and adaptation, such individuals may be managing the restrictions and limitations that occur across much of their lifestyle. These people may therefore evaluate and interpret their QoL within very different parameters to someone else at a similar stage of the disease who has not been through such a shift in expectations or an 'external' observer acting as proxy.

This framework has been used as a basis for the initial pool of BASQID items. The item pool was pretested (n=15) and then pilot tested in order to reduce the number of questions. The first of two pilot tests (n=60) reduced the item pool from 44 to 21 questions. Only those items found to be psychometrically sound and sensitive to the effects of dementia were retained. Therefore there are QoL issues contained within the conceptual framework, such as housing, finance and sleep, which are important to individuals but not contained within the BASQID. Such questions were excluded from the BASQID on the grounds that they did not show response variation in the sample of mild-moderate stage dementia patients. In this sense the content of the BASQID is restricted to those areas of QoL that show variation within people with mild to moderate-stage dementia and therefore useful in detecting differences in QoL between groups of people or within individuals over time.

A second, larger, pilot test (n=150) was carried out on the remaining items to investigate item performance, how these items grouped to form scales, scale properties and the responsiveness of scales to changes in QoL brought about through the use of acetylcholinesterase inhibitors in people with Alzheimer's disease (n=36). Seven further items were rejected from the BASQID as a result of this pilot study.

The BASQID contains 14 core items and uses two different five-point response scales. BASQID items can be used as a 14-item scale of QoL (BASQID) or split according to two distinct subscales that relate to life satisfaction (LS) and feelings of positive QoL (FPQ). Three additional questions (G1-G3) are included within the BASQID to provide global subjective ratings of QoL, health and memory. These questions should be analysed individually. A list of BASQID questions and subscale membership is given in Table 1.

The BASQID has been designed and validated for use with people who have mild to moderate-stage dementia, classified by a Mini Mental State Exam (MMSE) (Folstein et al., 1975) score of 12 or above. The BASQID is administered via interview, with the interviewer presenting each question visually and orally to the person with dementia. Each question is printed on an individual card (approximately 18 x 6 cm) in large sans serif font (Arial 26pt). The three response scales are printed on individual cards (approximately 30 x 10 cm) in the same font size to the questions. The response scales are set out horizontally with vertical lines separating points on the scale. The scale contains only the words defining each point on the scale and *not* the

scores associated with each response. Templates for both the question and response cards are available on request from the author or can be downloaded from www.rice.org.uk/BASQID.html

Table 1: BASQID items and scale membership

Q. No	Question	Subscale Membership
G1	How would you rate your overall QoL?	-
G2	How would you rate your health?	-
G3	How would you rate your memory?	-
1	How satisfied are you with your health?	BASQID, LS
2	How satisfied are you with your ability to look after yourself?	BASQID, LS
3	How satisfied are you with your level of energy?	BASQID, LS
4	How satisfied are you with your enthusiasm for doing things?	BASQID, LS
5	How satisfied are you with the way you usually spend your day?	BASQID, LS
6	How satisfied are you with your level of independence?	BASQID, LS
7	How satisfied are you with your personal relationships?	BASQID, LS
8	How satisfied are you with your ability to talk to other people?	BASQID, LS
9	To what extent are you able to move around your local community?	BASQID, FPQ
10	To what extent are you able to do all the activities that you want to?	BASQID, FPQ
11	To what extent are you able to things that you enjoy?	BASQID, FPQ
12	To what extent do you feel you have the choice to do the things that you want to do?	BASQID, FPQ
13	To what extent do you feel useful?	BASQID, FPQ
14	To what extent do you feel happy?	BASQID, FPQ

1.1 Scoring

The BASQID contains 14 core questions. Three additional questions (G1-G3) are not part of the main BASQID scale, but provide global subjective ratings of QoL, health and memory and should be analysed individually. A separate response scale is used for these global questions. These three questions provide an opportunity to evaluate the respondent's ability to answer questions using a five-point response scale. Questions 2 and 3 are also useful indicators of the respondent's awareness of health and cognitive dysfunction.

1.1.1 Item scores

All questions within the BASQID are scored 0-4 with 4 indicating a better QoL.

For Section A (Questions G1-G3) the scoring is:

- Very poor = 0
- Poor = 1
- Fair = 2
- Good = 3
- Very good = 4

For Section B (Questions 1-8) the scoring is:

- Not at all satisfied = 0
- A little satisfied = 1
- Satisfied = 2
- Very satisfied = 3
- Extremely satisfied = 4

For Section C (Questions 9-14) the scoring is:

- Not at all = 0
- A little = 1
- A moderate amount = 2
- Quite a lot = 3
- A great deal = 4

1.1.2 Scale scores

The BASQID can be scored as a 14-item scale of QoL or as two separate subscales. Scale scores are derived by calculating the sum of item scores in the scale and expressing this as a percentage of the maximum score possible. This transforms the subscales so that all are scored on a scale of 0-100, facilitating comparisons between the scales. This is achieved by multiplying the sum score by $100/(m \times (k-1))$ where m represents the number of items in the scale and k represents the number of response choices.

BASQID Total (BASQID) = [sum of questions Q1-Q14] x [100/(14x4)]

Life Satisfaction (LS) = [sum of questions Q1-Q8] x [100/(8x4)]

Feelings of Positive QoL (FPQ) = [sum of questions Q9-Q14] x [100/(6x4)]

To facilitate the transformation of raw subscale scores, transformation charts are provided on the final page of the administrators score sheet.

Administrators need only sum the item scores within each scale and then select the appropriate points on the chart to determine the transformed score. Transformation charts are provided for the scales BASQID, LS and FPQ.

1.1.3 Missing data

Scale values can be calculated if there is one missing item within the scale. A value for the missing item should be imputed by taking the mean score of other items within the scale. If there is more than one missing item in any scale, a value for that scale cannot be calculated.

1.2 Instructions for administrators

The administrator should ensure that they have a copy of the score sheet (containing information to be read to participants prior to each section) and that all questions and response scales should be printed on individual cards as per the recommendations outlined earlier. Templates for these question and response scales are available to download, as are copies of the score sheet.

1.2.1 Before administering the BASQID

- a) Every effort should be made to ensure that the interviewee is comfortable and relaxed.
- b) Explain that the participant will be asked to answer some questions on **how they feel** about their QoL.
- c) Ensure the participant understands what QoL means. If necessary, use phrases such as “how you feel about life in general”.
- d) Explain to the participant that there will be 17 questions about different aspects of their everyday life and that it should take approximately 10 minutes to complete them.
- e) Stress to the participant that the BASQID is not a test. Explain that there are no right or wrong answers but that the assessment is to find out how they feel about their life at this moment in time.

1.2.2 Administration of the BASQID

- a) Explain that all the questions are about the person’s recent QoL and that as a guide, they should think about **how they have been feeling over the last two weeks**.
- b) Place Response Scale A in front of the respondent and check that it is clearly visible and the respondent is able to read it.
- c) Read verbatim the instructions given on the BASQID Interviewer’s Score Sheet for Section A.
- d) Place Question G1 above Response Scale A and read it aloud. Then read the response options, pointing to each response as you say it.

Eg “How would you rate your quality of life? Would you say your quality of life is very poor, poor, fair, good or very good?”
- e) Repeat the question and response options as many times as necessary. **Never rephrase the question or response options**. If further explanation is required, use the standardised prompt given in italics after the question on the Interviewer’s Score Sheet. If the respondent is still unable to understand the question, move on to the next question.
- f) Repeat the respondent's answer to Question G1 back to them.

eg, “so you would say that your quality of life is good.”
- g) Probe the respondent’s answer to Question G1 to ensure that the response option that was selected accurately reflects the person’s appraisal of their QoL
- h) Repeat steps d-g for questions G2 and G3.

- i) If the respondent is unable to answer all of the questions in Section A (Questions G1-G3), stop the interview.
- j) If the respondent is able to provide satisfactory responses to questions G1-3, move on to Section B (Questions 1-8) and probe on Question 1 to ensure that the new response scale is being correctly interpreted and used. Repeat the probe for Question 2 if necessary.
- k) If the respondent is only able to answer one or two of the questions in Section A, move on to Section B and probe on Questions 1-5. If the respondent is unable to answer all of the Questions 1-5, stop the interview.
- l) Repeat steps b-g for questions in Section B, using response scale B and probing where necessary.
- m) Repeat steps b-g for questions in Section C (Questions 9-14), using response scale C. Probe the respondent's answer to Question 9 (and Question 10 if necessary) to ensure that the new response scale is being correctly interpreted and used.

1.2.3 Guidance notes for the interviewer

- a) **The respondent does not understand a question and asks for clarification**
 - Repeat the question and response options
 - Use the prompt provided in italics after the question.
 - Never rephrase the question
 - Suggest that the respondent bases their answer on what *they* think the question means
 - If the respondent is still unable to provide an answer, move on to the next question with minimum fuss. When all questions in the section have been completed, come back to the question and try again.
- b) **The respondent states that a different answer is appropriate for different situations eg “I can talk to some people but not to others” or “my memory is good in some situations but poor at other times”.**
 - Ask if they could give an answer which reflects their ‘overall’ or ‘average’ evaluation, taking both situations into account.
- c) **The respondent answers the question with a word or phrase that is not on the response scale.**
 - Say to the respondent *“so which one of these responses would you use for that question?”* and point to the response scale, saying each response option aloud. Repeat this as many times as appropriate.
- d) **The respondent answers the question with a word or phrase that is similar to one provided the response scale eg “quite satisfied”, “very happy”.**
 - Do not suggest an appropriate substitute from the response option. A minimum of three adjacent response options should always be given.

Eg “when you say quite satisfied do you mean a little satisfied, satisfied or very satisfied”

- e) **The respondent seems:**
- A) overly hesitant about an answer**
 - B) gives an unexpected answer**
 - C) says anything that indicates a lack of understanding**
 - Make sure that their answer is repeated back to them in full with the question stem (e.g. “so you are saying that you are satisfied with your energy levels?”). Probe and ask the respondent to clarify their answer with a brief explanation. If the respondent is certain that this is the answer they wish to give, and the interviewer still has doubts as to its reliability, it may be useful to continue to the end of the section/measure and then repeat the question.
- f) **The respondent wants to give an answer that falls between two points on the response scale eg between satisfied and very satisfied.**
- Tell the respondent that they must choose between the two responses. Suggest that they choose the response that is closest to their desired answer.
- g) **The respondent requests help in deciding which response to choose.**
- Explain that they should give an answer that best reflects how they feel and that no one else can decide this for them. Assure the person that there is no such thing as a ‘correct’ answer and that they should just describe how they feel.
- h) **The respondent is unable to answer a question**
- If the respondent is unable to answer even after several repetitions of the question and response, assure them that this is fine and move on to the next question.
 - Make a note of the reason for incompleteness. If appropriate, return to the question on completion of the section.
 - If the respondent is unable to provide a satisfactory answer to a question, increase the frequency of probes on subsequent questions.
 - Three consecutive failures to answer should indicate that the respondent is unable to complete the BASQID and the interview should stop.

References

- Ben-Shlomo, Y. (1999). Health Outcome Measures. *Journal of Neurology Neurosurgery and Psychiatry*, 66, 416-416.
- Brod, M., Stewart, A.L., Sands, L., Walton, P. (1999). Conceptualisation and Measurement of Quality of Life in Dementia: The Dementia Quality of Life Instrument (DQoL). *The Gerontologist*, 39, 25-35.
- Clancy, C.M., Cooper, J.K. (1999). Outcomes and Effectiveness Research in Alzheimer Disease. *Alzheimer Disease and Associated Disorders*, 11, 7-11.
- Conrad, P. (1990). Qualitative Research on Chronic Illness: A commentary on method and conceptual development. *Social Science and Medicine*, 30, 1257-1263.
- Cotrell, V., Schulz, R.. (1993).The perspective of the person with Alzheimer's disease: A neglected dimension of dementia research. *The Gerontologist*, 33, 205-211.
- de Leval, N. (1999). Quality of life and depression: Symmetry concepts. *Quality of Life Research*, 8, 283-291.
- Feinburg, L.F., Whitlatch, C.J. (2001). Are persons with cognitive impairment able to state consistent choices? *The Gerontologist*, 41, 374-382.
- Fitzpatrick, R., Davey, C., Buxton, M.J., Jones, D.R. (1998) Evaluating patient-based outcome measures for use in clinical trials. *Health Technology Assessment Review*, Vol2, No 14.
- Folstein, M.F., Folstein, S.E., McHugh, P.R. (1975). "Mini-Mental State": a practical method for grading the cognitive state of patients for the clinician. *Journal of Psychiatric Research*, 12, 189-198
- Gill, T.M., Feinstein, A.R. (1994) A critical appraisal of the quality of quality of life measurements. *Journal of the American Medical Association*, 272, 619-626
- Guyatt, G.H., Velduyzen Van Zanten, S.J., Feeny, D.H., Patrick, D.L. (1989) Measuring Quality of life in clinical trials: a taxonomy and review. *Can Med Assoc J*, 140, 1441-1448
- Kane, R.L. (1999).Which Outcomes Matter in Alzheimer Disease and Who Should Define Them? *Alzheimer Disease and Associated Disorders*, 11, 12-17.
- Kelly, C.A., Harvey, R.J., Cayton, H. (1997). Drug Treatments for Alzheimer's Disease. *British Medical Journal*, 314, 693
- Lawton, M.P. (1991). A multidimensional view of quality of life in frail elders. In JE Birren, JE Ludden, JC Rowe, GE Deutschman (eds), *The concept and measurement of quality of life in the frail elderly*. San Diego: Academic Press Inc.

- Leplege, A., Hunt, S. (1997). The Problem of Quality of Life in Medicine. *Journal of the American Medical Association*, 278, 47-50. Schneider LS. Assessing Outcomes in Alzheimer Disease. (2001). *Alzheimer Disease and Associated Disorders*, 15, S8-S18
- McDowell, I. & Newell, C. (1996) *Measuring Health: a guide to rating scales and questionnaires*. New York; Oxford United Press.
- Mozley, C.G., Huxley, P., Sutcliffe, C., et al. (1999). 'Not Knowing Where I Am Doesn't Mean I Don't Know What I Like': Cognitive Impairment And Quality Of Life Responses In Elderly People. *International Journal of Geriatric Psychiatry*, 14, 776-783.
- Muldoon, M.F., Barger, S.D., Flory, J.D., Manuck, S.B. (1998) What are quality of life measurements measuring? *British Medical Journal*, 316, 542-545.
- Russel, C. (1996). Passion and heretics: Meaning in life and quality of life in persons with dementia. *Journal of the American Geriatric Society*, 44 (11), 1400-1401
- Scientific Advisory Committee of the Medical Outcomes Trust (2002). Assessing health status and quality of life instruments: Attributes and review criteria. *Quality of Life Research*, 11, 193-205.
- Stewart, A., Sherbourne, C. & Brod, M. (1996). Measuring health-related quality of life in older and demented populations. In B Spilker (ed), *Quality of life and pharmacoeconomics in clinical trials: Second edition* (pp. 819-829). Philadelphia: Lippincott-Raven
- Stiles, P.G., McGarrahan, J.F. (1998) The Geriatric Depression Scale: A comprehensive review. *J Clin Geriopsychoy*, 4, 98-110
- The WHOQOL Group. (1995) The World Health Organisation Quality of Life assessment (WHOQOL): position paper from the World Health Organisation. *Social Science and Medicine*, 41, 1403-1409
- The WHOQOL Group (1998). Development of the World Health Organisation WHOQOL-BREF Quality of Life Assessment. *Psychological Medicine*, 28, 551-558.
- Whitehouse, P.J., Orgogozo, J., Becker, R.E., et al. (1997). Quality-of-Life Assessment in Dementia Drug Development. *Alzheimer Disease and Associated Disorders*, 11, 56-60.

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