

Evaluating the outcome of interventions on quality of life in dementia: Selection of the appropriate scale

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SUMMARY

Background A literature study was conducted to contribute to an adequate use of quality of life (QoL) instruments for the evaluation of interventions in dementia care by providing an overview of properties of QoL measures that acknowledge domains important to dementia patients.

Methods Domains important to patients, and domains that professional caregivers in different settings focus on, are compared to domains represented in nine QoL instruments. Data on psychometrics and applicability are generated.

Results Four instruments best represent domains of QoL important to patients and domains professional caregivers in 24-h care and daytime activities focus on. Two are self-rating instruments: Schedule for the Evaluation of Individual Quality of Life, applicable in mild dementia, measuring individual QoL of patient and informal caregiver, and Quality of Life-Alzheimer's Disease Scale, which can be applied up to moderately severe dementia. For patients with advanced dementia receiving residential care, the observational instruments Qualidem and Discomfort scale-Dementia of Alzheimer Type are recommended. The first is easily administered by nurse assistants or occupational therapists and covers several QoL domains on which they focus in daily practice. The second can be used by various professionals.

Conclusions QoL assessment provides a format for patients and (in)formal caregivers to express whether an intervention has made an important difference to the patient's life. Improvement of QoL in dementia should have high priority in care, treatment and research. This study shows that severity of dementia, care type, setting, and the specific QoL domains an intervention focuses on, determine which QoL instrument is most appropriate in a specific situation. Copyright © 2006 John Wiley & Sons, Ltd.

KEY WORDS — quality of life measures; dementia; caregivers; intervention

INTRODUCTION

Quality of life (QoL) is a multi-dimensional concept that includes well-being and has objective and

subjective aspects (Logsdon *et al.*, 2004; Sprangers, 2005). Domains in QoL-measures vary considerably (Albert *et al.*, 2001). Examples are: affect, self-esteem/awareness of self, social contact and physical/mental health. The QoL in dementia working group of the Leo Cahn Foundation investigated which domains patients and professional caregivers in nursing homes and meeting centres consider important. Most domains mentioned by patients were acknowledged

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by caregivers and represented in QoL-scales, although each instrument contains only a selection of the domains. Some were not mentioned by caregivers (being useful/giving meaning to life) and not represented in the scales (security/privacy, self-determination/freedom, being useful). Apparently there are differences in views on QoL between patients, caregivers and theoretical models (Dröes *et al.*, 2006).

The working group also investigated on which domains professional caregivers actually focus in daily practice (Gerritsen *et al.*, submitted). Caregivers focus on most of the domains that patients consider important. However, financial situation, self-determination/freedom and being useful/giving meaning to life are focused on least, the latter domain being particularly important to patients with dementia (Rabins, 2000).

QoL-scales must encompass the domains considered important by patients and the domains an intervention focuses on. Because cognitive decline may interfere with the ability to understand a complex topic such as QoL, the selection of the instrument is also influenced by the severity of dementia (Rabins, 2000). To contribute to an optimal use of QoL instruments in intervention studies, we reviewed their properties and the domains indicated as relevant by patients and focused on by professional caregivers. We propose which scales are best used to evaluate the outcome of care at different stages of dementia and for a specific research question/setting.

METHODS

Nine QoL-instruments were selected: Dementia QoL scale (DQoL) (Brod *et al.*, 1999b); Alzheimer's Disease Health-Related QoL (ADRQL) (Rabins *et al.*, 1999); Quality of Life-Alzheimer's Disease Scale (QoL-AD) (Logsdon *et al.*, 2002); Discomfort scale – Dementia of Alzheimer Type (DS-DAT) (Hurley *et al.*, 1992; Volicer *et al.*, 1999); Cornell-Brown Scale for QoL in Dementia (CBS) (Ready *et al.*, 2002); Vienna List (Porzolt *et al.*, 2004); DEMQOL (Smith *et al.*, 2005a, 2005b); Qualidem (Ettema *et al.*, 2006) and Schedule for the Evaluation of Individual QoL (SEIQoL), a non-dementia specific instrument validated in dementia (McGee *et al.*, 1991).

We investigated to what extent domains patients consider important are represented, if the scales measure the domains on which professional caregivers focus in daily practice and for which patients they are intended. For each scale we reviewed psychometric properties, setting, expertise necessary for application,

method of data collection, sensitivity to change and validated languages.

Because QoL of the caregiver/proxy is of major influence on coping with the patient (Logsdon *et al.*, 2004), we investigated whether the instrument also provides for measurement of their QoL. Finally, based on the earlier studies of the working group, we selected the scales best used to evaluate daytime activities/institutional 24-h care at different stages of dementia.

RESULTS

Domains of QoL

Table 1 summarizes domains considered important by patients, domains that professional caregivers focus on and representation of these domains in the nine scales.

Caregivers providing daytime activities/24-h care focus especially on affect, social contact, attachment, general health, security/privacy; to some degree on self-determination/freedom and spirituality and to a limited degree on financial situation. Differences between daytime activities/24-h care exist mainly in the degree of focusing on enjoyment of activities, sense of aesthetics and being useful/giving meaning to life (Gerritsen *et al.*, submitted).

The domain affect is represented in all scales, except for the DEMQOL. Self-esteem/social contact are often included. Only four instruments include attachment and physical/mental health (SEIQoL, DQoL, DSDAT, Qualidem), and two include enjoyment of activities/sense of aesthetics (ADR-QL, SEIQoL). Security/privacy, self-determination/freedom, being useful/giving meaning to life and spirituality can only be assessed with the SEIQoL. Yet all these domains are explicitly mentioned by patients as important aspects of their QoL.

Description and properties of QoL scales

Characteristics and practical applicability of the scales are presented in Table 2.

SEIQoL. The SEIQoL uses a technique derived from judgment analysis that enables respondents to nominate five areas most important to their QoL (McGee *et al.*, 1991; Schölzel-Dorenbos and Jellesma-Eggenkamp, 2001). The technique is applicable in mild dementia (Coen *et al.*, 1993; Schölzel-Dorenbos, 2000). For later stages the SEIQoL-DW (Direct Weighting; replacing weighting procedure with a pie chart format) offers an alternative (Hickey *et al.*,

Table 1. Domains important for Quality of Life according to patients with dementia, focused on by professional caregivers and their representation in measuring instruments for Quality of Life in dementia

Domain of quality of life	Affect	Self-esteem/ self-image	Social contact	Attachment	Physical and mental health	Enjoyment of activities	Sense of aesthetics	Financial situation	Security and privacy	Self-determination and freedom	Being useful/ giving meaning to life	Spirituality
Important to patients in NH/MC	+/+	+/+	+/+	+/+	+/+	+/+	+/–	+/+	+/+	+/+	+/+	–/+
Focused on by NA in 24-h care in NH	4*	4	4	4	4	3	3	2	4	3	3	3
Focused on by OT in day care MC	4*	4	4	4	4	4	4	2	4	3	3	3
SEIQoL McGee <i>et al.</i> (1991)	+	+	+	+	+	+	+	+	+	+	+	+
DQoL Brod <i>et al.</i> (1999a)	+	+		+			+					
ADR-QL Rabins <i>et al.</i> (1999)	+	+	+			+	+					
QoL-AD Logsdon <i>et al.</i> (1999)	+		+		+			+				
DSDAT Volicer <i>et al.</i> (1999)	+			+	+							
CBS Ready <i>et al.</i> (2002)	+	+			+							
Vienna List Porzsolt <i>et al.</i> (2004)	+		+		±							
DEMOOL Smith <i>et al.</i> (2005)		+	+		+							
Qualidem Ettema <i>et al.</i> (2006)	+	+	+	+		+						

NH = nursing home; MC = meeting and day-care centre; NA = nurse assistant; OT = occupational therapist; + = present; – = absent.

*5 = daily practice focused on the domain to a very high degree; 4 = a high degree; 3 = some degree; 2 = a limited degree; 1 = a very limited degree.

Table 2. Psychometric and practical properties of QoL measures in dementia

	SEIQoL McGee <i>et al.</i> (1991)	DQoL Brod <i>et al.</i> (1999a)	ADRQL Rabins <i>et al.</i> (1999)	QOL-AD Logsdon <i>et al.</i> (1999)	DS-DAT Volker <i>et al.</i> (1999)	CBS Ready <i>et al.</i> (2002)	Vienna List Porzolt <i>et al.</i> (2004)	DEMQOL Smith <i>et al.</i> (2005)	Qualidem Ettema <i>et al.</i> (2006)
Reliability									
Internal consistency	0.60–0.75	0.67–0.89	0.80	0.81–0.90	0.86–0.89	0.81	0.81–0.94	0.87	0.60–0.90
Inter-rater reliability	+	n.a.	n.a.	> 0.70	0.74–0.98	0.90	0.35–0.81	n.a.	0.66–0.88
Test–retest reliability	0.88	0.64–0.90	n.a.	P 0.76. C 0.92	0.97	n.a.	n.a.	0.76–0.84	0.74–0.88 [†]
Validity									
Criterion related ^a	–	–	–	–	–	–	–	–	–
Construct validity	+	+	+	+	+	+	+	+	+
Responsiveness									
Sensitive to intervention	+	n.a.	+	n.a.	+	n.a.	n.a.	n.a.	n.a.
Longitudinal change	+	+	+	+	n.a.	n.a.	n.a.	n.a.	n.a.
Applicability									
Stage of dementia	Mild	Mild-moderate	All stages	Mild-moderate	Severe	Mild-moderate	Severe	Mild-moderate ^b	Mild-severe
Data collection	Interview	Interview	Observation	Interview	Observation	Interview	Observation	Interview	Observation
Rating by	Patient	Patient	Proxy	Professional	Professional	Professional	Professional	Patient; Proxy	Professional
Assessm. QoL proxy	+	–	–	+	–	–	–	–	–
Setting	Community, institution	Community, institution	Institution	Community, institution	Institution	Community, institution	Institution	Community, institution	Institution
Inclusion environmental factors	+	–	+	+	–	–	–	–	+
Rating by	O	O	O	O	O, N	O	NA, O	Ph, N	2 NA
Difficulty of application	Trained interviewer	Easily administered	Trained interviewer	Easily administered	Trained interviewer	Easily administered	Easily administered	Easily administered	Easily administered
Validated in	E/D [†]	E	E	E	E/D	E	E	E	D

n.a. = not available.

O = other investigators/researchers; N = nurse; NA = nurse assistant; Ph = physician; E = English; D = Dutch.

[†]If assessed by 2 NA. If assessed by 1 NA: test-retest reliability 0.49–0.79.^aThere is no gold standard, because QoL is by definition subject to individual interpretations.^bSevere dementia: only DEMQOL-Proxy.

1996). The SEIQoL provides an overall score of QoL of both patient and proxy.

DQoL. Twenty-nine-item interview of patients with mild-moderate dementia (Mini-Mental State Examination (MMSE; 0–30) > 12) (Brod *et al.*, 1999b). Ten domains on five subscales (self-esteem/positive-negative affect/feelings of belonging/sense of aesthetics) are assessed with a five-point Likert-scale, providing a profile of scores. Subjects with a MMSE ≥ 13 understood the questions (Suzuki *et al.*, 2005). Sixty percent of people with a MMSE of 10 could complete the DQoL (Selwood *et al.*, 2005).

ADRQL. Dementia-specific scale applicable regardless of disease severity (Rabins *et al.*, 1999). The proxy-rated measure focuses on observable behaviour during the past 2–4 weeks. An overall QoL-score is obtained by a trained interviewer summarizing the scores of 47 items in five domains: social interaction/awareness of self/enjoyment of activities/feeling-mood/response to surroundings. The ADRQL-score is associated with disease severity. It measures efficacy of interventions/settings and is sensitive to change (Lyketsos *et al.*, 2003).

QOL-AD. Dementia-specific 13-item self-report scale covering physical health/energy/mood/living situation/memory/family/marriage/friends/chores/fun/money/self and life as a whole, scored on a four-point Likert-scale (Logsdon *et al.*, 2002). The QOL-AD can be used by patients (Participant self-reported QoL) and informal caregivers (Caregiver report of the Participant's QoL), yielding a single score, weighing the patient's score twice as heavily as the caregiver's. Caregivers can report on their own QoL with the CQoL (Caregiver QoL). Interrater-reliability, content and criterion-concurrent validity (DQoL, EQ-5D) are good (Thorgrimsen *et al.*, 2003). Subjects with mild-moderate dementia (MMSE ≥ 11) could complete the QOL-AD, including 3% of people with a MMSE of 11 (Selwood *et al.*, 2005). There is evidence for reliability in severe dementia (MMSE 3; Thorgrimsen *et al.*, 2003; Hoe *et al.*, 2005). QoL did not decrease as cognition deteriorated. The level of agreement between patient/caregiver ratings was modest, caregivers consistently rate the patient's QoL lower (Thorgrimsen *et al.*, 2003). This was not explained by cognitive ability of the patient and probably reflects a real difference in the way they perceive the patient's QoL. Caregiver reports corre-

lated strongly with both caregiver depression and burden.

DS-DAT. Objective scale for trained observers to measure discomfort in non-communicative patients with severe dementia (MMSE 0–2), by observing their behaviour during five minutes (Hurley *et al.*, 1992; Volicer *et al.*, 1999). It encompasses nine behavioural indicators, seven negative (noisy breathing/negative vocalization/sad/frightened facial expression/frowning/tense bodylanguage/fidgeting) and two positive (content facial expression/relaxed bodylanguage). The Dutch version of the DS-DAT showed good inter-observer reliability (Hoogendoorn *et al.*, 2001).

CBS. Modification of Cornell Scale for Depression in Dementia, based on the conceptualization that high QoL is indicated by presence of positive affect, satisfactions and self-esteem and relative absence of negative affect (Ready *et al.*, 2002); completed by a clinician after brief interview with patient and caregiver. The CBS is composed of 19 bipolar items, rated on a five-point scale, yielding a single QoL-score. Domains are mood, ideational/behavioural disturbances, physical signs and cyclic functions. The scale demonstrated adequate interrater/internal consistency reliability and criterion-validity (visual analogue positive mood ratings) in 50 patients (mean MMSE 22) (Ready *et al.*, 2002).

Vienna list. Description of well-being in severe dementia, based on observations of professionals. Containing five factors encompassing most of the behavioural repertoire in severe dementia: communication/negative affect/bodily contact/aggression/mobility. The psychometric properties have to be proved in further studies (Porzolt *et al.*, 2004).

DEMQOL. Self-report questionnaire administered by interviewer (Smith *et al.*, 2005a, 2005b). It has a patient (DEMQOL; 28 items) and carer (DEMQOL-Proxy; 31 items) version and assesses dementia-specific QoL from the patient's perspective. The two versions give different but complementary perspectives on QoL and it is recommended that both are used together. Five domains are covered: daily activities/looking after yourself/health/well-being/cognitive functioning/social relationships/self-concept. In severe dementia (MMSE < 10), only DEMQOL-Proxy should be used.

Qualidem. Forty-item behaviour observation-scale for patients up to severe dementia in institutions

(Ettema *et al.*, 2006; Ettema *et al.*, submitted). Nine subscales (care relationship/positive and negative affect/restless/tense behaviour/positive self image/social relations/social isolation/feeling at home/having something to do) provide a QoL-profile. It can be used for longitudinal investigation, and to evaluate effects of interventions and changes in daily care.

Selection of QoL instruments for application in practice

Selection of the appropriate instrument should take into account, apart from its psychometric properties, the following:

- Instruments that allow patients to rate their own QoL are preferred, if their judgment permits.
- For what stage of dementia and setting is the instrument to be used?
- Does the instrument measure the QoL-domains that the professional or intervention focuses on?
- In case of community-dwelling patients, it is preferable if the scale provides for QoL-measurement of the caregiver as well.

Based on these criteria four scales (Table 3) are recommended. For those offering daytime activities to people with mild dementia the SEIQoL seems the best choice, for 24-h care the QOL-AD is advised. The SEIQoL offers both patient and caregiver QoL-measurement. In moderately severe dementia, the SEIQoL-DW can be used. The QOL-AD contains most of the domains nurse assistants focus on in 24-h care, and remains applicable during disease progression, an advantage in longitudinal studies. With the CQOL-AD the QoL of the caregiver can be assessed. ADR-QL (all stages of dementia) and DQOL (mild-moderately severe dementia) are appropriate choices for professionals offering daytime activities focusing specifically on affect, self esteem, sense of aesthetics, social contact (DQOL) and enjoyment of activities (ADR-QL). For general evaluation of daytime activities these measures are less appropriate, because both instruments only represent a selection of the domains that professionals offering daytime activities focus on. A relative disadvantage of the ADR-QL is that the (in)formal caregiver reports on the patient, as it is known that informant and self-perception of QoL differ substantially. To date, neither source of information is superior (Ready *et al.*, 2004). Professional caregivers could assess the well-being of patients more positively if they are also the

Table 3. Four measures to evaluate the outcome of daytime activities and 24-h care on Quality of Life in dementia

	SEIQoL(-DW)	QOL-AD/CQOL-AD	Qualidem	DSDAT
Stage of dementia	Mild dementia (DW: moderate)	Mild-moderate severe dementia	Mild-moderate severe dementia	Severe dementia
Setting	Community and institution	Community and institution	Institution	Institution
Type of care	Daytime activities	24-h care	Daytime activities/24-h care	24-h care
Domains of QoL	All relevant domains	Sufficient	Attuned to institutional care	Attuned to institutional care
Rating QoL proxy	+	+	–	–
Difficulty of application	Trained interviewer, difficult	Easy after simple training	Easy after simple training	Easy after simple training
Rating by	Investigator	Investigator	Two nurse assistants	Nurse assistant/Investigator
Dutch validation	+	–	+	+
English validation	+	+	–	+

care-provider (Porsolt *et al.*, 2004). To measure QoL in mild-moderate dementia in 24-h institutional care the observational instrument Qualidem seems most appropriate, supplemented with the self-report QOL-AD instrument, which is also applicable in day-care. In severe dementia the Qualidem together with the DSDAT seem adequate to evaluate the influence of daytime activities and 24-h care on QoL. The selected instruments obviously do not cover all stages of dementia. Two instruments can assess QoL of both patient and caregiver: SEIQoL and QOL-AD (CQOL version).

DISCUSSION

Measuring cognitive and functional response in dementia is no longer enough (Bannerjee *et al.*, 2006). QoL-measures should be applied more often as currently no disease modifying therapy is available. Our aim was to operationalize QoL-criteria that are most important for patients and help professionals select the best scale, taking into account the relevant domains they focus on in daily practice.

Our overview shows three methods of QoL-assessment: self-report by patient, proxy-report by proxy or professional, and direct observation of behaviour assumed to be related to QoL. Dementia may interfere with understanding, ability to remember relevant events, making comparisons across complex domains and communicating (Rabins, 2000). Logsdon *et al.* (2002), however, showed that patients can rate their own QoL until late stages of dementia and that caregiver ratings do not substitute for patient ratings. Sands *et al.* (2004) found that caregivers rated patients' QoL lower than patients, associated with increased caregiver burden and depressive symptoms of the patient. Boyer *et al.* (2004) found poor patient/family proxy concordance for the dimension emotional reaction of the Nottingham Health Profile. The disadvantage of proxy ratings is that they filter a subjective measure through the opinion of another person.

Acknowledging the problem of potential bias of proxy-reports, self-rating methods are preferable if possible. If not, observational methods by an uninvolved professional are an acceptable alternative. We agree with Brod *et al.* (1999a) that the patient's subjective ratings should be the gold standard, but that independent observational ratings are of benefit for patients with (very) severe dementia.

In this paper we specifically focused on QoL-scales appropriate for professional caregivers providing

daytime activities/24-h care. We found no instruments that can be used in all stages of dementia, types of care/settings. Four measures best represent the domains of QoL that are important for patients and that professionals focus on in the mentioned care settings. The first two are self-rating instruments. For people living in the community who are offered daytime activities, and their proxies, we advise assessment of QoL with the SEIQoL (mild dementia) or SEIQoL-DW (mild-moderate dementia). The QOL-AD remains applicable up to MMSE scores of 3. Though the QOL-AD encompasses only four of the 13 domains mentioned as relevant for QoL by dementia-patients, this is sufficient if the intervention deals primarily with these domains, as is often the case in 24-h care. The CQOL-AD version assesses caregiver's QoL. If self-report is not possible we recommend the observational instruments Qualidem (for mild to severe dementia) and DSDAT (for severe dementia) by uninvolved professionals, both for evaluation of daytime activities and 24-h care. The other QoL-instruments are less appropriate, but could be useful in the evaluation of interventions that focus specifically on domains included in those instruments.

In conclusion, QoL-instruments must, if possible, acknowledge the opinion of patients with dementia. Interventions must take into account the domains they consider most important and the applied instrument should encompass the relevant domains for the care type/setting in question. If necessary more instruments could be used together to compensate for omissions in the application of one isolated scale. Investigators must select the scale(s) appropriate for the user, research question and care-type/setting. Rating of QoL of the caregiver is equally important, especially in community-dwelling patients. Improvement of QoL of dementia-patients and their caregivers should have a high priority in dementia care. QoL-assessment provide a format to express whether an intervention has made an important difference to the patient's life (Selwood *et al.*, 2005). The measures we recommend are tools to contribute to this goal. One should not assume that any instrument for QoL is automatically suitable to evaluate the effect of every intervention in all care-settings and stages of dementia. If the main focus in daily practice is on aspects that are not measured with the applied instrument, the effectiveness of the intervention cannot be assessed adequately. This study shows that severity of dementia, care-type/setting, and the specific QoL-domains an intervention focuses on, are important factors to decide which QoL-instrument would be best to use in a specific situation.

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AUTHORS' CONTRIBUTIONS

CSD prepared the first draft of this article and had primary responsibility. RMD contributed significantly to the preparation of the manuscript. The other authors gave comments on a draft of the article and/or participated in the field work and literature study on which this paper is based. All authors are members of the Quality of Life in dementia working group of the Leo Cahn Foundation and contributed to the development of the ideas contained herein. Members of the LCF working group are a psychogerontologist, neuro and health care psychologists, psychomotor therapist, clinical geriatrician, psychogeriatric researcher and sociologist.

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