

Value of Personalized Dementia-Specific Quality of Life Scales: An Explorative Study in 3 European Countries

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Abstract

Measuring Quality of Life (QOL) can be difficult due to its individual character. To explore the value of personalized QOL measurement for people with dementia, personalized versions of two dementia-specific QOL scales (Dementia quality of Life (DQoL) and Quality of Life in Alzheimer's Disease (QoL-AD)) were constructed. This study investigated whether the personalized measures are more valid to detect variations in QOL than their standard versions for people with mild to moderate dementia, with sufficient internal consistency. Moreover, the relationship between the personalized QOL measures and severity of dementia was investigated. Finally, the study explored the differences between countries regarding the personalized overall QOL and differences in the importance of QOL domains. This explorative one-group design study used baseline data from the MEETINGDEM study into the implementation of the Meeting Centres Support Programme in Italy, Poland and the UK. The personalized versions of the DQoL and QoL-AD were reliable, but not more valid than their standard versions. No relationship between severity of dementia and personalized QOL was found. While no differences were found between countries for the overall QOL score, some QOL domains were valued differently: people with dementia from the UK rated self-esteem, mood, physical health, energy level and the ability to do chores around the house significantly less important than people from Italy and Poland. The personalized versions of the DQoL and QoL-AD may offer dementia care practice important insights into what domains contribute most to an individual's QOL.

Keywords

dementia, quality of life, self-report, cross-cultural

Introduction

Patient-reported outcome measures are important in assessing the effectiveness of disease-modifying and psychosocial interventions. An outcome that is often used in patients with chronic diseases is Quality of Life (QOL). Quality of Life is defined by the WHO¹ as ‘the 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’. It is affected by the person’s physical health, psychological state, personal beliefs,

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social relationships and by their relationship to relevant features of their environment. In the last two decades, QOL is being recognized increasingly as an important construct and outcome.^{2–8} In their review, Van Leeuwen et al.⁹ identified nine QOL domains that older adults consider important: ‘Health perception’, ‘Autonomy’, ‘Role and activity’, ‘Relationships’, ‘Attitude and adaptation’, ‘Emotional comfort’, ‘Spirituality’, ‘Home and neighbourhood’ and ‘Financial security’ and that vary in different situations. Albeit in slightly different terms, these domains are mentioned by people with dementia as well.³ In dementia, the main focus in care is the promotion of optimal QOL as there is no cure available.¹⁰ At the same time, there appear to be discrepancies in views regarding the relevance of QOL domains among people with dementia¹¹ and between people with dementia, carers and theoretical models. For example, a study by Dröes et al.³ showed that several QOL domains, such as ‘safety and privacy’, ‘self-determination and freedom’, ‘being useful/giving meaning to life’ and ‘spirituality’, which were mentioned as relevant by community-dwelling people with dementia and by people with dementia living in nursing homes, were not represented in QOL instruments at that time. Today, the latter two are more often included.¹² ‘Sense of aesthetics in living environment’, ‘financial situation’ and ‘being useful/giving meaning to life’ were not mentioned by the professional caregivers as relevant and they paid very little attention in care practise especially to the latter two domains,¹³ although these are experienced as relevant by people with dementia. Disease-specific QOL instruments, including dementia-specific QOL scales, aim to target the domains most relevant to the condition and are therefore more likely to capture how the disease impacts the experienced well-being over time.¹⁴ Furthermore, personalized instruments allow for a better and feasible assessment of the individual’s QOL, as Schölzel-Dorenbos found in her study on the SEIQOL¹⁵ and Selai et al¹⁶ in their work on the QOLAS, offering persons the opportunity to indicate the importance of different life domains.^{7,17}

Several factors may affect self-reported QOL in dementia,¹⁸ including behavioural and non-cognitive symptoms as well as symptoms caused by the progressive cognitive decline, such as difficulties in abstract thinking and anosognosia. Hence, there has been a long-standing discussion about who should rate the QOL of people living with dementia. Cognitive limitations may affect people’s ratings; on the other hand, family carers typically rate the QOL of the person with dementia lower than people with dementia do themselves, due to factors inherent to caring for a person with dementia (e.g. burden, depressed mood and projection)¹⁸; and scoring by professional caregivers tends to be less extreme.¹⁹ A study by Conde-Sala et al²⁰ showed that several factors were particularly associated with greater discrepancies between patient and carer ratings of QOL, that is, severity of dementia, anosognosia, depression, as well as cognitive status in patients and female sex in carers. Also, Schiffczyk found a relationship between the difference in QOL assessments of proxies and

people with dementia and the severity of dementia, even in mild dementia stages.²¹ Given the subjective nature of QOL, the general opinion is that self-reported QOL is preferred for as long as possible^{17,22} and that reliable, sensitive scales should enable this until late dementia stages. Indeed, studies suggest that people with mild to moderate dementia are able to understand and answer questions regarding their lives^{23,24} and there is evidence for reliability of some scales in severe dementia.^{5,24,25}

The relationship between severity of dementia and QOL is complex due to the progressive cognitive decline, but also due to the disability paradox,²⁶ whereby people with a chronic disease report a higher QOL than proxies because they adapt to their illness. Although negative correlations were shown between proxy-rated observed QOL aspects (e.g. having social relations and being isolated) and severity of dementia,⁴ several studies into self-reported QOL suggested that the perceived QOL is not related to severity of dementia.^{25,27} In contrast with these findings, Conde-Sala²⁰ showed that patients with the lowest QOL ratings had a better cognitive status, more depression and less anosognosia. Conversely, the highest QOL was reported by patients with a poorer cognitive status, less depression and greater anosognosia. To our knowledge, no studies were conducted into the relationship between outcomes of personalized QOL measurement and severity of dementia.

Several self-report disease-specific instruments have been developed to assess QOL in dementia. Two of the most used scales are the Dementia Quality of Life instrument (DQoL)²³ and the Quality of Life in Alzheimer’s Disease scale (QoL-AD).²⁴ To explore the added value of personalized QOL measurement, we constructed personalized versions of the DQoL and QoL-AD. The development of personalized, dementia-specific, self-report QOL scales aims to enable a more valid measurement of QOL and, consequently, more effective decision-making with regard to interventions, allocation of healthcare resources and tailored dementia care.

The present study aimed to examine whether the personalized versions of DQoL and QoL-AD are more valid to detect intra- and interpersonal variations in QOL than their standard versions for people with mild to moderate dementia, while still being sufficiently reliable. It is hypothesized that there is a higher correlation between the personalized versions of the instruments and overall perceived QOL by persons with dementia. The study also intended to identify whether there is a relationship between the severity of dementia and self-reported QOL as measured with the personalized and standard versions of DQoL and QoL-AD. Although, as mentioned, previous research is not unambiguous about this relationship, it could be that the personalized QOL scales are more sensitive than the standard versions and therefore may confirm a positive association between severity of dementia and QOL. Insight into the association between personalized self-reported QOL and

dementia severity may provide information on the changing impact that dementia has in specific life domains as the condition progresses. This may be helpful to guide personalized support and care.

Finally, the study intended to explore whether there are differences between three European countries in the self-reported overall QOL as well as in the importance of QOL domains as assessed by people with mild to moderate dementia when they rate their QOL with the personalized DQoL and QoL-AD. Country differences in the importance of domains will aid the development of country-specific care policies and strategies to adaptively implement existing care methods and innovations.

Methods

Design

This study was part of the European MEETINGDEM project, funded by the Joint Programming Neurodegenerative Diseases. MEETINGDEM investigated the adaptive implementation and evaluation of the Meeting Centres Support Programme (MCSP) for people with dementia and their carers in Italy, Poland and the United Kingdom.²⁸ For the evaluation study, a controlled trial with a pre-test–post-test control group design was conducted, in which the MCSP (a community-based combined support programme offered in socially integrated community centres) was compared to usual care (UC) in each country. Measurements were performed at baseline (Month 0) and after 6 Months. For the present study on QOL measurement, only data from the baseline measurement were used. Ethical approval for the study was obtained from the relevant ethics committee in each country. An informed consent procedure was followed to make sure that people with dementia and their carers were well informed before confirming their willingness to participate in the study.

Setting and Participants

Participants were community-dwelling people with mild to moderate dementia and no age limit, recruited from meeting centres for people with dementia and their carers and via GPs, regular day care, home care or other in Italy, Poland and the United Kingdom. If the researcher considered possible participants physically or mentally unable to fill in the questionnaire or at risk of being overstrained by filling in the questionnaire, they were not included. Data were collected between May 2015 and December 2016.²⁸

Measurements

Background characteristics such as sex, age, marital status, highest educational level and co-morbidities were obtained for each participant. The severity of dementia was assessed using Reisberg's Global Deterioration Scale (GDS),²⁹ in which stages

1–3 are the pre-dementia stages, 4–5 refer to mild and moderate dementia and stage 6 and 7 refer to moderately severe and severe stages of dementia. Self-reported quality of life was measured with the DQoL²³ and the QoL-AD.²⁴ The DQoL (29 items) measures both positive and negative behaviours across five domains: Positive affect (6 items), negative affect (11 items), feelings of belonging (3 items), self-esteem (4 items) and sense of aesthetics (5 items), which are all scored on a five-point Likert scale. Scales were reversed so that for all scales higher scores indicate a better QOL. The QoL-AD consists of 13 items that measure the domains of physical health, energy, mood, living situation, memory, family, marriage, friends, chores, fun, money, self and life as a whole. The items are rated on a four-point scale ranging from poor (1) to excellent (4). The psychometric properties of the DQoL²³ (Cronbach's alpha .80 for self-esteem, .83 for positive affect, .89 for negative affect, .67 for feelings of belonging and .77 of sense of aesthetics, respectively) and QoL-AD³⁰ (Cronbach's alpha .82; interrater reliability kappa >.70; correlated (Pearson's r) .69 with DQoL) have been shown to be good. The DQoL can be completed by people with MMSE-scores of 12 or higher,²³ and the QoL-AD can be completed by people with an MMSE-score as low as 3.³¹

Both Italian and Polish versions of the DQoL and QoL-AD were translated through a process of back and forth translation from the original English versions.

Personalized QOL Measures

To personalize the measurement of QOL, so-called 'pre-questions' were added to the instruments about the value of the quality of life domains included in the DQoL and the QoL-AD as described in Brod et al²³ and Logsdon et al,²⁴ respectively. People were asked to indicate on a visual analogue scale ranging from one (completely unimportant) to ten (extremely important) how important each QOL domain was for their quality of life.

Personalized DQoL

The pre-questions added for the domains of the DQoL concerned self-esteem, mood, feelings of belonging and experiencing nature and music (which refers to the domain sense of aesthetics). The response option on a scale from 0 to 10 was chosen following the 'The Older Persons and Informal Caregivers Survey Minimum Data Set' (TOPICS-MDS) questionnaire, which uses one overall assessment of QOL on a scale of 0–10. The pre-question for mood accounted for both positive and negative affect domains as the distinction between these two aspects might not be well understood by the participants.

Personalized QoL-AD

The pre-questions for the QoL-AD concerned the 12 items/domains of the QoL-AD (physical health, energy level, mood,

living situation, memory, family, marriage/closest relationship, friends, self-image, ability to do chores around the house, ability to do things for fun and money/financial situation). For the 13th item (assessment of life as a whole), no pre-question was included as it refers to an overall assessment of the participant's quality of life.

Procedure

All people with dementia-carer dyads who started participating in the newly developed Meeting Centres Support Programme (MCSP) in Italy, Poland and the UK were invited to participate in the MEETINGDEM evaluation study by the Meeting Centre's (MC) Manager within the first two weeks of attendance. People in the UC group were recruited via, that is, GPs, home care organizations or regular day care centres within the same locality but outside the MC catchment area. Participation in the research was entirely voluntary.

Except for the GDS, which was administered by the manager of the MC or by a professional who knew the person in the UC group, all questionnaires were administered by trained researchers. Participants of the UC group were interviewed face-to-face at the MC or in their own homes. The trained researchers applied the pre-questionnaires in a standardized way according to the instructions (see [Supplementary File 1](#)). Before posing the pre-questions, the interviewer made sure the participant understood the method (see [Supplementary File 1](#)). All data were collected and cleaned in each country and subsequently sent to the research team in the UK for integrating all the data.

Data Analysis

To calculate the relative contribution of each domain to the overall quality of life, the standard score on each domain of the DQoL was multiplied by its corresponding pre-question rating. This created weighted scores for the personalized domains of the DQoL. A similar procedure was used for all five domains of the DQoL, where the rating for the Mood pre-question was used in both Positive Affect and Negative Affect domains. Ratings could range from 0–50, with higher scores representing higher quality of life.

Scores for each item of the standard QoL-AD measure were multiplied by their corresponding pre-question rating. For the 13th item, a weight was calculated as the average of the 12 pre-questions scores, in order to maintain the contribution of this item in the calculation of the total QoL-AD score. A total score for the personalized QoL-AD questionnaire was computed as the sum of all weighted scores. The total personalized QOL scores could range from 0–520, with higher scores representing higher quality of life. Similar to the procedure used for the standard questionnaire, for up to two missing values the mean score of the remaining items was imputed. If more than two scores were missing, the entire measure was considered missing.

In order to compare standard and personalized measures, scores were normalized. The transformation re-scaled all scores of the standard and personalized DQoL and QoL-AD to a 0–10 scale per formula, $E_i = (e_i - E_{\text{min}})/(E_{\text{max}} - E_{\text{min}}) * 10$ (where E_i =normalized score; e_i =standard score; E_{min} =minimum value of the variable; E_{max} =maximum value of variable).

To test the reliability (internal consistency) of the standard and personalized QoL-AD, Cronbach's alphas were calculated. For the DQoL, we only calculated Cronbach's alphas for the domains of the standard version. There was no point in calculating them for the personalized DQoL domains as all items within a domain received the same weight and thus the internal consistency was not expected to change.

The difference in validity between the personalized and standard DQoL was tested using the following procedure: (1) calculating for both the Spearman rank correlation coefficients between the five (personalized) domain scores of the DQoL and the scores on the DQoL item 'overall rated quality of life' which is a separate item in the questionnaire. For the QoL-AD, the difference in validity between the personalized and standard QoL-AD was tested by calculating for both the Spearman rank correlation coefficients between the (personalized) QoL-AD score (12 items) and the unweighted QoL-AD item 13 'assessment of life as a whole' and (2) testing whether the correlation coefficients for the standard and personalized versions of DQoL and QoL-AD differed significantly, using a Fisher Z-Transformation.

The relationship between the severity of dementia and QOL in people with dementia as measured with the personalized and standard versions of DQoL and QoL-AD was calculated using Spearman rank correlation coefficients.

The median scores on the pre-questions (domain weights) were described for the three countries. Kruskal Wallis tests were done to test for differences between the three countries in the overall QOL as well as in the importance of different QOL domains.

Results

Participants

A total sample of 227 participants joined the MEETINGDEM study. Of those, 138 were included in this QOL study because they met our inclusion criterion of a GDS score 4–5. Their mean age was 81.1 years ($SD = 6.78$, range 63–95). [Table 1](#) shows a detailed overview of their background characteristics.

Reliability and Validity of (Personalized) DQoL and QoL-AD

The DQoL domains proved reliable in our sample (Cronbach's alpha .67 for self-esteem, .84 for positive affect, .85 for negative affect, .51 for feelings of belonging (an acceptable level for a three-item scale) and .75 of sense of aesthetics,

Table 1. Characteristics of the Participants (N = 138).

Characteristics	N*	%
Country		
Italy	70	50.7
Poland	25	18.1
UK	43	31.2
Sex		
Male	55	74
Female	42.6	57.4
Partnership		
Yes	71	57
No	55.5	44.5
Relationship to carer		
Spouse	67	51.9
Off-spring	53	41.1
Grandchild	2	1.6
Other family	2	1.6
Friend	2	1.6
Other	3	2.3
Educational level		
Higher	28	22.0
A-level	29	22.8
GCSE	29	22.8
Level I	25	19.7
No education	15	11.8
Co-morbidities		
Yes	77	60.2
No	51	39.8
Cognitive impairment (GDS)		
Mild dementia (GDS=4)	90	65.2
Moderate dementia (GDS=5)	48	34.8

*Highest grade completed.

*N may vary because of missing values.

Totals may not equal 100% because of rounding.

respectively). This calculation was only performed without the multiplication of the corresponding pre-question score as they are the same for every item within the subscale. Therefore, these values are equal for both the standard and personalized versions. Both the standard (13 items; $\alpha = .80$) and the personalized QoL-AD (13 items; $\alpha = .86$) were found to be highly reliable.

Table 2 shows the correlations between the domains of the DQoL and the DQoL item ‘overall rating quality of life’ and between the score of the 12 QoL-AD items and the QoL-AD item ‘life as a whole’. The correlations vary from weak ($r_s=.10$) to moderate ($r_s=.44$). The difference tests between correlation coefficients did not show significant differences between the standard and the personalized DQoL and QoL-AD (see **Table 2**).

Relationship Between Severity of Dementia and QOL

Neither the personalized nor the standard DQoL revealed correlations between severity of dementia and the five

domains of the DQoL. Also, no correlations were found between severity of dementia and the total score of the personalized or standard QoL-AD.

Differences Between the Three Countries

The mean score on the item ‘overall rating quality of life’ of the standard DQoL was in the total sample 3.34 (range=1–5; SD=.965); for the GDS 4 group, the mean score was 3.34 and for the GDS 5 group 3.35. The mean score on the item ‘life as a whole’ of the standard QoL-AD was 2.85 (range=1–4; SD=.648); for the GDS 4 group, the mean score was 2.83 and for the GDS 5 group 2.88.

Table 3 shows an overview of the medians of the pre-question ratings on the importance of each quality of life domain per country. Although not all domains were assessed as equally important, the relatively high medians demonstrate that in general all domains included in the DQoL and QoL-AD were assessed as important for quality of life. The most important domains appeared to be family and marriage/closest relationship. Other domains that appeared to be of high importance to the persons with dementia were physical health, living situation and memory. The ability to do chores around the house was found to be the least important, even though this domain was still ranked as relatively important for QOL.

No difference was found between the countries for the self-measured QOL score as measured by the personalized QoL-AD ($H(2) = 2.833, P = .243$). A statistically significant difference between countries was found for the importance of the domain *mood*, as measured by the pre-questions of the DQoL ($H(2) = 6.476, P = .039$), with a mean rank of 64.48 for Italy, 68.92 for Poland and 49.38 for the UK. Differences between Italy, Poland and the UK were also found as measured by the pre-questions of the QoL-AD for *physical health* ($H(2) = 26.174, P = .000$), with mean ranks of 68.31, 77.92 and 40.19, respectively, and for *energy level* ($H(2) = 6.007, P = .050$), with mean ranks of 67.19, 59.92 and 49.91.

Discussion

To our knowledge, there are no dementia-specific instruments that measure self-reported QOL in a personalized way. We therefore constructed additional pre-questions that can be used together with the DQoL and/or QoL-AD to assess personalized QOL. Personalized QOL does not merely reflect satisfaction with the different domains of quality of life, but also how these domains are valued by the person.

The reliability of the positive affect, negative affect and sense of aesthetics domains of the DQoL was found to be high and comparable with the reliability of these domains found in the study of Brod.²³ The feelings of belonging and self-esteem domains however were found to be moderately reliable and less reliable than in the study of Brod.²³ Both the standard and personalized versions of the DQoL proved to be

Table 2. Correlations Between DQoL and 'Overall Rate of Quality of Life' and Between QoL-AD and 'Life as a Whole'.

	n	r _s	p	z	Difference Between S and P (Sig. (2-Tailed))
DQoL-feelings of belonging-S	121	.294**	.001	-.31	.757
DQoL-feelings of belonging-P	116	.331**	.000		
DQoL-sense of aesthetics-S	122	.061	.505	-1.04	.298
DQoL-sense of aesthetics-P	115	.195*	.038		
DQoL-self-esteem-S	121	.323**	.000	.67	.503
DQoL-self-esteem-P	117	.242 **	.009		
DQoL-positive affect-S	124	.429**	.000	.88	.379
DQoL-positive affect-P	118	.331**	.000		
DQoL-negative affect-S	124	.440**	.000	.60	.549
DQoL-negative affect-P	118	.375**	.000		
QoL-AD-S	123	.442**	.000	1.1	.271
QoL-AD-P	116	.319**	.000		

Abbreviations: DQoL, dementia-specific QoL scales; P, personalized version; S, standard version.

Table 3. Median Scores on the Pre-Questions of DQoL and QoL-AD Per Country.

	Italy (Median, Range) n = 55*	Poland (Median, Range) n = 25*	UK (Median, Range) n=39 ^a
DQoL			
Mood	8.5 (0–10)	9 (5–10)	8 (3–10)
Self-esteem	8 (1–10)	9 (4–10)	8 (2–10)
Feelings of belonging	9 (0–10)	9.5 (3–10)	8 (5–10)
Sense of aesthetics	9 (0–10)	8 (5–10)	8 (2–10)
QoL-AD			
Physical health	10 (5–10)	10 (6–10)	9 (5–10)
Energy level	9 (5–10)	8 (4–10)	8 (4–10)
Mood	9 (5–10)	9 (5–10)	8 (2–10)
Living situation	9 (5–10)	9 (5–10)	10 (5–10)
Memory	10 (5–10)	9 (5–10)	8 (2–10)
Family	10 (5–10)	10 (6–10)	10 (8–10)
Marriage/closest relationship	10 (5–10)	10 (6–10)	10 (8–10)
Friends	8 (0–10)	8 (2–10)	9 (3–10)
Self-image	8 (3–10)	8 (2–10)	8 (3–10)
Ability to do chores around the house	8 (0–10)	8 (4–10)	7.5 (1–10)
Ability to do things for fun	8 (0–10)	8 (3–10)	8 (3–10)
Money/financial situation	9 (4–10)	8 (0–10)	8.5 (0–10)

*N may vary because of missing value.

Abbreviation: DQoL, dementia-specific QoL scales.

reliable in our study as well as in the study by Thorgrimsen et al³⁰

All domains of both DQoL-versions, besides sense of aesthetics, were correlated with the DQoL item 'overall quality of life'. The twelve items of both the personalized and standard QoL-AD were correlated with the QoL-AD item 'life as a whole'. As the correlation coefficients did not significantly differ for the standard and the personalized DQoL and QoL-AD, we must conclude that there is no indication that the personalized versions of the instruments are more valid than the standard versions.

No correlations were found between severity of dementia and the five domains of the DQoL or the total score of the

QoL-AD, neither for the personalized nor for the standard version. For the standard version of the QoL-AD, this is consistent with the findings of Logsdon et al,²⁵ Conde-Sala et al²⁰ and Hoe et al²⁷ and could be an indication that the overall QOL as measured with the QoL-AD is indeed not related to severity of dementia, contrary to what is found in caregivers' evaluations of QOL of persons with dementia.²⁰ However, having only included people with mild to moderate dementia may have been the reason no potential relationship was detected.

Overall, all domains of the standard DQoL and QoL-AD were considered to be highly important by people with dementia, which underlines the validity of these instruments.^{25,30}

Nevertheless, some variability in importance of domains was found, which is in line with findings of Van Leeuwen et al³² where older adults expressed their preference for a QOL measure that reflect their personal concerns in life. No difference was found between countries for overall QOL as measured by the personalized QoL-AD. This is not in line with the findings of the European RightTimePlaceCare study of Beerens³³ as they found that people with dementia in the northern and western countries of Europe scored higher on the QoL-AD compared to people with dementia in the eastern and southern European countries.

A statistically significant difference was found for the importance of the domain self-esteem, with the people from the UK rating this less important than people from Italy and Poland. Differences between countries were also found for how people valued the domain mood of the DQoL and the QoL-AD, with the people from the UK rating this less important than people from Italy and Poland. Also, the physical health, energy level and the ability to do chores around the house were rated as less important by people in the UK as compared to the other two countries. These differences may be related to differences in the background characteristics of the participants in the three countries. In the MEETINGDEM project,³⁴ where the data were collected for this QOL study, participants in the UK were on average older and more likely to be male than in Italy and Poland.³⁴

Limitations

The results of this study should be interpreted carefully because of some limitations. This study reported on a specific sample of people with dementia: All participants had mild to moderate dementia. As a result, our findings may not be generalizable to people in a more severe stage of dementia. Having a sample of only people with mild and moderate dementia also limited the investigation of the relation between severity of dementia and QOL.

A second limitation is that within the MEETINGDEM study potential participants that were considered physically or mentally unable to fill in the questionnaires, including the QOL scales, or were at risk of being overstrained by filling in the questionnaires, were not included in the study. This may have led to selection bias.

A third limitation is that the study was insufficiently powered to detect small to moderate differences between the countries regarding self-reported QOL and importance of QOL-domains and that the sample was not large enough to investigate in more detail what background characteristics determine the country differences in opinions on importance of QOL domains.

A fourth limitation is the use of Cronbach's alpha to calculate the reliability of the personalized scale as it is bound to be lower than with standard measures due to the additional variance that is obtained with the personal weights.

Scientific and Societal Impact

Measuring QOL can be difficult because of its individual character: aspects of life which are important to one person may have little or no relevance to another.³⁵ The results of this study underscore that the importance of items/domains of QOL scales can vary between individuals³⁶ and countries. As expected from the literature,³ social relationships are ranked highly by all people in all countries: The most important QOL domains appear to be family and marriage/closest relationship. Some domains were valued less in the UK compared to the other countries. Further research into what determines the importance of QOL domains and intercultural differences is recommended.

This study can be relevant for clinical practice where the pre-questionnaires can be used together with the DQoL and the QoL-AD to select objectives of care and to monitor treatment based on the domains indicated to be relevant by the individual person. The results of this explorative study may also contribute to the knowledge about cultural differences in Europe regarding the importance of domains that contribute to QOL. This information can be of interest when adapting and implementing care methods and innovations in different countries.

Dröes et al³ found that the domains that are relevant for an individual's QOL were not limited to the domains measured with the DQoL and the QoL-AD. Therefore, in future studies, the pre-questions method could also be used together with other QOL measures that include other, or more, QOL domains. It is important to further study the acceptability and feasibility of the pre-questions by examining the perceptions of the users and interviewers regarding their use. It would be interesting to also study the applicability of the pre-questions of the QoL-AD in people with moderately severe to severe dementia. They might have more difficulties in expressing the importance of the domains, which may influence the reliability and validity of this instrument.

Conclusion

Although both the standard and personalized versions of the DQoL and QoL-AD were found to be reliable, the personalized versions of the DQoL and QoL-AD were not found to be more valid to detect intra- and interpersonal variations in QOL than the standard versions. However, the results of this study offer insights into the individualized QOL of people with dementia, which may have important implications for care practice. To properly design and apply personalized interventions for individuals with dementia, it is essential to understand which life domains contribute most to their QOL.

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Author Contributions

Iris Hendriks conducted the analyses and wrote the paper. Raquel Demetrio contributed to the analysis and writing the paper. Rose-Marie Dröes and Franka Meiland designed the study, supervised the data collection and analyses and contributed to writing the paper. Debby Gerritsen supervised the data analysis and contributed to writing the paper. Data were collected by Rabih Chattat, Joanna Rymaszewska, Dorota Szcześniak, Shirley Evans, Teresa Atkinson, Elisabetta Farina and Francesca Lea Saibene. Coordination and supervision of data collection was done by Dawn Brooker and Simon Evans.

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Supplementary Material

Supplementary Material for this article is available online.

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