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The Development and Validation of the Dementia Quality of Life Scale for Older Family Carers (DQoL-OC)

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Abstract

Purpose: Little is known about how caregiving affects the quality of life (QoL) of older family carers and no dementia and age-specific QoL scale is available for use with this population. This study aimed to develop and validate a unique dementia caregiving- and age-specific tool - the 'Dementia Quality of Life Scale for Older Family Carers' (DQoL-OC).

Methods: The scale items were identified in focus groups with older family carers in the UK. Content and face validity were evaluated by a panel of six experts. A set of 100 items assessed on a five-point Likert scale was tested with 182 older family carers. Test – Re-test reliability was conducted with 18 individuals. Exploratory Factor Analysis was used to identify the QoL model and reduce the number of scale items. Convergent construct validity and internal consistency were also established.

Results: A one-factor solution containing 22 items was obtained. Test - Re-test reliability (lower bound $r = 0.835$; $p<0.001$), internal consistency (Cronbach's $\alpha=0.936$), and convergent construct validity were established. Significantly lower levels of QoL were found in female older carers; those who perceived their relatives with dementia as being at the earlier stages of the disease and with unstable dementia symptoms; those providing care more hours per day and more days per week; and those in younger-old age.

Conclusions: The DQoL-OC is a valid and reliable scale that will be useful for research and in clinical practice with older family carers of people with dementia. These study results will inform future health and social care aiming to improve life quality for this overlooked population of carers.

Keywords: quality of life; caregivers; dementia; psychometrics; rating scale

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Background

Older people who are carers represent around 1.5 million people in the United Kingdom (UK) (White, 2013) and this number is likely to increase, especially in those aged 85 and over (Carers UK & Age UK, 2015). Caregiving can be particularly harmful to older individuals, as these people often have reduced income, are themselves living with the onset of long-term conditions, have reduced social networks and provide more intensive care, with more than half of carers aged over 85 providing 50 or more hours a week of care (Jopling, 2015). Even though research with older family carers of people with different diseases has identified poor QoL levels in this population (A. Ekwall, Sivberg, & Hallberg, 2004; A. K. Ekwall, Sivberg, & Hallberg, 2007; Godwin, Ostwald, Cron, & Wasserman, 2013; Ratcliffe, Lester, Couzner, & Crotty, 2013; Roth, Perkins, Wadley, Temple, & Haley, 2009; Steptoe, Shankar, & Snorri, 2015), it has been demonstrated that the QoL of life of older family carers of people with dementia is widely overlooked (Carers UK & Age UK, 2015; Oliveira, Vass, & Aubeeluck, 2015).

The few studies that do investigate the QoL of older family carers of people with dementia utilise a wide range of different instruments developed for the general population or for carers in all age groups (Oliveira et al., 2015). Therefore they do not cover the age-specific aspects associated with the QoL of older carers of people living with dementia. Aspects, such as concerns about their own health and future; energy and vitality in their care provision; role conflicts in being an older carer; identity; the higher impact of financial situations; confidence in providing care whilst being a frail older person; isolation and loneliness derived from a full-time carer role; and sleep deprivation are some of the issues reported by older carers as being important to their own QoL that are not fully represented in current QoL measures (Oliveira, Vass, & Aubeeluck, 2016). Additionally, current caregiving specific QoL scales contain limitations, for example, in appropriately establishing construct validity and practicality, as well as problems in scale design/measurement, and length (Brouwer, van Exel, van Gorp, & Redekop, 2006; Gallego et al., 2001; Joseph, Becker, Elwick, & Silburn, 2012; Moniz-Cook et al., 2008; Thomas et al., 2006; Vickrey et al., 2009). This is of concern as it could compromise the validity of the research and the responsiveness to change of these tools (Caballero et al., 2013; Hyde, Wiggins, Higgs, & Blane, 2003; Hyland, 2003; The WHOQoL Group, 2005). This can lead to invalid conclusions, impacting on decisions about treatments, allocation of resources, and the development of policies (Haynes, Richard, & Kubany, 1995). It is therefore paramount to develop a valid, reliable, and practical tool for use with older carers in order to improve the quality of future investigations with this particular population. This study aimed to develop and validate a unique age- and dementia-specific QoL scale for use with older family carers of people with dementia – the Dementia Quality of Life Scale for Older Family Carers (DQoL-OC). The first study phase generated a large number of scale through qualitative focus groups with older family carers. This helped to identify the particular issues associated with older family carers' QoL and to support the content and face validity of the new tool (Oliveira et al., 2016). These questions reflected a variety of broad QoL domains that are relevant for older people in general, as well as relevant QoL aspects for dementia caregiving. This current paper therefore presents the process of item reduction and the psychometric evaluation of the final scale version. This research was approved by the Research and Ethics Committee (REC) of the Faculty of Medicine & Health Sciences (University of Nottingham) and of the National Health Service Ethics Service, United Kingdom.

Methods

The DQoL-OC was developed and validated using a sequential exploratory mixed-methods design, in which a qualitative investigation was initially used to identify the variables underlying the QoL model (Oliveira et al., 2016). An expert panel of four researchers from the fields of dementia, psychometrics, QoL and family caregiving, and two older family carers were invited to independently evaluate the preliminary version of the DQoL-OC for word clarity, content, and face validity (Rubio, Berg-Weger, Tebb, Lee, & Rauch, 2003; Streiner & Norman, 2003). After addressing the comments of the expert panel, the test version of the DQoL-OC, now containing 100 items, was submitted to Exploratory Factor Analysis (EFA) in order to identify the QoL model and reduce the scale items. As advised in the literature (Costello, and Osborne, 2005), EFA was carried out several times following an iterative process, each time including and excluding items and checking for retained factor/item scores, until a robust and meaningful set of items was retained. After that, the final scale version was submitted to further psychometric evaluation.

Participants and recruitment

Individuals who met the following inclusion criteria were included in the study: 1) aged 60 or over; 2) currently providing care for a family member with dementia at home in the UK; and 3) understand English. A convenience sample of participants was recruited from a variety of voluntary organizations and community based carers' groups in the UK. Information about the study was also publicized in public areas, such as supermarkets, churches, and local community centres. On-line adverts were also posted on social media. Recruitment also included health services, such as general practice services, memory clinics, and home care services. Older carers either contacted the researcher directly after receiving information about the study, or were approached by the researcher or support group leaders.

Procedure

Participants were given a research booklet containing the participant information sheet, the preliminary version of the DQoL-OC, and other existing and previously validated scales: World Health Organization Quality of Life Scale for Aging Population (WHOQOL-AGE); Satisfaction with Life Scale (SWLS); Perceived Health Status Visual Analogue Scale (1-

100mm); and Overall Health Related Quality of Life - Visual Analogue Scale (1-100mm). Individuals were also invited to take part in the re-test reliability arm of the study. Those who agreed to take part were invited to complete the questionnaires a second time, within 2-week interval.

Study measures

Preliminary version of the DQoL-OC: The preliminary version of the DQoL-OC contained 100 items related to QoL and utilised a 1-5 Likert scale format. The first section of the questionnaire asked participants about a number of relevant sociodemographic and caregiving aspects, namely; age; gender; ethnicity; schooling; marital status; work status; multiple caregiving; current diseases; relationship with the person being cared for; living or not with the person with dementia; time per day spent caregiving; number of days per week spent caregiving; and number of years of being a carer. Carers were also asked to report their subjective perceptions of their relatives' dementia: i.e. presence of neuropsychiatric symptoms, dementia stage (early, moderate, advanced), and levels of dependence. The DQoL-OC also had two open questions asking participants about the most relevant aspects of their QoL and any additional aspects that were not covered in the questionnaire.

World Health Organization Quality of Life Scale for Aging Population (WHOQOL-AGE): This is a QoL scale developed by the WHO for use with older people. It contains 13 Likert scale items (1-5) and was validated with a large sample of older adults living in European countries. It is considered a short, of easy completion, and robust QoL instrument, which contains areas of QoL that are specific for older adults (Caballero et al., 2013).

Satisfaction with Life Scale (SWLS): This is a well-established scale used to measure the global cognitive judgements of satisfaction with one's life. It contains 5 items and usually requires only about one minute of a respondent's time. It has been translated and validated into various languages and cultures and is often used with older populations (Diener, Emmons, Larson, & Griffin, 1985).

Perceived Health Status and Overall Health Related Quality of Life - Visual Analogue Scales (1-100mm): Perceived Health Status Visual Analogue Scale (PHS-VAS) and Overall Health Related Quality of Life Visual Analogue Scale (OHRQOL-VAS) were used to evaluate participants' perception about their state and quality of health (Bowling, 2005; Boer et al., 2004; Carlsson, 1983).

Relevance and practicality: Participants were invited to give their opinions about the DQoL-OC by answering on a 1-5 Likert scale with regards to relevance, length, difficulty, and word clarity. Family carers were also asked about the presence of any upsetting/distressing questions. They were asked to record the time taken to complete the DQoL-OC items and the total study booklet.

Data analysis

Questionnaire responses were uploaded in SPSS® 22 and a confidence interval of 95% ($p \leq 0.05$) was considered for all calculations. Eighteen negatively worded questions were firstly reversed. The analysis for patterns of missing data showed the presence of 1.41% of random missing data, which were replaced using multiple imputations (Allison, 2003; Brown, 2015). Descriptive statistics and normality curves were checked to identify signs of skewness and any floor or ceiling effects (≤15%) (Terweea et al., 2007). Approximately 10% of the whole dataset was randomly inspected for the presence of univariate and multivariate outliers, and for multicollinearity. Item-total correlation was calculated for the 100 items and the results of each item were checked prior to item removal.

Item reduction and factor extraction

Exploratory Factor Analysis (EFA) was carried out using Principal Axis Factor and Promax rotation aiming to explore the latent structure of the new QoL model and to retain a small but robust and meaningful set of items for the measurement of QoL of older family carers (Costello & Osborne, 2005; DeVellis, 2012). The suitability of the data for EFA was checked by inspecting the significance of the Bartlett test of Sphericity (Bartlett, 1954) and by inspecting the extent of Kaiser-Meyer-Oklin (KMO) (Dziuban & Shirkey, 1974; Kaiser, 1970; Kaiser & Caffey, 1965). Factor extraction was guided by parallel analysis (Watkins, 2000) and scree plot inspection (DeVellis, 2012; Tabachnick & Fidel, 2014). Items were excluded based on their item-total correlations (<0.3), communality scores (<0.32), and pattern matrix loading scores (<0.4) (Tabachnick & Fidel, 2014). Due to the large number of variables for the sample size obtained, EFA was carried out several times through a systematic and iterative process aiming to retain a meaningful and robust smaller set of items, which was finally submitted to psychometric evaluation (Costello & Osborne, 2005).

Psychometric evaluation

Validity: Concurrent validity was established by correlating the sum of the total scores of the final version of the DQoL-OC with the sum of the total scores of the other scales, using Pearson statistics. Previous studies suggest poor QoL and health outcomes in carers with the following characteristics: female; advanced age; spouses of the cared for; less educated; married; those currently working; white ethnic background; poor health; co-residing with cared for; those providing care for longer periods of time and for a longer period of time; carers for individuals in the advanced stages of dementia; those more dependent of care; and with uncontrolled dementia symptoms (Chan & Chui, 2011; Clay et al., 2013; Godwin et al., 2013; Hosseinpoor, Bergen, & Chatterji, 2013; Kim & Spillers, 2010; Papastavrou, Kalokerinou, Papacostas, Tsangari, & Sourtzi, 2007; Pinquart & Sorensen, 2011; Steptoe et al., 2015). These correlations were assessed using Spearman-rho coefficient.

Reliability: Internal consistency was measured using Cronbach alpha and the overall score for the final version of the DQoL-OC was expected to be >0.7 (Cronbach, 1951; Streiner, 2003). Test-Re-test reliability was established with Intra-Class Correlation coefficient (ICC).

Practicality and relevance measures: Items evaluating relevance, length, difficulty, word clarity, time to complete the scale, and presence of any upsetting/distressing questions were analysed descriptively.

Results

The study included 182 participants. Their mean age was 72.15 years old (SD=8.31), with 32.2% aged 80 or above (Table 1). The majority were female (65%), married (89.5%), white (96%), and with no qualification (28%). A total of 15% had a job outside caregiving and 3.3% reported having stopped work due to their caregiving responsibilities. Around half of the sample had at least one current disease affecting their own health (49%).

(Table 1)

The majority of carers were spouses (80%), living in the same house as their cared-for (83%), and had been providing care for between 1 to 6 years for their relatives with dementia (78%), and who had predominantly been diagnosed 1 to 6 years prior to the study (75%). A total of 55% of participants provided care for more than 12 hours a day and 89% provided care 6 to 7 days a week. In addition, around 17% of participants were providing care for more than one person at the time of the study.

Preliminary analysis of the 100 items demonstrated that the sum of the total QoL scores was normally distributed. Initial Cronbach's alpha for all items was 0.974. The majority of the items showed acceptable item-total correlation levels. Initial KMO suggested that the sample size was adequate (r=0.868) and the Bartlett's Test of Sphericity reached statistical significance (14024.523, p<0.001), confirming the suitability of the data for factor analysis.

Practicality and relevance

Participants (n=182) spent an average time of 32.43 minutes (±15.82) completing the first version of the scale containing 100 items. The majority of participants (74%) perceived this scale size as ‘about right’ in length. Mostly, carers commented on the questionnaire as being thorough and that it included all relevant items for the measurement of their QoL (72%). Carers also made suggestions on items that they felt could be modified or removed. These opinions informed decisions about item retention or removal.

Item reduction and factor extraction

After a series of EFA rotations, scree plot inspection, and parallel analysis, 22 scale items were retained for further psychometric evaluation, each with acceptable loading scores within a single factor solution (Table 2). Residuals representing the difference between the original correlation matrix and reproduced matrix were very close to zero for almost all items, demonstrating that the factor extracted accounted for a great deal of the variance in the original correlation matrix, and that this single factor was therefore the best choice to represent the original data. Together, these items represented an eigenvalue of 9.64, which explained 43.83% of the scale total variance, covering a wide range of QoL dimensions.

(Table 2)

The final set of 22 items provided a mean value of 63.74 (SD=16.36) and showed no skewness in overall total scores. Participants scores ranged from 27 to 101 points and the majority scored between 45 and 88 points (22-44: 12.9%; 45-66: 48.0%; 67-88: 31.6%; 89-110:7.6%).

Psychometric evaluation of the DQoL-OC 22-item scale

Validity

As hypothesized, results showed a significant and positive correlation between the DQoL-OC 22-item scores and the other scales’ scores, particularly with the WHOQOL-AGE (r=0.736; p<0.001). Other measures also had significant correlations with the DQoL-OC, but with lower correlation scores (SWLS: r=0.651, p<0.001; PHS-VAS: r=0.389, p<0.001; OHRQOL-VAS: r=0.444, p<0.001). Further correlation analysis showed that age was positively associated with QoL levels (r=0.175; p=0.019). In addition, female older carers (0.307; p<0.001), those caring for longer periods of time (-0.285; p<0.001), for more days a week (-0.091; p=0.007), and for people with uncontrolled dementia symptoms (0.256; p<0.001) had significantly lower levels of QoL. Carers for people in the advanced stages of dementia had significantly higher QoL scores when compared to the moderate and earlier stages (0.186; p=0.012). No statistically significant correlation was identified between the variables of; carers' qualification, ethnicity, co-residing, relationship status, other job, multiple caregiving, current diseases, relationship with cared for, time of caregiving (years), or the level of dependence of the cared for.

Reliability

The final scale version demonstrated excellent internal consistency (Cronbach α=0.936) as a result of good levels of inter-item correlation among almost all items. A total of 18 individuals took part in the test-re-test study. Analysis showed excellent and significant correlation among the two set of measurements (lower bound r =0.835; p<0.001), suggesting that the 22-item scale provides consistent outcomes over a short period of time. The final scale version is provided in Table 3.

(Table 3)

Discussion

This sequential exploratory mixed-methods study demonstrated the DQoL-OC 22-item scale as a robust age- and dementia caregiving-specific QoL tool for use with older family carers of people with dementia. It provides valid and reliable outcomes within a single factor structure, similar to other age-specific and multidimensional measures of subjective QoL for older people (Hyde et al., 2003). The 22-item structure represents various QoL domains which are relevant to older carers and to the wider older population, such as social relationships; financial situation; psychological health; independence; control over life event & freedom; leisure; social and solo activities; physical health; general health; energy and vitality; satisfaction with life and caregiving; identity; and life in general (Bowling, 2005a; Farquhar, 1995; Oliveira et al., 2016).

In line with previous recommendations for the development of QoL scales for older individuals (Hickey, Barker, McGee, & O'Boyle, 2005), although the DQoL-C can be considered a disease-specific HRQoL scale, it is not focused on just physical health or specific dementia symptoms. Such characteristics may well indicate that it is not necessary to use a generic HRQoL scale together with the DQoL-OC when measuring the QoL of older carers of people with dementia, as previously advised (Guyatt, Feeny, & Patrick, 1993), as a broad range of domains are already included in this scale. Moreover, the DQoL-OC also has two open questions, which gives older carers the opportunity to express the QoL aspects that are most important to them or haven't been covered in the questionnaire. These are not available in most other QoL scales. In addition, as none of the 22 items need reversing for final calculation of total scores, this should reduce the possibility of errors in calculating older carer's QoL if the scale is utilised in clinical practice.

The DQoL-OC was tested with older carers from a variety of backgrounds, with sociodemographic characteristics which are representative of the wider population of older carers in the UK (Carers Trust, 2011; Carers UK & Age UK, 2015; White, 2013). With regards to acceptability and practicality, older carers rated the test version containing 100 items as being 'about right' in length. Considering that the final scale was reduced to 22 items, problems with the length of the questionnaire are not anticipated in future use. It is also relevant to mention that the WHOQOL-AGE had its measurement design and practicality evaluated by a large sample of older adults (Caballero et al., 2013). The layout and measurement of the DQoL-OC, which are the same as the WHOQOL-AGE, were deemed acceptable by the experts and participants in this study. This might indicate that the newly developed scale is likely to be acceptable by older carers from different cultures and nationalities.

With regards to the DQoL-OC's psychometric properties, the high Cronbach's α score obtained suggests high consistency among all items within the 22-item scale, meaning that this item group reliably measures the same construct (Cronbach, 1951). Moreover, the excellent agreement scores identified between the two sets of measurements suggests that the final version of the DQoL-OC provides consistent and reliable outcomes over time (Bonett, 2002). Even though the test-re-test sample was modest, the high agreement scores identified are clinically important and suggest that the scale shows no substantial change in the construct over time. This indicates that the DQoL-OC provides better precision of single measurements, which is a required property for better tracking of changes in measurements in research or practice settings (Hopkins, 2000).

Because responsiveness is critically related to reliability outcomes (Hays & Hadorn, 1992), measurement tools with high reliability scores are therefore more likely to present good responses to changes in QoL. Comparison between the psychometric properties of the DQoL-OC and other scales developed for use with the general older population indeed suggests that the reliability scores of the DQoL-OC are higher than the other measures of QoL for use with the general population of older people (Bowling, Hankins, Windle, Bilotta, & Grant, 2013; Caballero et al., 2013; Hyde et al., 2003; The WHOQOL-OLD Group, 2011; The WHOQoL Group, 2005). Even though it was not possible to measure responsiveness to change within this study, the excellent reliability scores for internal consistency and test- re-test reliability suggest that the DQoL-OC is likely to be responsive to changes in QoL in future tests.

Furthermore, as statistically significant correlation scores were found between the DQoL-OC and other previously validated scales that measure the same WHOQOL-AGE QoL model, as well as other caregiving and sociodemographic variables known to be associated with this population's QoL, it is possible to conclude that the final version of the DQoL-OC successfully measures dimensions of QoL that are particularly relevant for older people who are carers (Guyatt et al., 1993; Streiner & Norman, 2003). The correlation between the WHOQOL-AGE and the SWLS in previous research (Caballero et al., 2013) are closely related to the value obtained from the correlation between the DQoL-OC and the SWLS, confirming the capacity of the DQoL-OC to measure the subjective QoL of older people appropriately. The significant lower levels of QoL found in older carers providing more hours per day and those providing care for more days per week corroborate those of previous literature (Carers Trust, 2011; Carers UK & Age UK, 2015).

Even though participants were mostly of full-time carers and with at least one disease currently affecting them, age and stage of dementia were positively associated with carers' self-reported QoL. These findings could be a result of psychological adaptation and an internal response shift resulting from years of caregiving experience and the need to accommodate day-to-day challenges to facilitate their own well-being (Rapkin & Schwartz, 2004; Sprangers & Schwartz, 1999). As with other validated tools for use with older people, the DQoL-OC contains items that are particularly relevant to this population and is sensitive to positive QoL appraisal despite possible physical impairment, for example. At this stage it is not possible to conclude that the DQoL-OC can identify a difference in how the tools measure QoL across the life course. However, these findings suggest that concepts and concerns related to QoL in later life are different from the general population. As such, our findings would suggest that age plays a significant role in the subjective appraisal of QoL as carers may adapt their perception of well-being as dementia progresses (Schneider & Stone, 2016).

More thorough statistical investigation of the scale should be carried out in the future to clarify these relationships.

Limitations

This study focused on identifying the optimal underlying structure of the DQoL-OC as well as providing a preliminary evaluation of its psychometric characteristics. Even though one of the justifications for the development of an age- and dementia-specific scale is that such scales are likely to be more responsive to change than general QoL scales, this study did not provide complete evidence of such a property. The study also did not provide evidence of discriminant validity against differing psychological constructs such as burden or depression, for example. Although the characteristics of the sample were consistent with the older carers' profile in other studies in the existing literature, these were not randomized and therefore generalization should be made with caution. Furthermore, older family carers from other ethnic minority backgrounds may conceptualize and appraise QoL differently, and therefore no conclusion about the suitability of the DQoL-OC for other ethnic groups is possible at this stage. The test-re-test sample size of the study was modest and results from this should again be considered with caution. Further tests with larger samples sizes should be carried out with a similar population in order to confirm the test-re-test reliability of the scale.

Implications to research and clinical practice

Despite its limitations, the use of the DQoL-OC is expected to provide more robust QoL outcomes than scales currently being used with this particular aged population, helping to improve the quality of the evidence resulting from studies and interventions aimed at evaluating and enhancing the QoL of these individuals. The DQoL-OC can be validly and reliably used in surveys with older carers, observational studies, epidemiological studies, service evaluations, and clinical audits, for example. By measuring older carers' QoL more accurately, adequate funding can be allocated to these individuals to afford appropriate

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interventions focused on improving those aspects of caregiving that are most likely to affect these individuals' lives. In addition, due to its high levels of reliability, this tool may be useful for detecting how much age-specific interventions can enhance the QoL of older carers QoL. As the DQoL-OC is a dementia and caregiving-specific scale, it has the benefit of providing information on the aspects of life and caregiving are associated with self-reported QoL, which is meaningful for clinical practice and care in health services or in the community. Rather than just focusing on reducing burden and stress, having a valid and reliable measure to quantify the QoL of older family carers will help clinicians and researchers to identify which people's lives are more affected by the negative aspects of caregiving in order to help them to live better. In addition, because it easy to use, older family carers can measure their own QoL and use this 'self-measurement' as a launch pad for discussion with service providers in order to improve their life as carers.

Conclusion

This research provided an in-depth and novel exploration of the aspects of QoL that are relevant to older family carers of people with dementia in the UK. A sequential and exploratory mixed-methods research approach was used to develop and evaluate the psychometric properties of the 'Dementia Quality of Life Scale for Older Family Carers' (DQoL-OC). The DQoL-OC has been established as a valid and reliable dementia caregiving and age-specific tool for the evaluation of the QoL of older family carers. Results demonstrate that the QoL of older family carers of people with dementia can be validly and reliably measured by a single-factor structure containing 22 items, measured on a 1 to 5 Likert scale. This work addresses a number of important issues relevant to further developments in QoL research with older family carers of people with dementia in the UK and the scale itself is considered to be a relevant and practical measure by the older family carers themselves.

Current policies and public reports advise that more research should be carried out to understand the older family carers' needs. The current study therefore provides valuable information to improve our understanding of the QoL of older family carers of people with dementia in the UK, a currently overlooked population of family carers. Considering the increasing population affected by dementia and the increasing involvement of older people in caring for these individuals, it is anticipated that the DQoL-OC will become a useful tool for further investigation into the QoL of this particular group of individuals in both the research arena and within health and social care services.

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Conflict of Interest

The authors declare that they have no competing interests.

Ethical approval

All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards. This study was approved by the Research and Ethics Committee of the Faculty of Medicine & Health Sciences, University of Nottingham, and of the National Health Service Ethics Committee, United Kingdom. Acceptable principles of ethical and professional conduct were followed, and research ethics board approval was obtained at all participating institutions. Informed consent was obtained from all individual participants included in the study.

Trial registration

NCT02463734

Permission to use the DQoL-OC©

Permission for use, adapt or reproduce the ‘Dementia Quality of Life Scale for Older family Carers’ (DQoL-OC$^{©}$) should sought with the authors.

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Tables

Table 1. Sample demographics for psychometric study.

Variables	Frequency	Percent
Age group		
60 to 69	13	11.0
70-79	67	56.8
80-89	32	27.1
>90	6	5.1
Gender		
Female	117	64.6
Male	64	35.4
Relationship status		
Single	6	3.3
Married	162	89.5
Partnership	3	1.7
Divorced	9	5.0
Widowed	1	0.6
Maximum qualification		
No qualifications	51	28.2
Vocational	41	22.7
GCSE's	31	17.1
A level	11	6.1
A diploma	16	8.8
University degree	19	10.5
Post-graduate degree	7	3.9
Missing	4	2.2
Work		
Yes	28	15.5
No	92	50.8
Stopped working to be a carer	6	3.3
Retired	55	30.4
Ethnicity		
White	174	96.1
Afro-Caribbean	2	1.1
Asian	2	1.1
Other ethnic group	1	0.6
I prefer not to say	2	1.1
Current disease(s)		
Yes	89	48.9
No	88	48.3
Missing	5	2.7

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Table 2. Factor Matrix (22 items)

	Factor loading	Mean	SD
I feel that I have lost control over the everyday events and decisions in my life	.790	2.87	1.24
How often do you feel burdened by the care demands?	.771	3.47	1.02
I feel that I have given up things that I enjoy because my family member needs me	.763		
I feel isolated	.757	2.48	1.12
I feel as if the boundaries between my own life and my caring role have become blurred	.736		
How satisfied are you with your overall quality of life?	.711	2.75	1.15
I feel as if my family member has changed from who she/he used to be and this affects me negatively	.691		
I feel exhausted	.671	2.23	1.06
I feel worried about the future	.649	2.48	1.17
I feel sad or depressed	.633	3.17	1.17
How often is caring physically hard on you?	.623	3.40	1.04
I feel worried about my health	.619	2.86	0.99
I feel I have no choice in being a carer	.618	2.28	1.36
How often does the caring negatively affect your relationships with family or/and friends?	.607	2.94	1.15
How often is your financial situation affected by the demands of caring?	.591	2.39	1.13
How satisfied are you with how well you can cope with your caring situation?	.573	3.46	0.96
How often have you had to change your own life and interests to fit around your family member's needs?	.560	3.98	0.88
How often do you experience a conflict of interest between what you want and what your family member wants?	.559	3.26	0.92
How satisfied are you with the relationship with the family member you care for?	.551	3.61	1.13
I feel guilty	.533	3.43	1.43
How satisfied are you with how well you can sleep?	.504	2.70	1.27
How satisfied are you with how much confidence you feel with your caring role?	.499	3.65	0.82

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Table 3. DQoL-OC 22-item scale

	Questions	Always	Frequently	Occasionally	Rarely	Never
1	How often does the caring negatively affect your relationships with family or/and friends?	1	2	3	4	5
2	How often is your financial situation affected by the demands of caring?	1	2	3	4	5
3	How often do you experience a conflict of interest between what you want and what your family member wants?	1	2	3	4	5
4	How often have you had to change your own life and interests to fit around your family member's needs?	1	2	3	4	5
5	How often is caring physically hard on you?	1	2	3	4	5
6	How often do you feel burdened by the care demands?	1	2	3	4	5
		Very frequently	**Frequently**	**Occasionally**	**Rarely**	**Never**
7	I feel worried about my health	1	2	3	4	5
8	I feel exhausted	1	2	3	4	5
9	I feel as if my family member has changed from who she/he used to be and this affects me negatively	1	2	3	4	5
10	I feel worried about the future	1	2	3	4	5
11	I feel I have no choice in being a carer	1	2	3	4	5
12	I feel that I have lost control over the everyday events and decisions in my life	1	2	3	4	5
13	I feel that I have given up things that I enjoy because my family member needs me	1	2	3	4	5
14	I feel as if the boundaries between my own life and my caring role have become blurred	1	2	3	4	5
15	I feel sad or depressed	1	2	3	4	5
16	I feel isolated	1	2	3	4	5
17	I feel guilty	1	2	3	4	5
		Very dissatisfied	**Dissatisfied**	**Neither satisfied nor dissatisfied**	**Satisfied**	**Very satisfied**
18	How satisfied are you with how much confidence you feel with your caring role?	1	2	3	4	5
19	How satisfied are you with how well you can cope with your caring situation?	1	2	3	4	5
20	How satisfied are you with the relationship with the family member you care for?	1	2	3	4	5
21	How satisfied are you with how well you can sleep?	1	2	3	4	5

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22	How satisfied are you with your overall quality of life?	1	2	3	4	5
	Open questions					
1	What do you think would most help to improve your quality of life as a carer?					
2	Is there anything else that is related to your quality of life that you feel hasn't been covered in this questionnaire?					

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