Dementia Quality of Life Scale for Older Family Carers (DQoL-OC©)

MANUAL FOR USERS

Authors: Deborah Oliveira, Catherine Vass and Aimee Aubeeluck

Correspondence to:

Deborah Cristina de Oliveira

Faculty of Medicine and Health Sciences

Division of Psychiatry and Applied Psychology

D Floor, Institute of Mental Health

Jubilee Campus, The University of Nottingham

Triumph Road, Nottingham

NG7 2TU

Tel: (+44) 0115 74 84306

E-mail: deborah.deoliveira@nottingham.ac.uk or oliveiradc.phd@gmail.com

NOTE: If you wish to use or modify the DQoL-OC scale/questionnaire, please contact Deborah Oliveira via the e-mails: oliveiradc.phd@gmail.com or deborah.deoliveira@nottingham.ac.uk

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1. Objectives of the DQoL-OC

The Dementia Quality of Life Scale for Older Family Carers (DQoL-OC) was primarily developed to measure the quality of life (QoL) of older people (aged ≥60 years old) providing care for their family members with dementia (e.g. Alzheimer's disease, vascular dementia) being cared for at home in the United Kingdom, in order to implement and assess interventions.

The DQoL-OC:

Is multidimensional. The DQoL-OC items reflect various aspects of life that are particularly relevant to older family carers of people with dementia, such as an individual's psychological and physical health; energy and vitality; independence, control, and freedom; leisure, social, and solo activities; identity and relationships; satisfaction with life and caregiving; and financial situation.

Measures QoL from a subjective perspective. The DQoL-OC measures the individual's perception about the quality of his/her life. It evaluates relevant QoL areas via cognitive and affective psychological mechanisms, and therefore it provides evidence about feelings and satisfaction with life.

Has been validated for use with OLDER family carers of people with dementia being cared for at home. Because subjective QoL appraisal and the relevance of several life areas change in later life, the QoL of older people needs to be measured using age-specific scales. At present, the DQoL-OC has only been validated for use with older family carers of people with dementia (aged ≥ 60) being cared for at home in the UK.

Is psychometrically sound. The DQoL-OC was developed from focus groups with older family carers of people with dementia being cared for at home in the UK. A panel of experts evaluated its face validity and relevance for use with older family carers of people with dementia. It has been tested in a psychometric study with older family carers, demonstrating excellent internal consistency, evidence of test-retest reliability, and convergent construct validity. Participants in the psychometric study also evaluated its practicality, content, and face validity. Because the scale has been developed and tested in

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the UK, it is advisable for the researcher to check the psychometric properties if the scale is used outside the UK and/or with a population with a different background.

2. Administration

The DQoL-OC was developed to be self-administered, and it contains two sections:

Section 1: 12 demographic/objective items.

Section 2: 22 subjective items related to QoL.

Section 1 requests demographic and objective information from the older carer, and each question should be treated independently. This information can be used in research to investigate the factors that may predict QoL in caregiving, for example. It may also be used by the practitioner or researcher to build up an overall picture of a carer. As this section does not in itself constitute a scale, the tool administrator is able to either omit questions or include additional questions that may be of interest.

Section 2 comprises the QoL scale itself, containing 22 items about different aspects of dementia-specific and subjective QoL. Because the scale contains an overall factor, it provides a single QoL score about the individual being assessed. Final QoL scores can also be divided into poor (22 to 44), poor to moderate (45 to 66), good (67 to 88), or very good (89 to 110) QoL. The DQoL-OC should take about five to 10 minutes to complete.

3. Calculation of results

Whether the tool is used in clinical practice or in research, the DQoL-OC users should calculate an overall QoL score from the sum of the points obtained from each item of the scale. However, as each item reflects a different domain of life, practitioners and researchers may well identify which areas of QoL may be suffering for the purpose of individual monitoring in line with interventions (Table 1).

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DQoL-OC items and their respective QoL areas

Items	General QoL areas										
	Relationships	Financial situation	Psychological health	Independence, control over life, freedom	Leisure, social and solo activities	Physical health	General health	Energy and vitality	Satisfaction with life and caregiving	Identity	Life in general
1	x										
2		x									
3				x							
4				x							
5					x						
6						x					
7							x				
8								x			
9			x								
10			x								
11				x							
12				x							
13				x							
14										x	
15			x								
16					x						
17			x								
18									x		
19			x								
20	x										
21								x			
22											x

Section 1: These are demographic and objective variables. They do not form part of the QoL score. They do not need to be totalled in any way but can be used to build up an overall picture of the individual being assessed.

Section 2: Each of the 22 item-scores can simply be added up to give a total score, without the need to reverse the scores of any items. If an individual has completed all the items in this section, total scores can range from 22 to 110. The higher the final scores, the higher the QoL level. This final score can also be divided by five, generating four QoL level groups: poor (22 to 44), poor to moderate (45 to 66), good (67 to 88), or very good (89 to 110).

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4. Entering data into a statistical package

If you are using a statistical package such as SPSS®, enter the items using the following procedure:

Section 1: Demographic and objective information

This information can be used to investigate the factors that may predict or are associated with the QoL of older family carers of people with dementia. Alternatively, this information can be used to gain an overall picture of a carer.

Note: Each item in this component should be treated independently, as these items do not constitute a scale.

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Procedure for coding the answers to each item of Section 1:

Item	Enter:
1a) What is your date of birth?	The number of years
1b) What is your gender?	1 for "Male" 2 for "Female" 3 for "I prefer not to say"
1c) What is the highest qualification you hold?	1 for "No qualifications" 2 for "Vocational" 3 for "GCSE" 4 for "A level" 5 for "Diploma" 6 for "University degree" 7 for "Postgraduate degree" 8 for "Other"
1d) Are you currently and regularly providing care for MORE THAN ONE PERSON in a non-formal caring capacity? (including children or grandchildren)	1 for "No" 2 for "Yes"
1e) Do you live with the family member you care for?	1 for "No" 2 for "Yes"
1f) What is your relationship with the family member you care for?	1 for "Spouse" 2 for "Son or daughter" 3 for "Sibling" 4 for "Other"
1g) Approximately how long have you being caring for your family member?	1 for "Less than 1 year" 2 for "1 to 3 years" 3 for "4 to 6 years" 4 for "7 to 10 years" 5 for "More than 10 years"
1h) On average, how many HOURS PER DAY do you care for your family member? ('care' means anything that you need to do for your family member because he/she is not able to do this on their own any more)	1 for "Less than 3 hours" 2 for "3 to 6 hours" 3 for "6 to 12 hours" 4 for "More than 12 hours"
1i) On average, how many DAYS PER WEEK do you care for your family member?	1 for "1 day" 2 for "2 to 3 days" 3 for "4 to 5 days" 4 for "6 to 7 days"
1j) How would you describe your family member's dementia symptoms at this moment? (e.g. regarding memory loss, difficulty in communicating, inability to reason, disorientation)	1 for "Totally uncontrolled" 2 for "Mostly uncontrolled" 3 for "Partially (un)controlled" 4 for "Mostly controlled" 5 for "Totally controlled"
1k) How would you describe the stage of your family member's dementia at the moment?	1 for "Initial stage" 2 for "Moderate stage" 3 for "Advanced stage"

If you are using the questionnaire with a different population, please code as necessary.

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Section 2: Quality of life evaluation

These items should be summed up to provide a total QoL score. Alternatively, the scale user may look at which item(s) is mostly suffering for the purpose of monitoring in line with appropriate intervention.

Procedure for coding the answers in each item of Section 2:

It is suggested that the data are entered into the computer for each item independently according to the option chosen by the participant (1=1; 2=2; 3=3; 4=4; 5=5). You can then create an additional variable that will automatically sum up all the 22 items for each participant, providing individual total QoL scores. You can then create a new variable, in which you code "1" for poor QoL (22 to 44 points), "2" for poor to moderate QoL (45 to 66 points), "3" for good QoL (67 to 88 points), and "4" for very good QoL (89 to 110 points). **Note:** Use the score of 99 to allow computer identification of missing values. If this scheme is used, care needs to be taken that these '99' values are recognized as excluded values and not included as data.

5. Psychometric properties of the DQoL-OC

5.1. Construction of the DQoL-OC

The DQoL-OC was developed from the input of older family carers themselves. Experts in the field of dementia, family caregiving, QoL, and scale development were also consulted prior to field testing.

Validity

Face validity, content validity, and practicality:

Content validity refers to the extent to which a measure represents all facets of the construct being measured, whereas face validity is the extent to which a test is subjectively viewed as covering the construct. Practicality concerns the usability of the new scale (e.g. length, difficulty). There is no statistical way of measuring face and content validities, but there are strategies that one can use to ensure these properties. For the DQoL-OC, focus groups were carried out with older family carers of people with dementia,

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and the scale items were created based on what these people judged as being important to their QoL. Items developed based on these findings had their content and face validity ensured by a panel of experts and were also reviewed by all individuals taking part in the psychometric study. These procedures helped to make sure that the scale is relevant for measuring the QoL of the target population while being easy to complete.

Convergent construct validity:

Convergent construct validity establishes the validity of a new tool by correlating scores from it with scores from a previously validated test measuring the same construct. The total scores of Section 2 of the DQoL-OC were correlated with the WHOQOL-AGE (Caballero et al., 2013), a well-validated QoL scale developed by the World Health Organization for use with older adults. Results revealed strong positive correlation between the two scales (Pearson's correlation coefficient of $r=0.736$; $p<0.001$), which confirms that the DQoL-OC measures QoL of older people.

Reliability

Reliability of the DQoL-OC was measured by calculating the internal consistency across all items and by carrying out a test retest. Internal consistency was assessed using Cronbach's α coefficient, which measures the overall correlation between items as well as the level of correlation between items within a scale. Reliability scores range from 0 to 1; Cronbach's α scores ≥ 0.7 are considered acceptable, and Cronbach's α scores ≥ 0.9 are considered excellent (Cronbach, 1951). The DQoL-OC scale had a Cronbach's α total score of 0.936 and ≥ 0.930 for item–total correlation in all 22 items.

Test-retest reliability assesses whether an instrument produces highly similar results on repeated administrations when respondents have not changed, thus providing evidence of stability of QoL measurement across a short period of time. For testing the DQoL-OC, retest questionnaires were completed within a period of two weeks following the psychometric study, and both set of measurements were then correlated using Intraclass Correlation coefficient (ICC). Results demonstrated strong and significant correlation among the two set

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of measurements scores (lower bound r =0.835; p<0.0001).

Note: Please contact the researchers if you intend to use the scale for any purpose. You should also contact us for any further details of item analysis if required. We are continuing to develop and standardize the DQoL-OC for use in the UK and globally.

References

CABALLERO, F. F., MIRET, M., POWER, M., CHATTERJI, S., TOBIASZ-ADAMCZY, B., KOSKINEN, S., LEONARDI, M., OLAYA, B., MARIA HARO, J. & AYUSO-MATEOS, J. L. 2013. Validation of an instrument to evaluate quality of life in the aging population: WHOQOL-AGE. *Health and Quality of Life Outcomes,* 11, 1-12.

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