


C-DEMQOL – MEASUREMENT OF QUALITY OF LIFE IN FAMILY CARERS OF PEOPLE WITH DEMENTIA

INSTRUCTION MANUAL FOR ADMINISTRATION

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C-DEMQOL – Interviewer administered version

Instructions for administration

1. Introducing the questionnaire:

- 1.1 Ensure the carer is comfortable and happy to participate. Begin the interview by providing further information about the questionnaire. Explain the purpose of the interview and responses to the questionnaire are used to find out about the carer's life and experiences of caring for a person with dementia. Highlight to the carer how their answers will be useful (e.g. answers could be used to inform planning and improve service provision to better support carers).
- 1.2 If the person with dementia is also present during the interview with the carer, explain that it is the *carer's* feelings and experiences that you are interested in. As the questionnaire asks sensitive questions to assess carer quality of life, ensure the carer is happy to complete the measure in front of the person with dementia. It can be useful to advise the carer about this in advance to allow the carer make alternative arrangements to answer questions in privacy.
- 1.3 Explain to the carer that you are trying to get an overall impression of how things have been for them, and how they have felt in their caring role during the past 4 weeks. The four week window can be challenging for some carers as they may feel it does not reflect their caring role. Explain, you are looking to capture a snapshot of their feelings in their caring role in the past four weeks. The caring role can fluctuate for many carers, therefore in order to get an overall view of the caring journey including the positives and challenges, we ask for their feelings in the last four weeks.
- 1.4 Explain that not all questions may apply to the carer or the person they care for, but you ask everyone the same questions. State that there are no right or wrong answers, so the carer should be as open as possible and should try to answer all questions to the best of their judgement.
- 1.5 Reassure the carer that it is completely acceptable for them to feel upset by some of the questions. Ask them to let you know if they need to take a break at any time and explain that you will go through the questions at their own pace.
- 1.6 Read the instructions verbatim on the front of the questionnaire. Ask the carer if they have any questions before starting the questionnaire.

2. Administering the questionnaire items:

- 2.1 Begin each section of the questionnaire by reading the introduction and any examples exactly as they are written.
- 2.2 Read aloud each individual question and the response options verbatim.
- 2.3. When the carer has indicated his or her response, mark it on the questionnaire. Mark only one response for each question. If a question does not apply to the carer or the person they care for, write N/A (Not Applicable) next to the question.

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2.4. If the carer does not or cannot answer a question (for any reason), record the response as missing.

2.5. At the end of the interview go back to any missed questions.

3. Debriefing after the interview:

3.1. Explain that all questions have now been answered.

3.2. Ask whether the carer has any questions that he or she would like to ask. Answer any questions and thank the carer for taking part.

4. General queries and possible responses:

4.1 The carer does not wish to complete the questionnaire:

Remind the carer that participation is entirely voluntary. They are being asked to complete the questionnaire because it will help to understand more about carers' quality of life. If they still do not want to participate stop the interview and thank the carer.

4.2 The carer stops completing the questionnaire because he/she does not understand a question or set of responses:

Specific prompts for not understanding or querying are given on the next page. In general if the carer does not understand a particular question, re-read it verbatim, but do not re-phrase the question. If the carer does not understand the response options, re-read the response options verbatim but do not re-phrase them. The question and the response options can be re-read as many times as is necessary, but if it is clear that the carer does not understand code as missing.

4.3 Carer asks you to interpret a question:

Specific prompts for not understanding or querying are given on the next page. In general re-read the item verbatim. Do not try to explain an item. Suggest that the carer base his/her answer on what he/she thinks the question means. Re-phrasing or interpreting a question can bias results. It is very important that the questions are read verbatim and only the standard prompts are used.

4.4 Carer answers “don't know” or wants to miss out a question:

Acknowledge that it can be hard to choose a response, but encourage the carer to choose the response option that most applies to him/her. If a carer wants to miss out an item, explain to the carer that all the questions are very important. They should try to answer all of the questions. If the carer still does not want to answer a particular item, reassure the carer that it is alright, then go on to the next item. If the carer feels a question is not applicable to them, mark as N/A.

5. Possible queries and responses – specific:

5.1 If the carer answers simply “yes” instead of choosing one of the five response options:

- Repeat the response options and ask him/her to choose one.

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- If the person gives two response options, ask them to choose one and record it. If a carer feels their response is between the two, it can be helpful to prompt, in the past four weeks which response is more reflective of their feelings. If unable to answer, code as missing.

- If necessary repeat the question verbatim.

5.2 If the carer answers simply “no” instead of choosing one of the five response options:

- Repeat the response options and ask him/her to choose.
- If necessary repeat the question verbatim.
- If the carer feels it is not applicable code as N/A otherwise code as missing.

5.3 If the carer responds using their own phrase or form of words that is not one of the response options:

- Repeat the question and the response options verbatim and ask them to choose one of the response options.
- If they still don't use one of the response options but are answering in a way that is relevant to the question, reiterate that they need to choose one of the four response options.
- If they still fail to choose one of the response options, then accept their answer, but don't score it, mark the questionnaire as missing and move on to the next questions.

5.4 If the carer misunderstands question (ie answering something else entirely):

- Repeat question and response options verbatim.
- If the person still appears not to understand the question go on to the next question and code as missing.

5.5 If person explicitly queries what a question means:

- Do not re-phrase or interpret any question.

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- Repeat question and response options verbatim.
- Suggest that he/she bases their answer on what he/she think it means.
- If the person is still querying or appears not to understand go on to the next question and reassure him/her that they're doing very well and its fine to go on to the next question.
- You can return to the question at the end of the session.

5.6 If person refuses to answer a question:

- Accept his/her refusal and reassure the person that it is alright not to answer. Go on to the next question.

6. Scoring C-DEMQOL Questionnaire

6.1 Manually scoring C-DEMQOL

Apply the score to each response as indicated in figure 1.

Response option 1 = 5

Response option 2 = 4

Response option 3 = 3

Response option 4 = 2

Response option 5 = 1

For example: very good = 5; mostly good = 4; satisfactory = 3; quite poor = 2; very poor = 1.

No reverse scoring is needed. For all items, a higher score indicates higher quality of life. If there are no missing responses, total all items for an overall score of quality of life. Higher scores indicate higher quality of life.

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Participant ID: Date:

C-DEMQOL
A measure of carer quality of life
(formatted for self-report)

PURPOSE
This questionnaire is designed to find out about your life and experiences of being a carer of a person with dementia.

INSTRUCTIONS
Please think of how things have been and how you have felt **in your caring role in the past 4 weeks**. Of course, there might have been good and bad days, but we want to capture a snapshot of how you have felt on a typical day during the past month. For each question, choose **one option** that best describes how you feel and mark it by putting a cross in the box, as shown

Here is an example question:

My own physical health in the past 4 weeks has been...

very good
 mostly good
 satisfactory
 quite poor
 very poor

Please remember:

- There are no right or wrong answers, so please be as open as you can, and try to answer all the questions to the best of your judgement.
- If you feel that a question does not apply to you or to the person you care for, write "N/A" (stands for Not Applicable) next to the question.

CARER RESPONSIBILITIES AND PERSONAL NEEDS

First, we would like to know how you feel about your **caring responsibilities**, which may include managing medications, providing help with washing and dressing, medical visits or social outings, and also anything you need to do if the person with dementia is in a care home.

We would also like to know how your caring responsibilities affect your **ability to have time for yourself**, and doing the things that you enjoy or want to do, in particular activities that are **important to your quality of life**.

1. Carrying out my caring tasks and responsibilities takes up...

very little of my energy
 some of my energy
 a considerable amount of my energy
 most of my energy
 all of my energy

2. Being a carer for the person with dementia takes up...

very little of my time → Score = 5
 some of my time → Score = 4
 a considerable amount of my time → Score = 3
 most of my time → Score = 2
 all of my time → Score = 1

Figure 1. Scores for item response.

6.2 Calculation quality of life with missing items

A total quality of life score can be calculated if at least five responses are scored in each subdomain. Total “scores are estimated as the average of the present responses multiplied by the number of items in the scale (30 for the total scale, and six for each subscale). We therefore recommend mean replacement for missing responses when sum scores are computed” (1).

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6.3 Scoring calculator

A scoring calculator is available to download at BSMS CDS website. Data collected can be entered and will be scored automatically.

When entering missing data, ensure it is entered using the code MISS.

The scoring manual can be accessed and downloaded from the website under “manual and storing guides, C-DEMQOL measure calculator”. You can access the website at: <https://www.bsms.ac.uk/research/neuroscience/cds/research/cdemqol.aspx>

7. Further information and enquiries

Please visit our website at

<https://www.bsms.ac.uk/research/neuroscience/cds/research/cdemqol.aspx> for further details and to access our publication detailing the development of C-DEMQOL.

For any further information or queries, please contact the team:

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References

1. Brown, A., Page, T.E., Daley, S., Farina, N., Basset, T., Livingston, G., Budgett, J., Gallaher, L., Feeney, Y., Murray, J., Bowling, A., Knapp, M., Banerjee, S., 2019. Measuring the quality of life of family carers of people with dementia: development and validation of C-DEMQOL. Quality of Life Research. <https://doi.org/10.1007/s11136-019-02186-w>

End.