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QOLLI-F[®] Quality of Life in Life-Threatening Illness – Family Carer Version

The Quality of Life in Life Threatening Illness – Family Carer Version (QOLLI-F) was developed by Dr. Robin Cohen of the Division of Palliative Care, Departments of Oncology and Medicine, McGill University, along with Dr. A. Leis, Dr. D. Kuhl, Dr. C. Charbonneau, Dr. P. Ritvo and Dr. F.D. Ashbury, in order to measure the quality of life of the family carers of palliative care patients

The development and origin of items is detailed in the following publication:
Cohen SR et al. (2006). QOLLI-F: Measuring family carer quality of life, Palliative Medicine 20(8):755-67. The qualitative study from which the items were derived is not yet published, but has been presented at conferences (see attached list).

IF YOU WANT TO USE QOLLI-F

You are free to use QOLLI-F. We ask only that you return to us the completed **User and Information Registration Form** (attached) and acknowledge the source of QOLLI-F in any publications or professional activities where it is used. If you use QOLLI-F, we would appreciate any QOLLI-F data you could make available to us to help us learn more about its properties. Any feedback you might have about QOLLI-F would be gratefully received.

SCORING QOLLI-F

The present version of QOLLI-F includes 16 items, plus Question A, as well as 2 experimental items (#17 and #18) that are not presently included in the scoring. These 3 items do not form part of the calculation of the score of QOLLI-F. Question A is a single-item measure of overall quality of life. It is useful as a validity check for QOLLI-F. Items 17 and 18 are for experimental purposes only, to determine whether they have a better distribution than items 9 and 15 respectively.

All 16 QOLLI-F items, QOLLI-F subscale scores, and the QOLLI-F Total Score have a possible range from '0' to '10'. In order for '0' to always indicate the worst situation and '10' the best situation, the following items must have the scores transposed (T) prior to calculating the subscale and Total scores or data analysis.

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Prior to calculating QOLLTI-F scores or data analysis, transpose (or reverse) the scores for Items # 3, 4, 14, 15, and 16 by subtracting the raw score from 10 for each subject.

QOLLTI-F SUB-SCALES

There are 7 QOLLTI-F subscales. They are named as follows. Each subscale score is the mean of the items included in that subscale.

	Subscale	# of items	Item # (T= transposed)
1	Environment	2	1, 2
2	Patient State	1	3 (T)
3	Carer's own state	5	4 (T), 5, 6, 7, 8
4	Carer's outlook	3	9, 10, 11
5	Quality of care	2	12, 13
6	Relationships	2	14 (T), 15 (T)
7	Financial worries	1	16 (T)

QOLLTI-F Total Score

The QOLLTI-F Total score is the mean of the 7 subscale scores.

QOLLTI-P (Patient) (MQOL-Revised)

We have developed a measure of the quality of life of palliative care patients, QOLLTI-P. This is a revised version of the McGill Quality of Life Questionnaire (*Cohen et al, Cancer, 77 (1996) 576-586; Palliative Medicine, 11 (1997) 3-20*) and is available upon request (not yet published).

Please feel free to contact me if you have any questions. Please don't forget to let me know the strengths and weaknesses that you find with QOLLTI-F.

Sincerely,

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QOLLI – F[©]
QUALITY OF LIFE DURING SERIOUS ILLNESS – FAMILY CARERS

STUDY IDENTIFICATION #: _____

DATE: _____

Day/Month/Year

PLEASE READ THESE INSTRUCTIONS BEFORE ANSWERING

There are no right or wrong answers. Honest answers will be most helpful. This questionnaire includes a series of statements that we would like you to respond to by choosing a number from 0 to 10.

These numbers extend from one extreme answer (for example, “not at all”) to its opposite (for example, “completely”).

Please choose or circle the number between 0 and 10 that best represents how you feel.

Note that sometimes the best situation is at the 0 end of the scale, and sometimes the best situation is at the 10 end of the scale.

When the best situation is at the 0 end, the text will look like this.

We are interested in learning about your OVERALL quality of life, so please consider any issues that affect you, even if they are not related to your caregiving role.

A blank line in a sentence refers to the person you are caring for. For confidentiality, please do not write their name on the line.

A. Considering all parts of my life - physical, emotional, social, spiritual, and financial - over the past two days (48 hours) my quality of life has been:

very poor 0 1 2 3 4 5 6 7 8 9 10 excellent

1. Over the past two days (48 hours) I was satisfied with the place _____ was staying (home, hospital, other):
not at all 0 1 2 3 4 5 6 7 8 9 10 completely

2. Over the past two days (48 hours) I had the privacy I wanted:
not at all 0 1 2 3 4 5 6 7 8 9 10 completely

3. *Over the past two days (48 hours) the condition of _____ was distressing to me:*
not often 0 1 2 3 4 5 6 7 8 9 10 *always*

4. *Over the past two days (48 hours) the amount of control I had over my life was:*
not a problem 0 1 2 3 4 5 6 7 8 9 10 *a huge problem*

5. Over the past two days (48 hours) I had time to take care of myself:
never 0 1 2 3 4 5 6 7 8 9 10 always

6. Over the past two days (48 hours) I was able to think clearly:
not often 0 1 2 3 4 5 6 7 8 9 10 always

7. Over the past two days (48 hours) physically I felt:
extremely poor 0 1 2 3 4 5 6 7 8 9 10 extremely good

8. Over the past two days (48 hours) emotionally I felt:
extremely poor 0 1 2 3 4 5 6 7 8 9 10 extremely good

9. Over the past two days (48 hours) being able to provide care or company for _____ made me feel good:

rarely or never 0 1 2 3 4 5 6 7 8 9 10 always

10. Over the past two days (48 hours) I was comforted by my outlook on life, faith, or spirituality:

not at all 0 1 2 3 4 5 6 7 8 9 10 completely

11. Presently I feel that my life has meaning:

very little meaning 0 1 2 3 4 5 6 7 8 9 10 very much meaning

For questions 12 and 13, if you did not make important decisions or need health care in the past two (2) days, please answer for the last few times that you did.

12. Over the past two days (48 hours) I agreed with the way decisions were made for _____:

not at all 0 1 2 3 4 5 6 7 8 9 10 completely

13. Over the past two days (48 hours) the quality of health care we received was:

not satisfactory 0 1 2 3 4 5 6 7 8 9 10 extremely good

14. *Over the past two days (48 hours) I felt my interaction with _____ was:*

very comfortable 0 1 2 3 4 5 6 7 8 9 10 *stressful*

15. *Over the past two days (48 hours), overall, I felt my interaction with the other people most important to me was:*

very comfortable 0 1 2 3 4 5 6 7 8 9 10 *stressful*

16. *Over the past two days (48 hours) my financial situation has been stressful:*

not at all 0 1 2 3 4 5 6 7 8 9 10 *completely*

17. Over the past two days (48 hours), I was comfortable providing care:

not at all 0 1 2 3 4 5 6 7 8 9 10 completely

18. Over the past two days (48 hours) overall, I felt my relationships with the people most important to me made my quality of life:

much worse 0 1 2 3 4 5 6 7 8 9 10 *much better*

What do you most want the care team to know?

Do you want us to give this information to the team? Please circle: Yes No

Thank you!