



**NATIONAL MEDICAL CENTER AND
BECKMAN RESEARCH INSTITUTE**

Quality of Life Family Version

Dear Colleague:

The Quality of Life (FAMILY VERSION) is a thirty-seven item ordinal instrument that measures the Quality of Life of a family member caring for a patient with cancer. This tool can be useful in clinical practice as well as for research. This instrument can be administered by mail or in person. A Hispanic version of this questionnaire is also included.

Directions: The caregiver is asked to read each question thoroughly and decide if he/she agrees with the statement or disagrees. The caregiver is then asked to circle a number to indicate the degree to which he/she agrees or disagrees with the statement according to the word anchors on each end of the scale.

The scoring should be based on a scale of 0 = worst outcome to 10 = best outcome. Several items have reverse anchors and therefore when you code the items you will need to reverse the scores of those items. For example, if a subject circles "3" on such an item, ($10-3 = 7$) thus you would record a score of 7. The items to be reversed are 1-4, 6, 13-20, 22, 24-29 and 33. Subscales can be created for analysis purposes by adding all of the items within a subscale and creating a mean score.

The family version of the QOL tool is an adaptation of the patient version QOL tool. The instrument was revised and tested from 1994-1998 in a study of 219 family caregivers of cancer patients. The test-retest reliability was $r=.89$ and internal consistency was $\alpha=.69$. Factor analysis confirmed the 4 QOL domains as subscales for the instrument. Psychometric data is provided in the patient version QOL tool (see letter which accompanies Patient Version QOL Tool).

You are welcome to use this instrument in your research/clinical practices to gain information about Quality of Life of caregivers. You have permission to duplicate this tool.

Good luck with your research!!

Sincerely,

A handwritten signature in black ink that reads "Betty Ferrell PhD, FAAN".

Betty R. Ferrell, PhD, FAAN
Research Scientist

A handwritten signature in black ink that reads "Marcia Grant DNSc, FAAN".

Marcia Grant, DNSc, FAAN
Research Scientist
Director Nursing Research & Education

References

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QOL Scale - FAMILY

Directions: We are interested in knowing how your experience of having a loved one with cancer affects your Quality of Life. Please answer all of the following questions based on your life **at this time**. Please circle the number from 0 - 10 that best describes your experiences:

Physical Well Being

To what extent are the following a problem for you:

1. **Fatigue**
no problem 0 1 2 3 4 5 6 7 8 9 10 **severe problem**

2. **Appetite changes**
no problem 0 1 2 3 4 5 6 7 8 9 10 **severe problem**

3. **Pain or aches**
no problem 0 1 2 3 4 5 6 7 8 9 10 **severe problem**

4. **Sleep changes**
no problem 0 1 2 3 4 5 6 7 8 9 10 **severe problem**

5. **Rate your overall physical health**
extremely 0 1 2 3 4 5 6 7 8 9 10 **excellent**
poor

Psychological Well Being Items

6. How difficult is it for you to **cope** as a result of your family member's disease and treatment?
none at all 0 1 2 3 4 5 6 7 8 9 10 **extremely**

7. How good is your **overall quality of life**?
extremely 0 1 2 3 4 5 6 7 8 9 10 **excellent**
poor

8. How much **happiness** do you feel?
none at all 0 1 2 3 4 5 6 7 8 9 10 **completely**

9. Do you feel like you are **in control** of things in your life?
not at all 0 1 2 3 4 5 6 7 8 9 10 **completely**
10. How **satisfying** is your life?
not at all 0 1 2 3 4 5 6 7 8 9 10 **completely**
11. How is your present ability to **concentrate or to remember** things?
extremely poor 0 1 2 3 4 5 6 7 8 9 10 **excellent**
12. How **useful** do you feel?
not at all 0 1 2 3 4 5 6 7 8 9 10 **extremely**
13. How distressing was your family member's **initial diagnosis** for you?
not at all 0 1 2 3 4 5 6 7 8 9 10 **extremely**
14. How distressing were your family member's **cancer treatments**
(i.e. chemotherapy, radiation, BMT or surgery) for you?
not at all 0 1 2 3 4 5 6 7 8 9 10 **extremely**
15. How distressing has the time been **since your family member's treatment ended?**
not at all 0 1 2 3 4 5 6 7 8 9 10 **extremely**
16. How much **anxiety** do you have?
not at all 0 1 2 3 4 5 6 7 8 9 10 **severe**
17. How much **depression** do you have?
not at all 0 1 2 3 4 5 6 7 8 9 10 **severe**
18. Are you **fearful of a second cancer** for your family member?
not at all 0 1 2 3 4 5 6 7 8 9 10 **extremely**
19. Are you **fearful of recurrence** of your family member's cancer?
not at all 0 1 2 3 4 5 6 7 8 9 10 **extremely**
20. Are you **fearful of the spreading (metastasis)** of your family member's cancer?
not at all 0 1 2 3 4 5 6 7 8 9 10 **extremely**

21. Rate your **overall psychological well being**?
extremely poor 0 1 2 3 4 5 6 7 8 9 10 **excellent**

Social Concerns

22. How distressing has your family member's illness been for your **family**?
not at all 0 1 2 3 4 5 6 7 8 9 10 **extremely**

23. Is the amount of **support** you receive from others sufficient to meet your needs?
not at all 0 1 2 3 4 5 6 7 8 9 10 **completely**

24. To what degree has your family member's illness or treatment interfered with your **personal relationships**?
not at all 0 1 2 3 4 5 6 7 8 9 10 **completely**

25. To what degree has your family member's illness or treatment interfered with your **sexuality**?
not at all 0 1 2 3 4 5 6 7 8 9 10 **completely**

26. To what degree has your family member's illness or treatment interfered with your **employment**?
no problem 0 1 2 3 4 5 6 7 8 9 10 **severe problem**

27. To what degree has your family member's illness or treatment interfered with your **activities at home**?
no problem 0 1 2 3 4 5 6 7 8 9 10 **severe problem**

28. How much **isolation** is caused by your family member's illness or treatment?
none 0 1 2 3 4 5 6 7 8 9 10 **complete**

29. How much **financial burden** resulted from your family member's illness or treatment?
none 0 1 2 3 4 5 6 7 8 9 10 **extreme**

30. Rate your **overall social well being**?
extremely poor 0 1 2 3 4 5 6 7 8 9 10 **excellent**

Spiritual Well Being

31. Is the amount of support you receive from **religious activities** such as going to church or temple sufficient to meet your needs?
not at all 0 1 2 3 4 5 6 7 8 9 10 **completely**
32. Is the amount of support you receive from **personal spiritual activities** such as prayer or meditation sufficient to meet your needs?
not at all 0 1 2 3 4 5 6 7 8 9 10 **completely**
33. How much **uncertainty** do you feel about your family member's future?
none at all 0 1 2 3 4 5 6 7 8 9 10 **extreme**
34. Has your family member's illness made **positive changes** in your life?
none at all 0 1 2 3 4 5 6 7 8 9 10 **extreme**
35. Do you have a **purpose/mission** for your life or a reason for being alive?
Not at all 0 1 2 3 4 5 6 7 8 9 10 **completely**
36. How **hopeful** do you feel?
none at all 0 1 2 3 4 5 6 7 8 9 10 **extremely**
37. Rate your **overall spiritual well being**
extremely poor 0 1 2 3 4 5 6 7 8 9 10 **excellent**

Escala sobre la Calidad de Vida - FAMILIA

Instrucciones: Estamos interesados en saber cómo la experiencia de tener un pariente con cáncer afecta su calidad de vida. Favor de contestar todas las preguntas a continuación basándose en su vida en este momento.

Favor de marcar con un círculo el número del 0 - 10 que mejor describa sus experiencias:

Bienestar Físico

Hasta qué punto son los siguientes un problema para usted:

1. **Fatiga/Agotamiento**
ningún problema 0 1 2 3 4 5 6 7 8 9 10 problema severo
2. **Cambios de apetito**
ningún problema 0 1 2 3 4 5 6 7 8 9 10 problema severo
3. **Dolor**
ningún problema 0 1 2 3 4 5 6 7 8 9 10 problema severo
4. **Cambios en dormir**
ningún problema 0 1 2 3 4 5 6 7 8 9 10 problema severo
5. Clasifique su salud física en general
sumamente mala 0 1 2 3 4 5 6 7 8 9 10 excelente

Asuntos Referentes al Bienestar Psicológico

6. ¿Qué tan difícil es para usted **contender/lidiar** con su vida como resultado de tener un pariente con cáncer?
nada difícil 0 1 2 3 4 5 6 7 8 9 10 muy difícil
7. ¿Qué tan buena es su **calidad de su vida**?
excelente 0 1 2 3 4 5 6 7 8 9 10 sumamente mala
8. ¿Cuánta **felicidad** siente usted?
absolutamente ninguna 0 1 2 3 4 5 6 7 8 9 10 muchísima

9. ¿Se siente en **control** de las cosas en su vida?
nada en lo absoluto 0 1 2 3 4 5 6 7 8 9 10 completamente
10. ¿Hasta qué punto le **satisface** su vida?
Absolutamente nada 0 1 2 3 4 5 6 7 8 9 10 completamente
11. ¿Cómo clasificaría su capacidad actual para **concentrarse o recordar** cosas?
sumamente mala 0 1 2 3 4 5 6 7 8 9 10 excelente
12. ¿Qué tan **útil** se siente?
nada en lo absoluto 0 1 2 3 4 5 6 7 8 9 10 muchísimo
13. ¿Cuánta aflicción/angustia le causo el **diagnostico inicial** de su paciente?
nada en lo absoluto 0 1 2 3 4 5 6 7 8 9 10 muchísimo
14. ¿Cuánta aflicción/angustia le causo los **tratamientos del el cancer** de su pariente (Quimioterapia, radiación, transplante de medula ósea o cirugía)?
nada en lo absoluto 0 1 2 3 4 5 6 7 8 9 10 muchísimo
15. ¿Cuánta aflicción/angustia ha tenido desde que **termino el tratamiento de su pariente**?
nada en lo absoluto 0 1 2 3 4 5 6 7 8 9 10 muchísimo
16. ¿Cuánta **ansiedad/desperación** siente usted?
nada en lo absoluto 0 1 2 3 4 5 6 7 8 9 10 muchísimo
17. ¿Cuánta **depresión/decaimiento** siente usted?
nada en lo absoluto 0 1 2 3 4 5 6 7 8 9 10 muchísimo
18. Tiene **miedo/temor que le de un segundo cáncer** a su pariente?
nada en lo absoluto 0 1 2 3 4 5 6 7 8 9 10 muchísimo
19. Tiene **miedo/temor que le recurra el cáncer** a su pariente?
nada en lo absoluto 0 1 2 3 4 5 6 7 8 9 10 muchísimo

20. Tiene miedo/temor que se le propage el cáncer a su pariente?
 nada en lo absoluto 0 1 2 3 4 5 6 7 8 9 10 muchísimo

21. ¿Clasifique su **estado psicológico en general**?
 Sumamente malo 0 1 2 3 4 5 6 7 8 9 10 excelente

Preocupaciones Sociales

22. ¿Cuánta **aflicción/angustia** le ha ocasionado la enfermedad de su pariente?
 nada en lo absoluto 0 1 2 3 4 5 6 7 8 9 10 muchísimo

23. ¿Es el **nivel de apoyo** que recibe de parte de otros suficiente para satisfacer sus necesidades?
 nada en lo absoluto 0 1 2 3 4 5 6 7 8 9 10 muchísimo

24. ¿Hasta qué punto ha interferido la enfermedad y el tratamiento de su pariente con sus **relaciones personales**?
 nada en lo absoluto 0 1 2 3 4 5 6 7 8 9 10 muchísimo

25. ¿Hasta qué punto ha impactado la enfermedad y el tratamiento de su pariente con su **sexualidad**?
 nada en lo absoluto 0 1 2 3 4 5 6 7 8 9 10 muchísimo

26. Hasta qué punto ha impactado la enfermedad y el tratamiento de su pariente con su **empleo**?
 nada en lo absoluto 0 1 2 3 4 5 6 7 8 9 10 muchísimo

27. ¿Hasta qué punto ha interferido la enfermedad y el tratamiento de su pariente con **sus actividades en el hogar**?
 nada en lo absoluto 0 1 2 3 4 5 6 7 8 9 10 muchísimo

28. ¿Cuánto **aislamiento** le atribuye usted a la enfermedad y al tratamiento de su pariente?
 ninguno 0 1 2 3 4 5 6 7 8 9 10 muchísimo

29. ¿Cuánta **carga económica** ha incurrido usted como resultado de la enfermedad y el tratamiento de su pariente?
 Ninguna 0 1 2 3 4 5 6 7 8 9 10 muchísima

30. ¿Clasifique su **estado social en general**?
 sumamente malo 0 1 2 3 4 5 6 7 8 9 10 excelente

Bienestar Espiritual

31. ¿Es suficiente el nivel de apoyo que recibe de sus **actividades religiosas**, tales como ir a la iglesia o a el templo para satisfacer sus necesidades?
 nada en lo absoluto 0 1 2 3 4 5 6 7 8 9 10 muchísimo

32. ¿Es suficiente el nivel de apoyo que recibe de sus **actividades religiosas**, tales como rezar, ir a la iglesia o al templo?
 nada en lo absoluto 0 1 2 3 4 5 6 7 8 9 10 muchísimo

33. ¿Cuánta **incertidumbre/duda** siente usted en cuanto al futuro de su pariente?
 nada de incertidumbre 0 1 2 3 4 5 6 7 8 9 10 Mucha incertidumbre

34. ¿Hasta qué punto la enfermedad de su pariente ha realizado **cambios positivos** en la vida de usted?
 muchísimo nada en lo absoluto 0 1 2 3 4 5 6 7 8 9 10

35. ¿Siente usted una sensación de **propósito/misión** en cuanto a su vida o una razón por la cual se encuentra vivo?
 muchísimo nada en lo absoluto 0 1 2 3 4 5 6 7 8 9 10

36. ¿Cuánta **esperanza** siente usted?
 muchas esperanzas 0 1 2 3 4 5 6 7 8 9 10 nada de esperanzas

37. ¿Clasifique **en general su estado espiritual**?
 sumamente malo 0 1 2 3 4 5 6 7 8 9 10 excelente