



**NATIONAL MEDICAL CENTER AND
BECKMAN RESEARCH INSTITUTE**

Quality of Life Patient/Cancer Survivor Version

Dear Colleague:

The Quality of Life Instrument (CANCER PATIENT/CANCER SURVIVOR VERSION) is a forty one-item ordinal scale that measures the Quality of Life of a cancer patient. This tool can be useful in clinical practice as well as for research. This instrument can be administered by mail or in person. The instrument originated in our pain research and has been recently adapted for use in long term cancer survivors. A Hispanic version of this questionnaire is also included.

Directions: The patient is asked to read each question and decide if he/she agrees with the statement or disagrees. The patient 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: 1-7, 9, 16-27, & 29-34 and 38. Subscales can be created for analysis purposes by adding all of the items within a subscale and creating a mean score.

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

The QOL instrument is based on previous versions of the QOL instrument by researchers at the City of Hope National Medical Center (Grant, Padilla, and Ferrell). This instrument was revised in cancer survivorship studies and includes 41 items representing the four domains of quality of life including physical well being, psychological well being, social well being and spiritual well being. A study was conducted in 1995 to evaluate the psychometrics of this revised instrument as a mail survey to the membership of the National Coalition for Cancer Survivorship. This survey included a Demographic tool, the QOL tool and the FACT-G tool developed by Cella. Psychometric analysis was performed on 686 respondents including measures of reliability and validity. Two measures of reliability included re-test and internal consistency. In order to perform test re-test reliability, a randomly selected sample of 150 subjects who completed the initial QOL survey were asked to repeat this tool approximately two weeks later. 110 of the 150 subjects responded for an overall response of 73%. Of the 110 respondents, only those with complete data sets on all variables were used (N=70). The overall QOL-CS tool test re-test reliability was .89 with subscales of physical $r=.88$, psychological $r=.88$, social $r=.81$, spiritual $r=.90$. The second measure of reliability was

computation of internal consistency using Cronbach's alpha co-efficient as a measure of agreement between items and subscales. Analysis revealed an overall $r=.93$. Subscale alphas ranged from $r=.71$ for spiritual well being, $r=.77$ for physical, $r=.81$ for social, and $r=.89$ for psychological. Several measures of validity were used to determine the extent to which the instrument measured the concept of QOL in cancer survivors. The first method of content validity was based on a panel of QOL researchers and nurses with expertise in oncology. The second measure used stepwise multiple regression to determine factors most predictive of overall QOL in cancer survivors. Seventeen variables were found to be statistically significant accounting for 91% of the variance in overall QOL. Variables accounting for the greatest percentage were control, aches and pain, uncertainty, satisfaction, future, appearance and fatigue. The fourth measure of validity used Pearson's correlations to estimate the relationships between the subscales of the QOL-CS and the subscales of the established FACT-G tool. There was moderate to strong correlation between associated scales including QOL-CS Physical to FACT Physical ($r=.74$), QOL-CS Psych to FACT Emotional ($r=.65$), QOL Social to FACT Social ($r=.44$). The overall QOL-CS correlation with the FACT-G was $.78$. Additional measures of validity included correlations of individual items of the QOL-CS tool, Factor Analysis, and Construct Validity discriminating known groups of cancer survivors. This psychometric data is reported in reference #1 and 2.

Good luck with your research!!



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References from City of Hope Cancer Survivorship Studies:

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3. Ferrell BR. "The Quality of Lives: 1,525 Voices of Cancer." Oncology Nursing Forum, 1996; 23(6):907-916.
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5. Ferrell B, Hassey-Dow K. "Quality of Life Among Long-Term Cancer Survivors." Oncology, 1997; 11(4):565-576.
6. Juarez G, Ferrell BR, Borneman T. "Perceptions of Quality of Life in Hispanic Patients with Cancer." Cancer Practice, 1998; 6(6):318-324.
7. Hassey-Dow K, Ferrell B, Haberman M. "The Meaning of QOL in Cancer Survivors." Oncology Nursing Forum, 1999; 26(3):519-528.
8. Hassey-Dow K, Ferrell BR, Haberman MR, & Eaton L. "The meaning of quality of life in cancer survivorship." Oncology Nursing Forum, 1999; 26(3):519-528.
9. Ferrell B, Virani R, Smith S, Juarez G. "The Role of Oncology Nursing to Ensure Quality Care for Cancer Survivors: A Report Commissioned by the National Cancer Policy Board and Institute of Medicine." Oncology Nursing Forum, 2003; 30(1):E1-11 (online exclusive).

Note: Additional references from City of Hope Breast Cancer and Ovarian Cancer survivorship studies are listed under those headings.

Quality of Life Scale/CANCER PATIENT/CANCER SURVIVOR

Directions: We are interested in knowing how your experience of having 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 describe 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. **Aches or pain**

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. **Constipation**

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

6. **Nausea**

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

7. **Menstrual changes or fertility**

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

8. **Rate your overall physical health**

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

Psychological Well Being Items

9. How difficult is it for you to **cope** today as a result of your disease and treatment?

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

10. How good is your **quality of life**?

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

11. How much **happiness** do you feel?

none at all 0 1 2 3 4 5 6 7 8 9 10 **a great deal**

12. 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**

13. How **satisfying** is your life?

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

14. How is your present ability to **concentrate or to remember** things?

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

15. How **useful** do you feel?

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

16. Has your illness or treatment caused changes in your **appearance**?

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

17. Has your illness or treatment caused changes in your **self concept** (the way you see yourself)?

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

How distressing were the following aspects of your illness and treatment?

18. Initial diagnosis

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

19. Cancer treatments (i.e. chemotherapy, radiation, or surgery)

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

20. Time since my treatment was completed

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

21. How much anxiety do you have?

none at all 0 1 2 3 4 5 6 7 8 9 10 **a great deal**

22. How much depression do you have?

none at all 0 1 2 3 4 5 6 7 8 9 10 **a great deal**

To what extent are you fearful of:

23. Future diagnostic tests

no fear 0 1 2 3 4 5 6 7 8 9 10 **extreme fear**

24. A second cancer

no fear 0 1 2 3 4 5 6 7 8 9 10 **extreme fear**

25. Recurrence of your cancer

no fear 0 1 2 3 4 5 6 7 8 9 10 **extreme fear**

26. Spreading (metastasis) of your cancer

no fear 0 1 2 3 4 5 6 7 8 9 10 **extreme fear**

Social Concerns

27. How distressing has illness been for your **family**?

not at all 0 1 2 3 4 5 6 7 8 9 10 **a great deal**

28. 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 **a great deal**

29. Is your continuing health care interfering with your **personal relationships**?

not at all 0 1 2 3 4 5 6 7 8 9 10 **a great deal**

30. Is your **sexuality** impacted by your illness?

not at all 0 1 2 3 4 5 6 7 8 9 10 **a great deal**

31. To what degree has your illness and treatment interfered with your **employment**?

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

32. To what degree has your illness and treatment interfered with your **activities at home**?

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

33. How much **isolation** do you feel is caused by your illness or treatment?

none 0 1 2 3 4 5 6 7 8 9 10 **a great deal**

34. How much **financial burden** have you incurred as a result of your illness and treatment?

none 0 1 2 3 4 5 6 7 8 9 10 **a great deal**

Spiritual Well Being

35. How important to you is your participation in **religious activities** such as praying, going to church?

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

36. How important to you are other **spiritual activities** such as meditation?

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

37. How much has your **spiritual life** changed as a result of cancer diagnosis?

less 0 1 2 3 4 5 6 7 8 9 10 **more important**
important

38. How much **uncertainty** do you feel about your future?

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

39. To what extent has your illness made **positive changes** in your life?

none at all 0 1 2 3 4 5 6 7 8 9 10 **a great deal**

40. Do you sense a **purpose/mission** for your life or a reason for being alive?

none at all 0 1 2 3 4 5 6 7 8 9 10 **a great deal**

41. How **hopeful** do you feel?

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

**Escala Sobre la Calidad de Vida/DOLOR A RAZON DE CANCER – PACIENTE/
EL SOBREVIVIENTE DEL CANCER**

Direcciones: Estamos interesados en saber como la experiencia de tener cancer afecta su calidad de vida. Favor de contestar todas las preguntas a continuacion basandose en su vida **en esta momento**.

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

Bienestar Fisico

Hasta que punto son los siguientes un problema para usted:

1. Fatiga/Agotamiento

ningun problema	0	1	2	3	4	5	6	7	8	9	10	Problema severo
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2. Cambios de apetito

ningun problema	0	1	2	3	4	5	6	7	8	9	10	Problema severo
------------------------	---	---	---	---	---	---	---	---	---	---	----	------------------------

3. Dolor (es)

ningun problema	0	1	2	3	4	5	6	7	8	9	10	Problema severo
------------------------	---	---	---	---	---	---	---	---	---	---	----	------------------------

4. Cambios en dormir

ningun problema	0	1	2	3	4	5	6	7	8	9	10	Problema severo
------------------------	---	---	---	---	---	---	---	---	---	---	----	------------------------

5. Estrenimiento

ningun problema	0	1	2	3	4	5	6	7	8	9	10	Problema severo
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6. Nausea/asco

ningun problema	0	1	2	3	4	5	6	7	8	9	10	Problema severo
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7. Cambios en la Menstruacion/Fertilidad

ningun problema	0	1	2	3	4	5	6	7	8	9	10	Problema severo
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8. Clasifique su salud fisica en general:

sumamente mala	0	1	2	3	4	5	6	7	8	9	10	excelente
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Asuntos Referentes al Bienestar Psicologico

9. Que tan dificil es para usted **contender/lidiar** con su vida como resultado de su enfermedad y tratamiento?

nada 0 1 2 3 4 5 6 7 8 9 10 **muy dificil**
dificil

10. Que tan buena es la **calidad de su vida**?

sumament 0 1 2 3 4 5 6 7 8 9 10 **excelente**
e mala

11. Cuanta **felicidad** siente usted?

absolutame 0 1 2 3 4 5 6 7 8 9 10 **muchisima**
nte ninguna

12. Se siente **en control** de las cosas en su vida?

nada en lo 0 1 2 3 4 5 6 7 8 9 10 **completamente**
absoluto

13. Hasta que punto **le satisface** su vida?

absolutame 0 1 2 3 4 5 6 7 8 9 10 **completamente**
nte nada

14. Como clasificaria su capacidad actual para **concentrarse o recordar** cosas?

sumament 0 1 2 3 4 5 6 7 8 9 10 **excelente**
e mala

15. Que tan **util** se siente?

nada en lo 0 1 2 3 4 5 6 7 8 9 10 **muchisimo**
absoluto

16. Ha causado su enfermedad o tratamiento cambios en su **apariencia**?

nada en lo 0 1 2 3 4 5 6 7 8 9 10 **muchisimo**
absoluto

17. Ha ocasionado su enfermedad o tratamiento cambios en su **autoconcepto** (la manera en que usted se percibe/se ve)?

nada en lo 0 1 2 3 4 5 6 7 8 9 10 **muchisimo**
absoluto

Cuanta afliccion/angustia le ocasiono los siguientes aspectos de su enfermedad y tratamiento?

18. El diagnostico inicial

nada de 0 1 2 3 4 5 6 7 8 9 10 **muchisima**
afliccion/angustia **afliccion/angustia**

19. Los tratamientos de cancer (tales como la quimioterapia, radiacion o cirugia)

nada de 0 1 2 3 4 5 6 7 8 9 10 **muchisima**
afliccion/angusti **afliccion/angustia**
a

20. El tiempo desde que su tratamiento termino

nada de 0 1 2 3 4 5 6 7 8 9 10 **muchisima**
afliccion/angusti **afliccion/angustia**
a

21. Cuanto ansiedad/desperacion tiene?

nada de 0 1 2 3 4 5 6 7 8 9 10 **muchisima**
afliccion/angustia **afliccion/angustia**

22. Cuanto depresion/decaimiento siente usted?

nada de 0 1 2 3 4 5 6 7 8 9 10 **muchisima**
afliccion/angustia **afliccion/angustia**

Hasta que punto tiene miedo/temor a:

23. Futuros examenes diagnosticos (tales como rayos-x o exploracion ultrasonica)

nada en lo 0 1 2 3 4 5 6 7 8 9 10 **muchisimo**
absoluto

24. Un segundo cancer

nada en lo 0 1 2 3 4 5 6 7 8 9 10 **muchisimo**
absoluto

25. Retorno de su cancer

nada en lo 0 1 2 3 4 5 6 7 8 9 10 **muchisimo**
absoluto

26. Que se le extienda (metastasis) el cancer

nada en lo 0 1 2 3 4 5 6 7 8 9 10 **muchisimo**
absoluto

Preocupaciones Sociales

27. Cuanta afliccion/angustia le ha ocasionado su enfermedad a su **familia**?

nada en lo absoluto 0 1 2 3 4 5 6 7 8 9 10 **muchisimo**

28. Es suficiente el nivel de **apoyo** que usted recibe de parte de otros para satisfacer sus necesidades?

nada en lo absoluto 0 1 2 3 4 5 6 7 8 9 10 **muchisimo**

29. Interfiere su cuidado continuo de salud con sus **relaciones personales**?

nada en lo absoluto 0 1 2 3 4 5 6 7 8 9 10 **muchisimo**

30. Ha sido impactado/afectado su **sexualidad** por su enfermedad?

nada en lo absoluto 0 1 2 3 4 5 6 7 8 9 10 **muchisimo**

31. Hasta que punto ha interferido su enfermedad y tratamiento con su **empleo**?

nada en lo absoluto 0 1 2 3 4 5 6 7 8 9 10 **muchisimo**

32. Hasta que punto ha interferido su enfermedad y tratamiento con sus **actividades/quehaceres en el hogar**?

nada en lo absoluto 0 1 2 3 4 5 6 7 8 9 10 **muchisimo**

33. Cuanto **aislamiento** le atribuye usted a su enfermedad y tratamiento?

ninguno 0 1 2 3 4 5 6 7 8 9 10 **muchisimo**

34. Cuanta **carga economica** ha tenido como resultado de su enfermedad y tratamiento?

ninguna 0 1 2 3 4 5 6 7 8 9 10 **muchisima**

Bienestar Espiritual

35. Que tan importante es para usted su participacion en **actividades religiosas** tales como rezar, ir a la iglesia o al templo?

nada importante 0 1 2 3 4 5 6 7 8 9 10 **muy importante**

36. Que importantes le son a usted otras **actividades espirituales** tales como la meditacion?

nada importante 0 1 2 3 4 5 6 7 8 9 10 **muy importante**

37. Como ha cambiado su vida espiritual como resultado del **diagnostico de cancer**?

nada en lo absoluto 0 1 2 3 4 5 6 7 8 9 10 **muchisimo**

38. Cuanta **incertidumbre/duda** siente usted en cuanto el futuro?

nada de incertidumbre 0 1 2 3 4 5 6 7 8 9 10 **Mucha incertidumbre**

39. Hasta que punto su enfermedad a realizado **cambios positivos** en su vida?

nada en lo absoluto 0 1 2 3 4 5 6 7 8 9 10 **muchisimo**

40. Siente usted una sensacion de **proposito/mision** en cuanto a su vida o una razon por la cual se encuentra vivo?

nada en lo absoluto 0 1 2 3 4 5 6 7 8 9 10 **muchisimo**

41. Cuanta **esperanza** siente usted?

nada de esperanzas 0 1 2 3 4 5 6 7 8 9 10 **muchas esperanzas**