



**NATIONAL MEDICAL CENTER AND
BECKMAN RESEARCH INSTITUTE**

Quality of Life Instrument -- Ovarian Cancer Patient Version

Dear Colleague:

The Quality of Life Instrument (OVARIAN CANCER PATIENT VERSION) is a forty-five item ordinal scale that measures the Quality of Life of an ovarian 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 was later extended to several cancer survivorship studies. It was adapted for use in ovarian cancer survivors in 1996 and revised in 2002. A Spanish version of this questionnaire is also included.

Directions: The patient is asked to read each question and decide if 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: 1-8, 10, 17-28, & 30-37, 41 and 45. 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 or clinical practice. You have permission to duplicate this tool. This QOL instrument is based on previous versions of the QOL instrument by researchers at the City of Hope National Medical Center. This instrument was revised in cancer survivorship studies and includes 45 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 mailed 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 test/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 ($r=.65$), and 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 published in references #1 and 2.

The instrument was modified to create an ovarian cancer version in 1996 and evaluated in 153 ovarian cancer survivors (reference #4). In 2001 Cindy Melancon, the founder and editor of "Conversations! The Newsletter for Those Fighting Ovarian Cancer," contacted Dr. Betty Ferrell to suggest that the correspondence from the newsletter be analyzed in order to share the experience of her readership with others. The archived correspondence was sent to the City of Hope. A total of 21,806 letters, cards, and e-mails were received, reflecting 8 years of "conversations" between Cindy and her readers. All data were read, and significant responses were bracketed and coded according to the individual items within the four domains of the Quality of Life Ovarian Cancer Patient Instrument. After completing this research, the investigators compared the findings of the studies with the individual items of the Quality of Life Ovarian Cancer Patient Instrument, and made revisions to reflect the most prominent concerns of ovarian cancer patients, thus creating this revised version of the Quality of Life Ovarian Cancer Patient Instrument (references 6-9).

Good luck with your research!



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Quality of Life Scale/OVARIAN CANCER PATIENT

Directions: We are interested in knowing how your experience of having ovarian 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. General 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

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

8. Neuropathy (i.e. burning/tingling pain or loss of sensation)

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

9. Rate your overall physical health

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

Psychological Well Being Items

10. 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

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

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

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

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

13. 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**

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

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

15. 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

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

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 **appearance**?

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

18. 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?

19. **Initial diagnosis**

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

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

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

21. **Time since treatment** was completed

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

22. How much **anxiety** do you have?

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

23. 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:

24. **Future diagnostic tests**

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

25. **A second cancer**

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

26. **Recurrence or spreading (metastasis)** of your cancer

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

27. **Dying**

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

Social Concerns

28. 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**

29. 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**

30. 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**

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

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

32. To what degree are you concerned about your **fertility**?

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

33. 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**

34. 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**

35. 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**

36. 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**

37. How concerned are you about your **relatives being diagnosed** with cancer?

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

Spiritual Well Being

38. 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

39. 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

40. 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

41. 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

42. 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**

43. 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**

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

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

45. To what extent have you experienced **“survivorship guilt?”** (i.e. feeling guilty that you have survived while others have not)

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

Escala Sobre la Calidad de Vida/DOLOR A RAZON DE CANCER - PACIENTE

Direcciones: Estamos interesados en saber cómo su experiencia de tener cancer afecta su Calidad de Vida. Por favor conteste todas las siguientes preguntas, basada en su vida en este momento.

Por favor ponga un círculo en el número 0-10 que mejor describa sus experiencias:

Bienestar Físico

Hasta que punto lo siguiente es un problema para usted:

1. Fatiga/Agotamiento

no es problema	0	1	2	3	4	5	6	7	8	9	10	problema severo
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2. Cambios de apetito

no es problema	0	1	2	3	4	5	6	7	8	9	10	problema severo
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3. Dolor(es)

no es problema	0	1	2	3	4	5	6	7	8	9	10	problema severo
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4. Cambios al dormir

no es problema	0	1	2	3	4	5	6	7	8	9	10	problema severo
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5. Estreñimiento

no es problema	0	1	2	3	4	5	6	7	8	9	10	problema severo
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6. Nausea/asco

no es problema	0	1	2	3	4	5	6	7	8	9	10	problema severo
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7. Cambios en la Menstruación

no es problema	0	1	2	3	4	5	6	7	8	9	10	problema severo
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8. **Neuropatía** (ardor/hormigueo doloroso ó pérdida de sensación):

no es problema 0 1 2 3 4 5 6 7 8 9 10 **problema severo**

9. Evalúe su salud física en general

extremadamente pobre 0 1 2 3 4 5 6 7 8 9 10 **excelente**

Asuntos Referentes al Bienestar Psicologico

10. ¿Qué tan difícil es para usted **sobrellevar** el día de hoy como resultado de su enfermedad y tratamiento?

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

11. ¿Qué tan buena es su **calidad de su vida**?

extremadamente pobre 0 1 2 3 4 5 6 7 8 9 10 **excelente**

12. ¿Cuánta **felicidad** siente?

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

13. ¿Hasta qué grado siente usted que **controla** las cosas que pasan en su vida?

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

14. ¿Qué tan satisfactoria es su vida?

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

15. ¿Cómo es su habilidad en el presente para **concentrarse y recordar** cosas?

extremadamente pobre 0 1 2 3 4 5 6 7 8 9 10 **excelente**

16. ¿Qué tan **útil** se siente?

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

17. ¿Su enfermedad o tratamiento han causado cambios en su **aparencia**?

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

18. ¿Su enfermedad o tratamiento han causado cambios en el **concepto que tiene de sí misma**? (la manera como se vé a sí misma)

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

¿Qué tan angustiosos fueron los siguientes aspectos de su enfermedad y tratamiento?

19. **El diagnóstico inicial**

No fué angustioso 0 1 2 3 4 5 6 7 8 9 10 **muy angustioso**

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

No fué angustioso 0 1 2 3 4 5 6 7 8 9 10 **muy angustioso**

21. **Cumplimiento de su tratamiento**

No fué angustioso 0 1 2 3 4 5 6 7 8 9 10 **muy angustioso**

22. ¿Cuanta **ansiedad/desesperacion** tiene?

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

23. ¿Cuánta **depresión** tiene?

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

Hasta que punto tiene miedo/temor a:

24. **Pruebas de diagnóstico** (tales como rayos-x o exploracion ultrasonica) en el futuro

No tengo miedo 0 1 2 3 4 5 6 7 8 9 10 **miedo extremo**

25. **Un segundo cancer**

No tengo Miedo 0 1 2 3 4 5 6 7 8 9 10 **miedo extremo**

26. Recurrencia o que se desparrame (metástasis) su cáncer

no tengo miedo 0 1 2 3 4 5 6 7 8 9 10 **miedo extremo**

27. El morir

nada de miedo 0 1 2 3 4 5 6 7 8 9 10 **miedo extremo**

Preocupaciones Sociales28. ¿Qué tan angustiada ha sido su enfermedad para su **familia**?

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

29. ¿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 **gran cantidad**

30. ¿Interfiere su cuidado de salud continuous con sus **relaciones personales**?

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

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

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

32. ¿Hasta que grado le preocupa su **fertilidad**?

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

33. ¿Hasta qué grado su enfermedad y tratamiento han interferido con su **empleo**?

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

34. ¿Hasta qué grado su enfermedad y tratamiento han interferido con sus **actividades/quehaceres en el hogar**?

nada en lo absolute 0 1 2 3 4 5 6 7 8 9 10 **gran cantidad**

35. ¿Cuánto **aislamiento** le atribuye usted a su enfermedad y tratamiento?

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

36. ¿Cuánta **carga financiera** ha enfrentado como resultado de su enfermedad y tratamiento?

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

37. ¿Que tanto le preocupa el **diagnostico de cancer de su pariente**?

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

Bienestar Espiritual

38. ¿Qué 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**

39. ¿Qué tan importantes son para usted otras **actividades espirituales** tales como la meditacion?

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

40. ¿Cuánto ha cambiado su vida espiritual como resultado de su **diagnóstico de cancer**?
Es:

menos importante 0 1 2 3 4 5 6 7 8 9 10 **más importante**

41. ¿Qué tan **inseguro** se siente de su futuro?

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

42. ¿Hasta que punto su enfermedad a hecho **cambios positivos** en su vida?

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

43. ¿Siente que tiene un **propósito/misión** en la vida o una razón para estar viva?

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

