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 ($r=0.74$), QOL-CS Psych to FACT Emotional ($r=0.65$), and QOL Social to FACT Social ($r=0.44$). The overall QOL-CS correlation with the FACT-G was $0.78$. 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!

Betty R. Ferrell, RN, PhD, FAAN
Research Scientist

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

City of Hope National Medical Center
1500 E. Duarte Road
Duarte, CA 91010
Email: bferrell@coh.org
mgrant@coh.org
References from City of Hope Ovarian Cancer studies:


7. Ferrell BR, Smith SL, Cullinane CA, Melancon CH. “Psychological Well Being and Quality of Life in Ovarian Cancer Survivors.” Accepted for publication by *CANCER* (2003).


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

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

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

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

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
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
   distressing

21. **Time since treatment** was completed

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

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

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

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

less important  0 1 2 3 4 5 6 7 8 9 10  more important
41. How much **uncertainty** do you feel about your future?

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

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

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

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

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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

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

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

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

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

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

7. Cambios en la Menstruación
   - no es problema
   - 0 1 2 3 4 5 6 7 8 9 10 problema severo
8. **Neuropatía** (ardor/hormigueo doloroso ó perdida de sensacion):

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

9. Evalúe su salud física en general

| extremadamente probre | 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 dificil |

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

| extremadamente probre | 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 probre | 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 apariencia?

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

18. ¿Su enfermedad o tratamiento han causado cambios en el concepto que tiene de sí misma? (la manera como se ve 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 fue angustioso 0 1 2 3 4 5 6 7 8 9 10 muy angustioso

20. Los tratamientos de cáncer (tales como la quimioterapia, radiación o cirugía)

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

21. Cumplimiento de su tratamiento

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

22. ¿Cuánta ansiedad/desesperación tiene?

nada 0 1 2 3 4 5 6 7 8 9 10 muchísima

23. ¿Cuánta depresión tiene?

nada 0 1 2 3 4 5 6 7 8 9 10 muchísima

Hasta que punto tiene miedo/temor a:

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

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

25. Un segundo cáncer

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

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**Preocupaciones Sociales**

28. ¿Qué tan angustiosa ha sido su enfermedad para su familia?

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

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

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

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32. ¿Hasta qué grado le preocupa su fertilidad?

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

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

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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. ¿Qué 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 participación 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 meditación?

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 ha 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
44. ¿Qué tan llena de esperanza se siente?

| sin esperanza | 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 | muy llena de esperanza |

45. ¿Hasta que grado ha sentido "La culpa de sobrevivir"?
(Por ejemplo. Sentirse culpable que usted ha sobrevivido, mientras otras no)

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