Instrument Title: Quality of Life Patient/Cancer Survivor Version (QOL-CSV)

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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 $r = 0.93$. Subscale alphas ranged from $r = 0.71$ for spiritual well being, $r = 0.77$ for physical, $r = 0.81$ for social, and $r = 0.89$ 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 ($r = 0.65$), 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 reported in reference #1 and 2.

Good luck with your research!!

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References from City of Hope Cancer Survivorship Studies:


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 difficult

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

10. How good is your quality of life?

extremely poor

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

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 poor

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

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 distressing

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

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

not at all distressing

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

20. Time since my treatment was completed

not at all distressing

0 1 2 3 4 5 6 7 8 9 10 very 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 important | 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 | very important |

36. 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 |

37. 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 |

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

| not at all uncertain | 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 | very 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 hopeful | 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 | very hopeful |
Escala Sobre la Calidad de Vida/DOLOR A RAZON DE CANCER – PACIENTE/EL SOBREVIVIENTE DEL CANCER

**Direcciones:** Estamos interesados en saber cómo la experiencia de tener 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 (es)**
   - **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. **Estreñimiento**
   - **ningún problema**
   - 0 1 2 3 4 5 6 7 8 9 10 Problema severo

6. **Náusea/asco**
   - **ningún problema**
   - 0 1 2 3 4 5 6 7 8 9 10 Problema severo

7. **Cambios en la Menstruación/Fertilidad**
   - **ningún problema**
   - 0 1 2 3 4 5 6 7 8 9 10 Problema severo

8. **Clasifique su salud física en general:**
   - **sumamente mala**
   - 0 1 2 3 4 5 6 7 8 9 10 excelente
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?

   sumamente buena   0 1 2 3 4 5 6 7 8 9 10 excelente
e mala

11. Cuanta felicidad siente usted?

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

12. 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

13. Hasta que punto le satisface su vida?

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

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

   sumamente mala   0 1 2 3 4 5 6 7 8 9 10 excelente

15. Que tan util se siente?

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

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

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

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

   nada en lo absoluto   0 1 2 3 4 5 6 7 8 9 10 muchisimo
Cuanta afliccion/angustia le ocasiono los siguientes aspectos de su enfermedad y tratamiento?

18. El diagnostico inicial

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

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

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

20. El tiempo desde que su tratamiento termino

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

21. Cuanto ansiedad/desesperacion tiene?

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

22. Cuanto depresion/decaimiento siente usted?

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

Hasta que punto tiene miedo/temor a:

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

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

24. Un segundo cancer

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

25. Retorno de su cancer

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

26. Que se le extienda (metastasis) el cancer

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

27. Cuánta aflicción/angustia le ha ocasionado su enfermedad a su familia?

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

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  muchísimo

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  muchísimo

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  muchísimo

31. Hasta qué 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  muchísimo

32. Hasta qué 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  muchísimo

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

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

34. Cuánta carga económica ha tenido como resultado de su enfermedad y tratamiento?

   ninguna  0 1 2 3 4 5 6 7 8 9 10  muchísima
**Bienestar Espiritual**

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

<table>
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<tr>
<th>nada importante</th>
<th>0 1 2 3 4 5 6 7 8 9 10 muy importante</th>
</tr>
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</table>

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

<table>
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<tr>
<th>nada importante</th>
<th>0 1 2 3 4 5 6 7 8 9 10 muy importante</th>
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37. Como ha cambiado su vida espiritual como resultado del diagnóstico de cáncer?

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<tr>
<th>nada en lo absoluto</th>
<th>0 1 2 3 4 5 6 7 8 9 10 muchísimo</th>
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38. Cuánta incertidumbre/duda siente usted en cuanto el futuro?

<table>
<thead>
<tr>
<th>nada de incertidumbre</th>
<th>0 1 2 3 4 5 6 7 8 9 10 Mucha incertidumbre</th>
</tr>
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39. Hasta que punto su enfermedad ha realizado cambios positivos en su vida?

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

<table>
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<tr>
<th>nada en lo absoluto</th>
<th>0 1 2 3 4 5 6 7 8 9 10 muchísimo</th>
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41. Cuánta esperanza siente usted?

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<tr>
<th>nada de esperanzas</th>
<th>0 1 2 3 4 5 6 7 8 9 10 muchas esperanzas</th>
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