



**NATIONAL MEDICAL CENTER AND
BECKMAN RESEARCH INSTITUTE**

Quality of Life Instrument - Breast Cancer Patient Version

Dear Colleague:

The Quality of Life Instrument (BREAST CANCER PATIENT VERSION) is a forty-six item ordinal scale that measures the Quality of Life of a breast 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. It is based on our previous research and was adapted to represent the special QOL needs of breast cancer survivors.

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: 1-7, 9, 10, 17-29, 31, 33-39 & 43. 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 breast cancer patients. You have permission to duplicate this tool. If possible we would like copies of your data so that we may include it in our database to continue evaluating the tool.

The QOL Breast Cancer instrument is based on previous versions of the QOL instrument by researchers at the City of Hope National Medical Center. The revised instrument includes 46 items representing the four domains of quality of life including physical well being, psychological well being, social well being and spiritual well being. The study was conducted as a mail survey to the membership of the National Coalition for Cancer Survivorship. The total N was 686 and 294 of these were breast cancer survivors. 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 ($r=.65$), 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 references 1 and 2.

The instrument has also been used in breast cancer survivors in several City of Hope studies (references 3-8).

Good luck with your research!!

Sincerely,



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References from City of Hope studies:

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2. Ferrell BR, Hassey-Dow K, Leigh S, Ly J, Gulasekaram P. "Quality of life in long-term cancer survivors." Oncology Nursing Forum, 1995; 22(6):915-922.
3. Ferrell BR, Grant M, Funk B, Garcia N, Otis-Green S, Schaffner MLJ. "Quality of life in breast cancer." Cancer Practice, 1996; 4(6):331-340.
4. Hassey-Dow K, Ferrell BR, Leigh S, Ly J, Gulasekaram P. "An evaluation of the quality of life among long-term survivors of breast cancer." Breast Cancer Research and Treatment, 1996; 39:261-273.
5. Ferrell BR, Grant MM, Funk B, Otis-Green S, Garcia N. "Quality of life in breast cancer survivors as identified by focus groups." Psycho-Oncology, 1997; 6:13-23.
6. Ferrell BR, Grant M, Funk B, Otis-Green S, Garcia N. "Quality of life in breast cancer Part I: Physical and social well being." Cancer Nursing, 1997; 20(6):398-408.
7. Ferrell BR, Grant M, Funk B, Otis-Green S, Garcia N. "Quality of life in breast cancer Part II: Psychological and spiritual well being." Cancer Nursing, 1998; 21(1):1-9.
8. Ferrell BR, Grant M, Funk B, Otis-Green S, Garcia N. "Quality of life in breast cancer survivors: Implications for developing support services." Oncology Nursing Forum, 1998; 25(5):887-895.

Quality of Life Scale/BREAST CANCER PATIENT

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:

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. **Weight gain**

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

6. **Vaginal dryness/menopausal symptoms**

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

Psychological Well Being Items

9. How difficult is it for you to **cope** today as a result of your disease?
 not at all 0 1 2 3 4 5 6 7 8 9 10 very difficult
 difficult
10. How difficult is it for you to **cope** today as a result of your 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 situations 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 chemotherapy**
 not at all 0 1 2 3 4 5 6 7 8 9 10 very distressing
 distressing

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

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

23. **Completion of treatment**
 not at all 0 1 2 3 4 5 6 7 8 9 10 very distressing
 distressing

24. How much **anxiety** do you have?
 none at all 0 1 2 3 4 5 6 7 8 9 10 a great deal

25. 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:

26. Future diagnostic tests

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

27. A second cancer

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

28. Recurrence of cancer

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

29. Spreading (metastasis) of your cancer

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

30. To what degree do you feel your life is back to **normal?**

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

Social Concerns

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

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

32. 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

33. 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

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

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

35. 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

36. 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

37. How much **isolation** do you feel is caused by your illness?

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

38. How much **concern** do you have for your daughter(s) or other close female relatives regarding breast cancer?

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

39. 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

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

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

41. How important to you are other **spiritual activities** such as meditation or praying?

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

42. 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

43. 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

44. 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

45. 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

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

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