



NATIONAL MEDICAL CENTER AND
BECKMAN RESEARCH INSTITUTE

Quality of Life Bone Marrow Transplant Survivors

Dear Colleague:

Enclosed is the information you requested regarding our Quality of Life in Bone Marrow Transplant Survivors tools. This instrument has been derived from research in quality of life (QOL) conducted since 1983 by the investigators at the City of Hope National Medical Center, Duarte, CA. It is adapted to our bone marrow transplant (BMT) population in 1989. The instrument is based on our conceptualization of quality of life which includes the four domains of physical well being, psychological well being, social concerns, and spiritual well being.

The instrument has two components. The first component consists of 20 forced-choice and open-ended items that relate to patient demographics and other patient characteristics. The second component contains 64 QOL items using 10-point scales. We have found it helpful to conduct QOL evaluation before transplant and at various points of time post-transplant.

The quality of life items are divided into the four domains or subscales conceptualized by our QOL model. Following is the list of items identified by subscale.

- Physical well being: Items 21 through 38.
- Psychological well being: Items 39 through 61.
- Social concerns: Items 62 through 74.
- Spiritual well-being: Items 75 through 82.

The last item (Items 38, 61, 74, and 82) in each of the domains asks the patient to rate his overall well being for that domain or subscale. These items are used in calculating a subscale score.

Item 83 asks the patient whether or not he would recommend a BMT to a family member or close friend with the same illness. We have found this item useful in identifying whether or not the patient would undergo another BMT.

Item 84 provides information as to whether or not the patient found that completing the tool was useful.

The instrument was developed specifically for QOL as it relates to BMT and was tested from 1990 through 1992 at the City of Hope National Medical Center. Psychometric analysis of the first version revealed content validity .90, test-retest reliability ($r = .71$, $p = .001$), total score internal consistency ($r = .85$, $p = .01$), subscale alphas of $r = .40$ to $r = .86$, and evaluation by multiple regression analysis, factor analysis, and item correlations. Complete discussion of the psychometrics is provided in the first reference of the attached bibliography.

The current version of the tool (also attached) was developed based on the results of two studies ($N = 212$ and $N = 174$). Analysis of this data is still in progress.

Also attached is a bibliography of our QOL research publications which includes citations specific to this BMT population. The fifth publication cited in the bibliography is attached for your convenience.

You are welcome to use our instrument. We require no further request for permission. Please use the instrument as prepared and acknowledge it as **Quality of Life in Bone Marrow Transplant Survivors**, City of Hope National Medical Center (Grant, Ferrell, Rivera, Molina, and Forman).

Scoring: It is important when coding the 10-point items that all items be coded to reflect 0 = worst outcome/negative QOL to 10 = best outcome/positive QOL. Many of the items are scored in the reverse. The following items need to be reverse coded prior to data entry or your results will be inaccurate.

- Items 21 through 37; 39, 50 through 60; 62 through 64, 67 through 70; 72; 73; and 75

Subscale scores are produced by adding the scores on each item within the subscale and then dividing the number of items in that subscale. (This calculation does not include the last item in each subscale [Items 38, 61, 74, and 82], nor items 83 and 84.) A total QOL score is obtained by adding the scores of items 21 through 37, 39 through 60, 62 through 73, and 75 through 81 and then dividing by 58.

Each 10-point QOL item has a NA (not applicable) option. Score each NA item yes or no and separate from the 10-point scale. Thus, each QOL item is scored in two ways: 1) from 0 to 10 and 2) NA - yes or no.

We hope that our Quality of Life in Bone Marrow Transplant Survivors tool is useful to your research.

Sincerely,



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QUALITY OF LIFE IN BONE MARROW TRANSPLANT SURVIVORS

Thank you for taking the time to complete this questionnaire.

We want to ensure that your responses are anonymous and confidential. Once your completed questionnaires are received, a number will be assigned and your name will not appear on any questionnaires.

All results will go directly to the Department of Nursing Research. Your individual responses will not be reported to your nurse, physician, or social worker. Therefore, if you have any specific concerns, please contact your nurse, physician, or social worker directly. See the enclosed colored sheet for their telephone numbers.

Name _____ Date _____

Current address, if changes have occurred within the last year.

Current address, if changes have occurred within the last year.

Current telephone number including area code _____

ID # _____

CITY OF HOPE NATIONAL MEDICAL CENTER STUDY
QUALITY OF LIFE IN BONE MARROW TRANSPLANT SURVIVORS

Please complete the following information:

1. Marital status prior to your bone marrow transplant (BMT).

Single _____ Married _____ Divorced

Widowed _____ Separated

Marital status now.

Single _____ Married _____ Divorced

Widowed _____ Separated

2. Age

3. Height

4. Current weight

5. Are you satisfied with your current weight?

No _____ Yes

6. Has a substantial weight change occurred since your BMT?

No _____ Yes

If yes, has it been an:

Increase _____ Please identify the number of pounds

Decrease _____ Please identify the number of pounds

7. How many colds and episodes of flu do you have per year?

Is this more than _____, less than _____, or the same as

before your BMT?

ID # _____

11. If you have not been able to return to work, why not? _____

12. If you have returned to work, are you employed in the same occupation as before your BMT?
No _____ Yes _____
If no, why did you change your occupation? _____

13. Have you been able to return to school since your BMT?
No _____ Yes (part-time) _____ Not applicable _____
Yes (full-time) _____

14. If you have not been able to return to school, why not? _____

15. Are you using any home treatments or remedies?
No _____ Yes _____
If yes, please identify what you are using. _____

ID # _____

16. Please identify any activities that you participate in such as exercise, sports, or other recreational activities. _____

17. Do you currently have health insurance?

No _____ Yes

18. Have you experienced any difficulty with acquiring or maintaining health insurance?

No _____ Yes

If yes, please explain. _____

19. Have you experienced any problems with your employer related to your disease or treatment?

No _____ Yes

If yes, please explain. _____

ID # _____

20. Do you belong to a support group?

No _____ Yes

If yes, to which group do you belong? _____

ID # _____

Directions: We are interested in knowing how your experience of having cancer and having a BMT 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 describes your experiences.

NA = not applicable to me/doesn't apply to me

Physical Well Being

To what extent are the following a problem for you.

- 21. **Skin changes**
no problem 0 1 2 3 4 5 6 7 8 9 10 severe problem
- 22. **Bleeding problems**
no problem 0 1 2 3 4 5 6 7 8 9 10 severe problem
- 23. **Mouth dryness**
no problem 0 1 2 3 4 5 6 7 8 9 10 severe problem
- 24. **Changes in vision**
no problem 0 1 2 3 4 5 6 7 8 9 10 severe problem
- 25. **Hearing loss**
no problem 0 1 2 3 4 5 6 7 8 9 10 severe problem
- 26. **Fatigue**
no problem 0 1 2 3 4 5 6 7 8 9 10 severe problem
- 27. **Ringling in your ears**
no problem 0 1 2 3 4 5 6 7 8 9 10 severe problem
- 28. **Appetite changes**
no problem 0 1 2 3 4 5 6 7 8 9 10 severe problem
- 29. **Physical strength**
no problem 0 1 2 3 4 5 6 7 8 9 10 severe problem
- 30. **Sleep changes**
no problem 0 1 2 3 4 5 6 7 8 9 10 severe problem

31. **Sexual activity**
no problem 0 1 2 3 4 5 6 7 8 9 10 **severe problem**
32. **Pain or aches**
no problem 0 1 2 3 4 5 6 7 8 9 10 **severe problem**
33. **Loss of feeling, tingling, or pain in your hands or feet**
no problem 0 1 2 3 4 5 6 7 8 9 10 **severe problem**
34. **Shortness of breath or difficulty breathing**
no problem 0 1 2 3 4 5 6 7 8 9 10 **severe problem**
35. **Constipation**
no problem 0 1 2 3 4 5 6 7 8 9 10 **severe problem**
36. **Nausea**
no problem 0 1 2 3 4 5 6 7 8 9 10 **severe problem**
37. **Fertility changes**
no problem 0 1 2 3 4 5 6 7 8 9 10 **severe problem**
38. **Rate your overall physical health**
extremely poor 0 1 2 3 4 5 6 7 8 9 10 **excellent**

Psychological Well Being

39. **Do you have any distress from visual changes?**
not at all 0 1 2 3 4 5 6 7 8 9 10 **a great deal**
40. **Has it been difficult for you to adjust to your illness?**
very difficult 0 1 2 3 4 5 6 7 8 9 10 **not at all**
41. **How good is your overall quality of life?**
extremely poor 0 1 2 3 4 5 6 7 8 9 10 **excellent**
42. **How much enjoyment are you getting out of life?**
none at all 0 1 2 3 4 5 6 7 8 9 10 **a great deal**
43. **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

44. **How useful do you feel?**
not at all 0 1 2 3 4 5 6 7 8 9 10 **extremely**
45. **How much happiness do you feel?**
none at all 0 1 2 3 4 5 6 7 8 9 10 **complete**
46. **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**
47. **Do you enjoy the things in life now that you used to take for granted?**
none at all 0 1 2 3 4 5 6 7 8 9 10 **a great deal**
48. **How satisfying is your life?**
not at all 0 1 2 3 4 5 6 7 8 9 10 **extremely**
49. **How much have you been able to focus on being well again?**
not at all 0 1 2 3 4 5 6 7 8 9 10 **a great deal**
50. **Has your illness or treatment caused unwanted changes in your appearance?**
not at all 0 1 2 3 4 5 6 7 8 9 10 **a great deal**
51. **Are you fearful of recurrence of your cancer?**
not at all 0 1 2 3 4 5 6 7 8 9 10 **extremely**
52. **How difficult is it for you to cope as a result of your disease and treatment?**
not at all 0 1 2 3 4 5 6 7 8 9 10 **extremely**
53. **Has your illness or treatment decreased your self-concept (the way you see yourself)?**
not at all 0 1 2 3 4 5 6 7 8 9 10 **extremely**
54. **How distressing was the initial diagnosis of your cancer?**
not at all 0 1 2 3 4 5 6 7 8 9 10 **extremely**
55. **How distressing were your cancer treatments (i.e. chemotherapy, radiation, BMT, or surgery)?**
not at all 0 1 2 3 4 5 6 7 8 9 10 **extremely**
56. **How distressing has the time been since your treatment ended?**
not at all 0 1 2 3 4 5 6 7 8 9 10 **extremely**
57. **How much anxiety do you have?**
none at all 0 1 2 3 4 5 6 7 8 9 10 **severe**
58. **How much depression do you have?**
none at all 0 1 2 3 4 5 6 7 8 9 10 **severe**

59. **Are you fearful of a second cancer?**
 not at all 0 1 2 3 4 5 6 7 8 9 10 **extremely**
60. **Are you fearful of the spreading (metastasis) of your cancer?**
 not at all 0 1 2 3 4 5 6 7 8 9 10 **extremely**
61. **Rate your overall psychological well being**
 extremely poor 0 1 2 3 4 5 6 7 8 9 10 **excellent**

Social Concerns

62. **How much financial burden resulted from your illness or treatment?**
 none 0 1 2 3 4 5 6 7 8 9 10 **extreme**
63. **How distressing has your illness been for your family?**
 not at all 0 1 2 3 4 5 6 7 8 9 10 **extremely**
64. **Has your illness or treatment interfered with your personal relationships?**
 not at all 0 1 2 3 4 5 6 7 8 9 10 **completely**
65. **Is the amount of affection you receive sufficient to meet your needs?**
 not at all 0 1 2 3 4 5 6 7 8 9 10 **completely**
66. **Is the amount of affection you give sufficient to meet your needs?**
 not at all 0 1 2 3 4 5 6 7 8 9 10 **completely**
67. **Has your illness or treatment interfered with your sexuality?**
 not at all 0 1 2 3 4 5 6 7 8 9 10 **completely**
68. **Has your illness or treatment interfered with your plans to have children?**
 not at all 0 1 2 3 4 5 6 7 8 9 10 **a great deal**
69. **Has your illness or treatment interfered with your employment?**
 not at all 0 1 2 3 4 5 6 7 8 9 10 **completely**
70. **Has your illness or treatment interfered with your family goals?**
 not at all 0 1 2 3 4 5 6 7 8 9 10 **completely**
71. **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**
72. **Has your illness or treatment interfered with your activities at home?**
 not at all 0 1 2 3 4 5 6 7 8 9 10 **completely**
73. **How much isolation is caused by your illness or treatment?**
 none 0 1 2 3 4 5 6 7 8 9 10 **complete**

74. **Rate your overall social well being**
extremely poor 0 1 2 3 4 5 6 7 8 9 10 excellent

Spiritual Well Being

75. **How much uncertainty do you feel about your future?**
none at all 0 1 2 3 4 5 6 7 8 9 10 extreme

76. **Do you sense a purpose/mission for your life or a reason for being alive?**
not at all 0 1 2 3 4 5 6 7 8 9 10 a great deal

77. **Do you have a sense of inner peace?**
not at all 0 1 2 3 4 5 6 7 8 9 10 completely

78. **How hopeful do you feel?**
not at all 0 1 2 3 4 5 6 7 8 9 10 extremely

79. **Is the amount of support you receive from personal spiritual activities such as prayer or meditation sufficient to meet your needs?**
not at all 0 1 2 3 4 5 6 7 8 9 10 completely

80. **Is the amount of support you receive from religious activities such as going to church or synagogue sufficient to meet your needs?**
not at all 0 1 2 3 4 5 6 7 8 9 10 completely

81. **Has your illness made positive changes in your life?**
none at all 0 1 2 3 4 5 6 7 8 9 10 extreme

82. **Rate your overall spiritual well being**
extremely poor 0 1 2 3 4 5 6 7 8 9 10 excellent

83. **Would you recommend a bone marrow transplant to a family member or close friend with the same illness?**
not at all 0 1 2 3 4 5 6 7 8 9 10 definitely yes

84. **Has filling out this tool been useful to you?**
not at all 0 1 2 3 4 5 6 7 8 9 10 extremely

Quality of Life in Bone Marrow Transplant Survivors

Bibliography

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4. Schmidt GM, Niland JC, Forman SJ, Fonbuena P, Dagens AC, Ferrell BR, Grant M, Barr TA, Stallbaum BA, Chao NJ, & Blume KG. Extended follow up in 201 long-term allogeneic bone marrow transplant survivors: Addressing issues of quality of life. Transplantation, March 1993.
5. Grant M, Ferrell B, Schmidt G, Fonbuena P, Niland J, & Forman S. Researching quality of life indicators: Their part on the daily life of bone marrow transplant patients. In CD Bailey (ED.), Proceedings of the Seventh international Conference on Cancer Nursing (Cancer nursing Changing Frontiers, Vienna, August 16-21, 1992) (pp. 80-84). Oxford, UK: Rapid Communications of Oxford.