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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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 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?
8. List all medications you are currently taking.

<table>
<thead>
<tr>
<th>Medication Name and Dose</th>
<th>Physician's Instructions for Taking the Medication</th>
<th>How are You Taking the Medication?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Example: Advil 200 mg</td>
<td>1 tablet 4 times a day</td>
<td>1 tablet 3 times a day</td>
</tr>
</tbody>
</table>

9. Do you have chronic graft versus host disease?
   No _____ Yes

10. Have you been able to return to work since your BMT?
    No _____ Yes (part-time) _____ Not applicable
        Yes (full-time)
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 #  __________

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20. Do you belong to a support group?
No     Yes
If yes, to which group do you belong?  ______________________________________________________

________________________________________________________________________________________
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. Ringing 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 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 0 1 2 3 4 5 6 7 8 9 10 not at all
difficult
41. How good is your overall quality of life?
   extremely 0 1 2 3 4 5 6 7 8 9 10 excellent
   poor
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
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 0 1 2 3 4 5 6 7 8 9 10 excellent poor

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

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

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
Bibliography


