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Instrument Author:	Grant, M., Ferrell, B. R., Dean, G., Uman, G., Chu, D., & Krouse, R.
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AND BECKMAN RESEARCH ISNTITUTE

Quality of Life Questionnaire for a Patient with an Ostomy

Dear Colleague:

Enclosed is the information regarding our Quality of Life for a Patient with an Ostomy. This questionnaire has been derived from the research in quality of life (QOL) conducted since 1983 by the investigators in Nursing Research at the City of Hope National Medical Center, Duarte, CA. The questionnaire is based on our conceptualization of quality of life which includes the four domains of physical well being, psychological well being, social well being, and spiritual well being.

CONTENT

The questionnaire has two components. The first component consists of 47 forced-choice and open ended items that relate to patient sociodemographic characteristics as well as work-related items, health insurance, sexual activity, psychological support, clothing, diet, and daily ostomy care. The second component contains 43 QOL items using 10-point scales. These QOL 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 1 through 11
Psychological well being: Items 12 through 24
Social well being: Items 25 through 36
Spiritual well being: Items 37 through 43

These QOL items are followed by a statement asking the patient to share a story about living with an ostomy, and include the great challenges encountered in having an ostomy.

RELIABILITY AND VALIDITY

The psychometric analysis of the questionnaire is published in Quality of Life Research, the reference is below

SCORING

It is important when scoring the 10-point QOL items that all items be coded to reflect 0 = worst outcome/negative QOL and 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 1 – 12, 15, 18-19, 22-30, 32-34, 37

Subscale scores are produced by adding the scores on each item with the subscale and then dividing by the number of items in that subscale. A total QOL score is obtained by adding the scores on all 10-point items and dividing by the total number of items (43).

Other versions of the City of Hope Quality of Life Questionnaire for a Patient with an Ostomy have been created for the VA population and the Kaiser Permanente population. The Kaiser version also includes a questionnaire for colorectal cancer patients without an ostomy. To get information about these questionnaires contact robert.krouse@va.gov and cc mary.wagner@va.gov.

USING THIS QUESTIONNAIRE

You are welcome to use our questionnaire. We require no further request for permission. You have permission to duplicate this questionnaire. And, good luck with your research!!

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ID# 0

CITY OF HOPE NATIONAL MEDICAL CENTER
QUALITY OF LIFE QUESTIONNAIRE FOR PATIENTS WITH AN OSTOMY

In advance, thank you for taking the time to complete this questionnaire.

We want to ensure that your responses are anonymous. Your completed questionnaire is mailed directly to the Department of Nursing Research at City of Hope where an identification number will be assigned to the questionnaire. This front sheet will be separated from the questionnaire.

Name _____ Date _____

A current address, if changes have occurred.

_____

_____

Current telephone number including area code

_____

CITY OF HOPE NATIONAL MEDICAL CENTER
QUALITY OF LIFE QUESTIONNAIRE FOR PATIENTS WITH AN OSTOMY

Demographic Information

Following are some questions about yourself.

1. What kind of Ostomy do you have? (Check (√) all that apply)
   ileostomy _____ colostomy _____ urinary diversion _____
2. If you have a colostomy, is it **permanent**? _____ or **temporary**? _____
3. If you have a urinary diversion, do you wear a bag at all times? **No _____ Yes _____**
4. What illness or diagnosis led to your need for an ostomy? _____
5. If cancer was the reason for your ostomy, please specify the type of cancer.
   _____
6. For how many months/years have you had your
   ileostomy? _____ colostomy? _____ urinary diversion? _____
7. What is your gender? **Male _____ Female _____**
8. What is your **current age**? _____
9. What is your **height**? _____
10. What is your current **weight**? _____
11. What is your **ethnicity**?
    African American _____ American Indian _____ Asian _____ Black _____
    Caucasian _____ Hispanic _____ Other ___, please specify _____
12. What was your **marital status prior** to the surgery for your ostomy?
    Single _____ Married _____ Divorced _____ Widowed _____ Separated _____
13. What is your marital status now?
    Single _____ Married _____ Divorced _____ Widowed _____ Separated _____

For the following questions, please answer **NO, YES, or NA (NOT APPLICAABLE)** by placing a check mark (√) in the appropriate column.

	No	Yes	NA
Work Related Items			
14. Are you working full-time?			
15. Are you working part-time?			
16. Are you retired			
17. Are you working in the same occupation that you had before your ostomy?			
18. If you are not working in the same occupation as before your ostomy, was the change related to having an ostomy?			
Health Insurance			
19. Do you currently have health insurance?			
20. Have you had difficulty getting health insurance?			
21. Have you had difficulty maintaining your health insurance?			
22. Does your insurance pay **all costs** for your ostomy supplies?			
23. Does your insurance pay **part of the costs** for your ostomy supplies?			
Sexual activity			
24. Were you sexually active before getting your ostomy?			
25. Have you resumed sexual activity since having your ostomy?			
26. Is your sexual activity satisfying?			
27. If you are male, do you have a problem getting an erection or keeping an erection?			

	No	Yes	NA
Psychological Support/Concerns			
28. Were you depressed after having your ostomy?			
29. Since having your ostomy, have you ever considered or attempted suicide?			
30. Do you belong to an ostomy support group?			
31. Do you belong to another kind of support group?			
32. Have you had the opportunity to talk with someone else who was going to have or had a new ostomy?			
Clothing			
33. Does the location of your ostomy cause you problems?			
34. Have you changed the style of clothing you wear because of your ostomy?			
Diet			
35. Do you adjust your diet because of your ostomy?			
36. Do you change your diet to prevent passing gas in public?			

Please answer the following questions in relation to the amount of time since the surgery for your ostomy. Your choices are **MONTHS, YEARS, or NEVER**. Please place a check mark (√) in the appropriate column.

	Months	Years	Never
37. How long was it before you felt comfortable with your daily ostomy care?			
38. How long was it before you felt comfortable with your diet?			
39. Hoe long was it before your appetite returned?			

For the following questions, please answer **NO, YES, or NA (NOT APPLICABLE – meaning that you do not drink or eat these foods)** by placing a check mark (√) in the appropriate column.

Food Groups	No	Yes	NA
40. I avoid drinking carbonated beverages.			
41. I avoid eating dairy products.			
42. I avoid eating fruits.			
43. I avoid eating snacks.			
44. I avoid eating vegetables.			

Following are some questions related to the care of your ostomy. Please write in your answers.

45. On the average, how long does it take to do your daily ostomy care? _____

46. If you wear a pouch, please identify the brand name. _____

47. If you wear a pouch AND have encountered any problems with it, please explain what those problems are/were.

_____

_____

_____

_____

Directions: We are interested in knowing how the experience of having an ostomy affects your quality of life. Please answer all of the following questions based on **your life at this time**.

Please circle the number form 0 – 10 that best describes your experiences. For example:

How difficult is it for you to **climb stairs**?

Not at all difficult 0 1 2 3 4 5 6 7 8 9 10 extremely difficult

Circling (2) means you have some but not a lot of difficulty climbing stairs.

Related to your ostomy, to what extent are the following a problem for you?

1. Physical strength

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

2. Fatigue

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

3. Skin surrounding the ostomy

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

4. Sleep disorders

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

5. Aches or pains

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

6. Gas

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

7. Odor

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

8. Constipation

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

9. Diarrhea

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

10. Leaking from the pouch (or around the appliance)

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

11. Overall physical well-being

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

12. How difficult has it been for you to adjust to your ostomy?

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

13. How useful do you feel?

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

14. How much satisfaction or enjoyment in life do you feel?

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

15. How much are you embarrassed by your ostomy?

not at all 0 1 2 3 4 5 6 7 8 9 10 **extremely embarrassed**

16. How good is your overall quality of life?

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

17. How is your ability to remember things?

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

18. How difficult is it to look at your ostomy?

not at all 0 1 2 3 4 5 6 7 8 9 10 **extremely difficult**

19. How difficult is it for you to care for your ostomy?

not at all 0 1 2 3 4 5 6 7 8 9 10 **extremely difficult**

20. 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**

21. How satisfied are you with your appearance?

not at all 0 1 2 3 4 5 6 7 8 9 10 **extremely satisfied**

22. How much anxiety do you have?

none at all 0 1 2 3 4 5 6 7 8 9 10 **severe**

23. How much depression do you have?

none at all 0 1 2 3 4 5 6 7 8 9 10 **severe**

24. Are you fearful that your disease will come back?

not at all 0 1 2 3 4 5 6 7 8 9 10 **extremely fearful**

25. Do you have difficulty meeting new people?

not at all 0 1 2 3 4 5 6 7 8 9 10 **extremely difficult**

26. How much financial burden resulted from your illness or treatment?

none at all 0 1 2 3 4 5 6 7 8 9 10 **extreme**

27. How distressing has your illness been for your family?

not at all 0 1 2 3 4 5 6 7 8 9 10 **extremely distressing**

28. How much does your ostomy interfere with your ability to travel?

not at all 0 1 2 3 4 5 6 7 8 9 10 **completely**

29. Has your ostomy interfered with your personal relationships?

not at all 0 1 2 3 4 5 6 7 8 9 10 **completely**

30. How much isolation is caused by your ostomy?

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

31. Is support from friends and family sufficient to meet your needs?

not at all 0 1 2 3 4 5 6 7 8 9 10 **extremely**

32. Has your ostomy interfered with your recreational/sports activities?

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

33. Has your ostomy interfered with your social activities?

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

34. Has your ostomy interfered with your ability to be intimate?

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

35. Do you have enough privacy at home for doing your ostomy care?

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

36. Do you have enough privacy when traveling for conducting your ostomy care?

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

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

none at all 0 1 2 3 4 5 6 7 8 9 10 **extreme**

38. Do you sense a reason for being alive?

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

39. Do you have a sense of inner peace?

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

40. How hopeful do you feel?

not at all 0 1 2 3 4 5 6 7 8 9 10 **extremely**

41. Is support you receive from personal spiritual activities such as prayer or mediation sufficient to meet your needs?

not at all 0 1 2 3 4 5 6 7 8 9 10 **completely**

42. Is 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**

43. Has having an ostomy made positive changes in your life style?

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

Many people have shared stories about their lives with an ostomy. Please share with us the greatest challenge you have encountered in having an ostomy.