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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Director and Professor
Nursing Research and Education
City of Hope National Medical Center
1500 East Duarte Rd.
Duarte, CA 91010

References


Ostomy and CRC Publications


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 APPLICABLE)** by placing a check mark (✓) in the appropriate column.

<table>
<thead>
<tr>
<th><strong>Work Related Items</strong></th>
<th>No</th>
<th>Yes</th>
<th>NA</th>
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<tbody>
<tr>
<td>14. Are you working full-time?</td>
<td></td>
<td></td>
<td>✓</td>
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<tr>
<td>15. Are you working part-time?</td>
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<td>16. Are you retired</td>
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<td>17. Are you working in the same occupation that you had before your ostomy?</td>
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<tr>
<td>18. If you are not working in the same occupation as before your ostomy, was the change related to having an ostomy?</td>
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<table>
<thead>
<tr>
<th><strong>Health Insurance</strong></th>
<th>No</th>
<th>Yes</th>
<th>NA</th>
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<tbody>
<tr>
<td>19. Do you currently have health insurance?</td>
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<td>20. Have you had difficulty getting health insurance?</td>
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<tr>
<td>21. Have you had difficulty maintaining your health insurance?</td>
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<td>22. Does your insurance pay <strong>all costs</strong> for your ostomy supplies?</td>
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<tr>
<td>23. Does your insurance pay <strong>part of the costs</strong> for your ostomy supplies?</td>
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<tr>
<th><strong>Sexual activity</strong></th>
<th>No</th>
<th>Yes</th>
<th>NA</th>
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<tr>
<td>24. Were you sexually active before getting your ostomy?</td>
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<td>25. Have you resumed sexual activity since having your ostomy?</td>
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<td>26. Is your sexual activity satisfying?</td>
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<td>27. If you are male, do you have a problem getting an erection or keeping an erection?</td>
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<tr>
<td>Psychological Support/Concerns</td>
<td>No</td>
<td>Yes</td>
<td>NA</td>
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<td>28. Were you depressed after having your ostomy?</td>
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<td>29. Since having your ostomy, have you ever considered or attempted suicide?</td>
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<td>30. Do you belong to an ostomy support group?</td>
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<td>31. Do you belong to another kind of support group?</td>
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<td>32. Have you had the opportunity to talk with someone else who was going to have or had a new ostomy?</td>
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<td>Clothing</td>
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<td>33. Does the location of your ostomy cause you problems?</td>
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<td>34. Have you changed the style of clothing you wear because of your ostomy?</td>
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<td>Diet</td>
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<td>35. Do you adjust your diet because of your ostomy?</td>
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<td>36. Do you change your diet to prevent passing gas in public?</td>
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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.

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<tr>
<th></th>
<th>Months</th>
<th>Years</th>
<th>Never</th>
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<tr>
<td>37. How long was it before you felt comfortable with your daily ostomy care?</td>
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<td>38. How long was it before you felt comfortable with your diet?</td>
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<td>39. How long was it before your appetite returned?</td>
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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.

<table>
<thead>
<tr>
<th>Food Groups</th>
<th>No</th>
<th>Yes</th>
<th>NA</th>
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<tr>
<td>40. I avoid drinking carbonated beverages.</td>
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<td>41. I avoid eating dairy products.</td>
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<td>42. I avoid eating fruits.</td>
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<td>43. I avoid eating snacks.</td>
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<td>44. I avoid eating vegetables.</td>
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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?
   not 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.