



**NATIONAL MEDICAL CENTER AND
BECKMAN RESEARCH INSTITUTE**

Quality of Life - THYROID VERSION

Dear Colleague:

The Quality of Life (**THYROID VERSION**) is a 30-item ordinal scale that measures the Quality of Life (QOL) of a thyroid 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. The QOL instrument originated in our pain and cancer survivors research and has been adapted for use in thyroid cancer. The tool was developed and tested in a study which evaluated QOL in patients undergoing follow up evaluation for thyroid cancer.

Directions: The patient is asked to read each question and decide if he/she agrees or disagrees with the statement. 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, 3, 10-23, 27. 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 thyroid patients. You have permission to duplicate this tool.

The QOL instrument is based on previous versions of the QOL instrument by researchers at the City of Hope National Medical Center (Grant, Padilla, and Ferrell). This thyroid version was adapted from a form created for use in the general population of cancer survivors. A study was conducted in 1995 to evaluate the psychometrics of the cancer survivor instrument as a mail survey to the membership of the National Coalition for Cancer Survivorship. 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-retest and internal consistency. In order to perform test-retest reliability, a randomly selected sample of 150 subjects who completed the initial QOL survey were asked to repeat this tool approximately two weeks later. One hundred and ten 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 coefficient 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 pains, 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. We have not had a large enough sample of thyroid patients to repeat the psychometric analysis of the version in thyroid patients only. However, the tool is very similar to the cancer survivors version with items 1 h-1, 12, 20, and 21 added to capture the specific QOL concerns of thyroid cancer or thyroid withdrawal.

Good luck with your research!!

A handwritten signature in black ink that reads "Betty R. Ferrell PhD, FAAN". The signature is written in a cursive, flowing style.

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References to QOL Instrument

1. Ferrell BR, Wisdom C, Wenzl C, Schneider C. "Quality of Life as an Outcome Variable in Pain Research." Cancer, 1989; 63:2321-2327.
2. Padilla G, Ferrell BR, Grant M, Rhiner M. "Defining the Content Domain of Quality of Life for Cancer Patients with Pain." Cancer Nursing, 1990; 13(2):108-115.
3. Ferrell BR, Hassey-Dow K, Grant M. "Measurement of the QOL in Cancer Survivors." Quality of Life Research, 1995; 4:523-531.
4. 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.
5. Ferrell BR. "The Impact of Pain on Quality of Life." Nursing Clinics of North America, 1995; 30(4):609-624.

References from Thyroid Cancer - QOL Research

1. Dow KH, Ferrell BR. "Balancing Demands of Cancer Surveillance Among Thyroid Cancer Survivors." Cancer Practice, 1997; 5(5):289-295.
2. Dow KH, Ferrell BR, Annelo C. "Quality of Life Changes in Patients with Thyroid Cancer after Withdrawal of Thyroid Hormone Therapy." Thyroid, 1997; 7(4):613-619.

Quality of Life Scale/THYROID

Directions: We are interested in knowing how your experience of having thyroid cancer affects your Quality of Life. Please answer all of the following questions based on how you have been feeling during the previous week.

Physical Well Being

1. To what extent have the following been a problem during your illness and treatment:
 - a) Fatigue

| | | | | | | | | | | | | |
|----------------|---|---|---|---|---|---|---|---|---|---|----|----------------|
| no | 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 | severe |
| problem | | | | | | | | | | | | problem |
 - b) Appetite changes

| | | | | | | | | | | | | |
|----------------|---|---|---|---|---|---|---|---|---|---|----|----------------|
| no | 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 | severe |
| problem | | | | | | | | | | | | problem |
 - c) Aches or pain

| | | | | | | | | | | | | |
|----------------|---|---|---|---|---|---|---|---|---|---|----|----------------|
| no | 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 | severe |
| problem | | | | | | | | | | | | problem |
 - d) Sleep changes

| | | | | | | | | | | | | |
|----------------|---|---|---|---|---|---|---|---|---|---|----|----------------|
| no | 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 | severe |
| problem | | | | | | | | | | | | problem |
 - e) Constipation

| | | | | | | | | | | | | |
|----------------|---|---|---|---|---|---|---|---|---|---|----|----------------|
| no | 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 | severe |
| problem | | | | | | | | | | | | problem |
 - f) Menstrual changes or fertility

| | | | | | | | | | | | | |
|----------------|---|---|---|---|---|---|---|---|---|---|----|----------------|
| no | 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 | severe |
| problem | | | | | | | | | | | | problem |
 - g) Weight gain

| | | | | | | | | | | | | |
|----------------|---|---|---|---|---|---|---|---|---|---|----|----------------|
| no | 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 | severe |
| problem | | | | | | | | | | | | problem |
 - h) Tolerance to cold or heat

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

i) Dry skin or hair changes

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

j) Voice changes

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

k) Motor skills/coordination

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

l) Swelling/fluid retention

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

2. Rate your overall physical health:

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

Psychological Well Being Items

3. How difficult is it for you to cope with your disease and treatment?

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

4. How good is your quality of life?

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

5. How much happiness do you feel?

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

6. Do you feel like you are in control of things in your life?

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

7. How satisfying is your life?

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

8. How is your present ability to concentrate or to remember things?

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

9. How useful do you feel?

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

10. 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**

11. Has your illness 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**

12. How distressing were the following aspects of your illness and treatment:

a) Initial diagnosis

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

b) Surgeries

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

c) Time since my treatment was completed

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

d) Initial radioiodine ablation/treatment

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

e) Whole body scanning

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

f) Thyroglobulin testing

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

- g) Withdrawal from thyroid hormone
- not at all** 0 1 2 3 4 5 6 7 8 9 10 **very distressing**
13. How much anxiety do you have?
- none at all** 0 1 2 3 4 5 6 7 8 9 10 **a great deal**
14. How much depression do you have?
- none at all** 0 1 2 3 4 5 6 7 8 9 10 **a great deal**
15. To what extent are you fearful of:
- a) Future diagnostic tests
- no fear** 0 1 2 3 4 5 6 7 8 9 10 **extreme fear**
- b) A second cancer
- no fear** 0 1 2 3 4 5 6 7 8 9 10 **extreme fear**
- c) Recurrence of your cancer
- no fear** 0 1 2 3 4 5 6 7 8 9 10 **extreme fear**
- d) Spreading (metastasis) of your cancer
- no fear** 0 1 2 3 4 5 6 7 8 9 10 **extreme fear**

Social Concerns

16. 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**
17. 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**
18. 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**
19. Is your sexuality impacted by your illness?
- not at all** 0 1 2 3 4 5 6 7 8 9 10 **a great deal**

20. To what degree has your illness and treatment interfered with your employment?

a) Motivation to work

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

b) Time away from work

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

c) Productivity at work

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

d) Quality of work

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

21. To what degree has your illness and treatment interfered with your activities at home?

a) Driving a car

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

b) Household chores

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

c) Preparing meals

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

d) Leisure activities

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

22. How much isolation do you feel is caused by your illness and treatment?

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

23. 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

24. How important to you is your participation in religious activities such as praying, going to church?

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

Quality of Life/Thyroid

25. How important to you are other spiritual activities such as meditation?
not at all important 0 1 2 3 4 5 6 7 8 9 10 **very important**
26. How much has your spiritual life changed as a result of cancer diagnosis?
less important 0 1 2 3 4 5 6 7 8 9 10 **more important**
27. How much uncertainty do you feel about your future?
not at all uncertain 0 1 2 3 4 5 6 7 8 9 10 **very uncertain**
28. 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**
29. 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**
30. How hopeful do you feel?
not at all hopeful 0 1 2 3 4 5 6 7 8 9 10 **very hopeful**