

Validation of the long-term quality of life breast cancer scale (LTQOL-BC) by health care professionals

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Abstract

Introduction Quality of life has become an important measure of treatment success and is currently being explored not only for patients on active treatment, but also for long-term breast cancer survivors. The long-term quality of life breast cancer scale (LTQOL-BC) is a tool to assess QOL in breast cancer survivors. This study aimed to validate the tool with health care professionals (HCPs).

Methods Six HCPs with extensive experience working with breast cancer survivors were selected. HCPs completed the LTQOL-BC and were asked to assess the relevance of each included item to the disease-free breast cancer population. They were also instructed to identify items that could be upsetting for patients, irrelevant to this population, and to assess the tool's breadth of coverage.

Results Feedback indicated that some items such as the body image and sexual functioning questions were potentially upsetting to patients and should be rephrased or removed. The overall breadth of coverage of the tool was inadequate, with employment status, economic situation, ability to meet needs of family, health care insurance coverage, and overall sense of well-being not being addressed by the LTQOL-BC. HCPs also identified that certain items should be edited including those specifying pain in the lower body and the item containing the term “homemaker”.

Conclusion The LTQOL-BC may need to be modified to take into the recommendations provided by HCPs.

Keywords Breast cancer · Quality of life · Health care professional · LTQOL-BC · Breast cancer survivors

Introduction

As breast cancer survival rates continue to increase, with 5 year survival rates currently at 88 % [1], improving patient quality of life (QOL) throughout the entire breast cancer journey has become a primary focus of health care professionals (HCPs). While QOL is commonly assessed for patients on active treatment, the long-term issues with QOL experienced by breast cancer survivors are less explicitly documented. The impact of having survived cancer influences the QOL of breast cancer patients both positively and negatively, with both physical and psychological changes differing from being newly diagnosed to those on active treatment. Long-term issues affecting QOL commonly experienced by breast cancer patients include fatigue, sleep disturbances, fear of recurrence, pain, anxiety, and body image issues [2]. It is also known that women treated with hormone therapy such as aromatase inhibitors are at an increased risk of bone loss/fractures post treatment. Similarly, those treated with radiation are at an increased risk of sarcomas and lymphedema [3]. While newer extended therapies have successfully decreased breast cancer mortality rates, they are simultaneously exposing patients to long-term and potentially unknown toxicities and/or side effects, which may negatively impact QOL [4]. As treatment effects can last well beyond the patients' active cancer journey, it is becoming essential to evaluate patient QOL on a long-term basis.

QOL is most commonly assessed with the use of self-administered questionnaires. Currently, one tool exists that is

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specifically designed for the assessment of long-term QOL in breast cancer survivor populations: the Long-Term Quality of Life Breast Cancer scale (LTQOL-BC) (Appendix 1). The LTQOL-BC was developed in 2010 with a group of women with stage I–III breast cancer; 7–30 years post diagnosis whom had all been treated with modified radical mastectomies as their primary surgical treatment [5]. The 28-item tool assesses QOL in the domains of physical function, social support, body image, sexual function, coping, future orientation, cognitive function, and breast cancer impact. Long-term cancer survivors are defined as having survived a minimum of 5 years since the date of diagnosis of their primary cancer by the American Cancer Society [6]. Thus, the LTQOL-BC aims to assess QOL in patients 5 years or more from their breast cancer diagnosis.

The creators of the LTQOL-BC evaluated its reliability and validity after its development [5]. The questionnaire has been deemed reliable, with Cronbach's coefficient alpha being 0.88 for the tool as a whole, with alphas for the individual subscales ranging from 0.61 to 0.85. Convergent and divergent validities have also been evaluated for the LTQOL-BC. Convergent validity was assessed through revision of *t* tests for factor loadings. Results indicated that all items within a factor do in fact measure the same construct. The LTQOL-BC was also found to have excellent divergent validity [5]. The next step for the LTQOL-BC is the interview with HCPs to evaluate the relevance of included module items as well as to identify any upsetting, irrelevant, or missing items. The purpose of the study was to validate the tool with the HCPs.

Methods

A panel was composed of six expert HCPs with experience working with breast cancer survivors from the Louise Temerty Breast Cancer Centre at Sunnybrook Health Sciences Centre participated. Health care professionals who worked with breast cancer patients were contacted individually to be included in the expert panel. Six health care professionals agreed. In order to maintain confidentiality of the six HCPs, who agreed, no demographic data was collected. All HCPs who were involved in the care of breast cancer patients and survivors were eligible for the panel. The selected HCPs included oncologists and nurses of various areas of expertise. Each panel member was given a copy of the LTQOL-BC questionnaire and asked to assess each item from 5 (strongly agree, relevant) to 1 (strongly disagree, not relevant) for how relevant they perceived included items to be for a breast cancer survivor. They were also asked to indicate for each item if they felt it should be included in a final version of the questionnaire regardless of the numerical score that was

chosen by indicating yes or no. In addition, the HCPs were asked to write down the top 10 items that they believed are most influential on QOL for disease-free breast cancer populations.

An additional segment was added to the LTQOL-BC to allow for written comments from the HCPs. They were asked to indicate any items that could be potentially confusing, upsetting, or difficult to answer for a disease-free breast cancer patient and to explain why they felt the item could be perceived as such. The last section evaluated the breadth of coverage of the tool. The HCPs were asked to indicate any issues pertaining to the QOL of a disease-free breast cancer patient that were not assessed by the LTQOL-BC that they felt should be included in the tool (Appendix 1). All questionnaires were anonymously completed.

Results

The perceived relevance of each question varied between HCPs, with the selected most relevant items being displayed in Table 1. HCPs ranked the relevancy of each item based on the number of times they received this complaint from a patient or a patient brought up this concern. The most relevant items were ones that HCPs ranked most highly for relevancy. The items that had the highest number of relevancy votes were pooled into the most relevant items list. None of the items were unanimously selected as being relevant by all involved HCPs. The items that were perceived as being most applicable to breast cancer survivors were “I feel fatigued all the time”, “intimate relationships are difficult for me”, “I have difficulty remembering things”, and “when I get sick I feel very anxious”. There were also five items that were not identified by any participating HCPs as being relevant to QOL issues in the disease-free population. These items included “I have difficulty walking up or down stairs”, “I have restrictions of

Table 1 Eleven most relevant items on the LTQOL-BC for disease-free breast cancer survivors as selected by each health care professional

-
1. I have difficulty remembering things
 2. I feel fatigued all the time
 3. Intimate relationships are difficult for me
 4. When I get sick I feel very anxious
 5. I do not feel feminine or especially attractive
 6. I have little sexual interest
 7. I take each day and make the most of it
 8. I can concentrate easily
 9. I have difficulty thinking clearly
 10. I can count on those closest to me for everyday help
 11. I think about my breast cancer everyday
-

movement in my arms”, “since having had breast cancer I feel cheated”, “sexual intimacy is easy for me”, and “I am a stronger person since surviving my breast cancer”.

Feedback from the HCPs identified many shortcomings of the LTQOL-BC including inappropriate and irrelevant questions as well as inadequate breath of coverage. HCPs reported inappropriateness of the item “I have had trouble getting or keeping a job/functioning as a homemaker”. Questions were raised as to why the term homemaker was implemented and/or singled out. Rephrasing of this item would be viable and that omitting the term homemaker would be ideal. The LTQOL-BC item “I have aching or pain in my lower body and legs” was also reported as needed revision. HCPs felt that it was odd to single out the lower body and legs when evidently breast cancer has a greater effect on the upper body and arms.

Issues with the body image and sexual function domains were also raised. It was felt that certain items were inappropriately worded and could potentially be upsetting to patients. For example, it was identified that the item “Sexual intimacy is easy for me” is boldly phrased. The panel revealed that patients most often have difficulty with sexual intimacy even years post breast cancer, and thus wording the statement as it currently is would render the question irrelevant to the majority of the patients. It was felt that the item should be phrased in a manner such as “I have difficulty with sexual intimacy” or something of this nature that would be more applicable to the large majority of breast cancer survivors. In a more broad sense, one HCP felt that the body image domain as a whole could be upsetting for patients. Perhaps rephrasing of these items should be considered to probe such relevant issues in a softer manner.

The breadth of coverage of the LTQOL-BC was identified as being inadequate by all involved HCPs. Many relevant topics that were not addressed on the LTQOL-BC were revealed. Financial concerns were not touched upon by the LTQOL-BC. The panel felt that whether or not the patient was able to return to work since their breast cancer should be asked. Also, pertaining to employment, it would be viable to include an item to address the patients’ feelings about their work; if they are working full-time or part-time, and how they feel about their daily work (i.e., is it fulfilling? Are they having difficulty working to the same standards as they did prior to their breast cancer journey?).

Issues raised pertaining to breadth of coverage also included health insurance coverage. With many patients being treated with ongoing endocrine therapy currently between 5 and 10 years, as well as ongoing annual screening precautions, it was felt that to gain a comprehensive sense of the long-term financial burden of breast cancer on the patient it would be useful to inquire about their degree of health insurance coverage. Additionally, a commonly reported long-term issue post breast cancer treatment is having difficulty taking care

of small children or grandchildren as a result of increased fatigue or enduring physical pain. This could potentially be included in a broader item addressing any issues with family demands. Finally, the last issue discussed that is lacking from the LTQOL-BC is asking the patient about their self-perceived sense of well being. It was noted that many patients, even years after breast cancer treatment, have reported having to “define a new normal” as they feel they never quite return to the way they felt before having had cancer.

Discussion

Validation of the LTQOL-BC by six HCPs with extensive experience working with breast cancer survivors raised many issues with the current tool. None of the currently included items were unanimously selected as being of utmost relevance to breast cancer survivors; however, certain items were identified by majority of HCPs as being of high relevance, as previously outlined, and should be considered in the final version of the tool. The five items that were not highlighted as being relevant by any HCPs may perhaps be omitted from the tool or reworded to pin-point the aspect of each topic that is specific to the population at hand.

Current literature documents several common ongoing symptoms experienced by breast cancer survivors that are not addressed by the current LTQOL-BC module. Incidence of lymphedema in breast cancer patients is over 15 %, with late development in some patients. It has been reported that 15 % of lymphedema cases in breast cancer patients are diagnosed 5 years or more post surgery [7]. Since incidence rates of lymphedema remain high and diagnosis can be well-delayed post breast cancer treatment, it should be considered to include an item addressing this incurable symptom on the long-term QOL questionnaire. Insomnia is another symptom present in 17 % of breast cancer survivors [8]. While fatigue is addressed on the current LTQOL-BC module, no items addressing sleep disturbances or quality of sleep are included. It is also reported that long-term side effects of breast cancer treatment can leave patients at a much higher risk of developing certain comorbidities including adverse cardiovascular events and accelerated bone loss or fractures [9]. While the development of such comorbidities could not be solely attributed to a previous breast cancer, breast cancer survivors are at a higher risk of such symptoms and it should be considered to address these issues on the LTQOL-BC.

Breadth of coverage of the current tool was felt to be inadequate. Since breast cancer survivors are disease free, and not experiencing adverse symptom burden, it is not

essential that the QOL tool be kept condensed. Adding more items to the current tool should be considered to increase its breadth of coverage. This would allow HCPs to gain a holistic sense of patient well-being by assessing issues such as financial situation and employment status that influence the lives of breast cancer survivors but are currently omitted from the QOL tool.

Limitations of this study include the small HCP sample size. As only six HCPs contributed to the validation of the LTQOL-BC, it would be advised to repeat the validation of this questionnaire with the assistance of a larger group of HCPs to gain a broader perspective of issues impacting QOL in disease-free breast cancer populations. Also, lack of demographic data on the participating HCPs limits the generalizability of their feedback to all HCPs. Gender, age, area of expertise, and number of years working with disease-free breast cancer populations would be valuable information to assess if any differences existed in feedback between HCPs of varying demographic groups. Finally, as all the participating HCPs practice at the same center, it would be wise to conduct HCP validation at various other centers, in regions with different patient demographics. This would improve the external validity of the module, and perhaps shed light upon further QOL issues impacting the lives of disease-free breast cancer patients that have not been mentioned by the cohort of disease-free breast cancer patients seen at the Odette Cancer Centre.

Conclusion

HCP feedback has indicated modifications need to be made to the LTQOL-BC tool. Further revision of the module and repeat evaluation by HCPs is advised.

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Conflicts of interest None.

Appendix 1: HCP content validation of LTQOL-BC for disease free patients

Long-term quality of life–breast cancer scale

PART A: Relevance

Could you please indicate for each issue separately the extent to which you find it relevant for patients that are disease free from breast cancer (response categories may range from (5) “strongly agree relevant” to (1) “strongly disagree, not relevant”). Relevance refers to the frequency with which a specific complaint occurs and, when it occurs, the trouble it may cause. Thus, the more frequently a complaint occurs and the more trouble it causes, the more relevant it will be for patients. Please also indicate if this item should be included in the final questionnaire.

RELEVANT?

	Strongly agree	Agree	No opinion	Disagree	Strongly disagree	Include in final?
Physical function						
1. I am physically strong. ^a	5	4	3	2	1	YES/NO
2. I feel fatigued all the time.	5	4	3	2	1	YES/NO
3. I have difficulty walking up or down stairs.	5	4	3	2	1	YES/NO
4. I find it difficult doing physical activities such as housework.	5	4	3	2	1	YES/NO
5. I have restrictions of movement in my arms	5	4	3	2	1	YES/NO
6. I have aching or pain in my lower body and legs.	5	4	3	2	1	YES/NO
7. I have or had trouble getting or keeping a job/functioning as a homemaker.	5	4	3	2	1	YES/NO
Body image						
8. I do not feel feminine or especially attractive.	5	4	3	2	1	YES/NO
9. I feel incomplete as a woman.	5	4	3	2	1	YES/NO
10. Since having had breast cancer I feel cheated.	5	4	3	2	1	YES/NO
11. Since having had breast cancer I feel incomplete.	5	4	3	2	1	YES/NO
Sexual function						
12. Intimate relationships are difficult for me.	5	4	3	2	1	YES/NO
13. I have little sexual interest.	5	4	3	2	1	YES/NO
14. Sexual intimacy is easy for me. ^a	5	4	3	2	1	YES/NO

Coping						
15. I take each day and make the most of it.	5	4	3	2	1	YES/NO
16. I appreciate things and don't take them for granted.	5	4	3	2	1	YES/NO
17. I don't sweat the small stuff.	5	4	3	2	1	YES/NO
18. I am a stronger person since surviving my breast cancer. ^a	5	4	3	2	1	YES/NO
Cognitive function						
19. I have difficulty remembering things.	5	4	3	2	1	YES/NO
20. I can concentrate easily a	5	4	3	2	1	YES/NO
21. I have difficulty thinking clearly.	5	4	3	2	1	YES/NO
Social support						
22. I can count on those closest to me for everyday help. ^a	5	4	3	2	1	YES/NO
23. I am alone.	5	4	3	2	1	YES/NO
24. I have friends who would help me if I had a crisis. ^a	5	4	3	2	1	YES/NO
Anxiety						
25. When I get sick I feel very anxious.	5	4	3	2	1	YES/NO
26. I feel uncertain about things.	5	4	3	2	1	YES/NO
27. I make very frequent visits to the doctor.	5	4	3	2	1	YES/NO
28. I think about my breast cancer every day. ^a	5	4	3	2	1	YES/NO

^aDenotes a question recoded so that it is consistent with direction of other questions.

Scoring is 5, *strongly agree*; 4, *agree*; 3, *no opinion*; 2, *disagree*; 1, *strongly disagree*

1. If you circled “Yes” for more than 10 issues (in Part A), please indicate which 5 to 10 issues affect the quality of life of

disease free breast cancer patients most profoundly, that we should definitely include in the final questionnaire. (*Items do not need to be ranked*)

a) # _____	d) # _____	g) # _____	i) # _____
b) # _____	e) # _____	h) # _____	j) # _____
c) # _____	f) # _____		

2. Could you please tell me for each issue that you circled a 1 (“strongly disagree, not relevant”) or 2

(“disagree, not relevant”) why you consider it not or only a little relevant?

Question Number	Reason why you consider it not or only a little relevant:

3. Please let us know if you think any of the questions are inappropriate, irrelevant, or upsetting to patients.

PART B: Breadth of Coverage

Please read and review the LTQOL-BC. This is a long-term questionnaire that was designed to assess quality of life of breast cancer patients that are disease free. You may have thought of other things that are not

included in this questionnaire or the previous list of issues you have just rated.

Can you think of anything else that may be of relevance to disease free breast cancer patients and is not included in the two questionnaires? *(please circle)*

YES NO

If “yes”, please name these issues and record them in the following table.

Relevant Issue Not Covered in the LTQOL-BC, or ESAS.	Please explain

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