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ORIGINAL PAPER

What constitutes breast-related quality of life? A comparison of normative scores of two BREAST-Q modules

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Abstract

Background BREAST-Q, with modules for augmentation, reduction/mastopexy, and breast cancer is the most frequently used instrument for assessing breast-disease specific quality of life which, according to the BREAST-Q-manual, also can be used to compare different patient groups. The primary aim of the present study was to compare scores from the pre-operative breast cancer module and the reduction/mastopexy module from healthy women. The secondary aim was to compare version 1 and 2 of the two modules.

Methods This study extends on previously published data and compares the result of the two studies creating Swedish normative scores for BREAST-Q. All participants answered the two BREAST-Q modules at the same time.

Results There was a difference between average and range of scores for some domains, especially for the physical well-being domain. Moreover, there was a difference in scores between version 1.0 and 2.0 of the domains.

Conclusions The results suggest that different modules cannot be used to compare different patient groups. This begs the question if the time has come for a comprehensive pre-operative BREAST-Q domains that measure breast-related quality of life irrespective of any specific breast-conditions. The difference between version 1.0 and 2.0 of BREAST-Q, might lead to difficulty when results from different studies are compared.

Level of Evidence Not ratable

Keywords BREAST-Q · Patient reported outcomes · PROM · Quality of life · Breast satisfaction

Introduction

Patient reported outcome measurements (PROMs) and health-related quality of life (HRQoL) instruments are fundamental in evaluating the result of both cosmetic and reconstructive breast surgery [1]. HRQoL instruments are divided into generic instruments, such as the Medical Outcomes Study 36-Item Short Form (SF-36), Health Utilities Index (HUI), and EuroQol Instrument (EQ-5D), that can be used in any health condition, and disease- or condition-specific instruments that measure symptoms considered relevant to a certain condition [2]. For different breast conditions treatable with plastic surgery a number of disease specific instruments, such as BREAST-Q, BRECON-31, EORTC QLQ-BRECON-23, and the Breast-Related Symptoms Questionnaire (BRSQ), have been developed and validated [3, 4]. One of the most commonly used is BREAST-Q [5], which has modules for augmentation, reduction/mastopexy, and breast cancer (mastectomy, reconstruction, breast conserving surgery) [6]. The modules were developed based on qualitative research [7, 8], exploring what is important to stake holders, and previously published literature. Additionally, the modules have been psychometrically tested [8–10]. As the three patient groups (augmentation, reduction/mastopexy, and cancer) have slightly different symptoms, needs, and expectations, the qualitative research resulted in both mutual and different items for the three modules. This begs the question how distinct breast-specific HRQoL

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Table 1 Overview of the pre-operative module of BREAST-Q cancer reconstruction as well as reduction/mastopexy

BREAST-Q	Domains				
	Satisfaction with breast	Psychosocial well-being	Physical well-being: Chest		Sexual well-being
Cancer/reconstruction module					
No.of items	4	10	v.1: 16	v.2: 10	6
Distribution-based MIDs [17]	4	4	3		4
Scores (*n*=146)					
Mean (SD)	57 (13)	66 (19)	84 (13)	98 (5)	50 (20)
Median (range)	58 (0-100)	63 (0-100)	85 (39-100)	100 (55-100)	48 (0-100)
Reduction/mastopexy module					
No.of items	11	9	v. 1: 14	v.2: 12	5
Distribution-based MIDs ADDIN EN.CITE [18]	6	6	8		9
Scores (*n*=146)					
Mean (SD)	56 (15)	63 (22)	78 (14)	87 (14)	48 (25)
Median (Range)	54 (19-100)	62 (0-100)	79 (44-100)	90 (37-100)	46 (0-100)

Comparison of scores from the pre-operative breast cancer module and the reduction/mastopexy module from healthy women, as well as a comparison of version 1 and 2 of the domain Physical wellbeing chest. Some of the scores have been published previously in [11] (*submitted*)

MIDs minimal important differences

SD standard deviation

instruments should be and if breast-related QoL could be viewed and measured as one entity, irrespective of how the patients need for surgery has arisen. According to the BREAST-Q manual [6] the modules are psychometrically linked across the different groups and can be used to compare different patient groups that have breast conditions treatable by plastic surgery, and the scores are equivalent between version 1.0 and version 2.0 [6]. The pre-operative breast cancer and reduction/mastopexy module have the same four domains: satisfaction with breasts, psychosocial well-being, sexual well-being, and physical well-being: chest but they contain different items. We hypothesise that the scores will be different depending on the individual items are included in the module. The primary aim of the present study was to compare scores from the pre-operative breast cancer module and the reduction/mastopexy module from healthy women. The secondary aim was to compare version 1 and 2 of the two modules.

Material and methods

This study extends on previously published data [11] (*submitted*) and compares the result of the two studies creating Swedish normative scores for BREAST-Q. The study was pre-registered at ClinicalTrials.Gov (identifier NCT04526561 and NCT05233891). For information on setting, participants and data collection please refer to previously published articles [11] (*submitted*). All participants answered the two BREAST-Q modules at the same time.

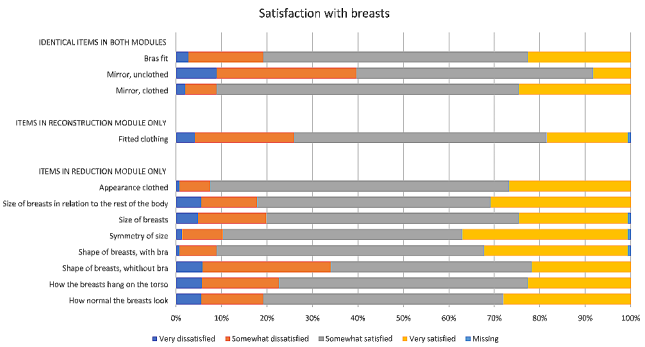

Fig. 1 Distribution of BREAST-Q scores for satisfaction with breast

The study was vetted and approved by the Regional Ethical Committee of Gothenburg (254 – 18) and the Swedish Ethical Review Authority (2021–03165 and 2022-06237-02) and conducted in accordance with the Helsinki Declaration and the Good Clinical Practice (GCP) guidelines. All participants gave their informed consent to participation.

The preoperative modules BREAST-Q reduction/mastopexy and cancer/reconstruction were used. The modules have the same domains: satisfaction with breast/s, psychosocial well-being, sexual well-being, and physical well-being chest, but the included items vary between the modules (Table 1). Differences in items can be seen in Figs. 1, 2, 3 and 4.

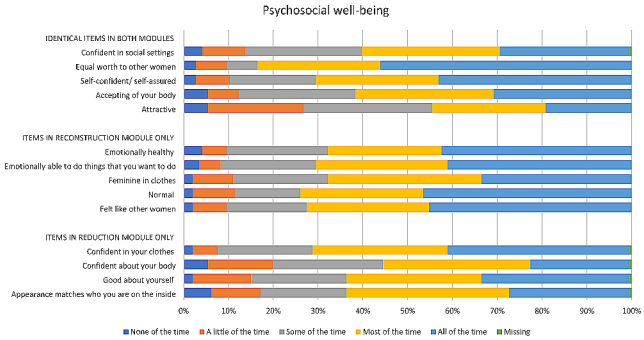

Fig. 2 Distribution of BREAST-Q scores for Psychosocial well-being

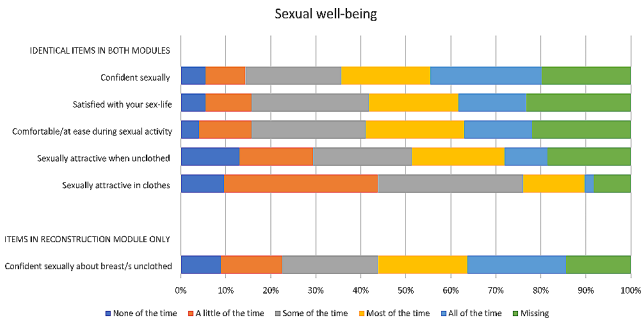

Fig. 3 Distribution of BREAST-Q scores for sexual well-being

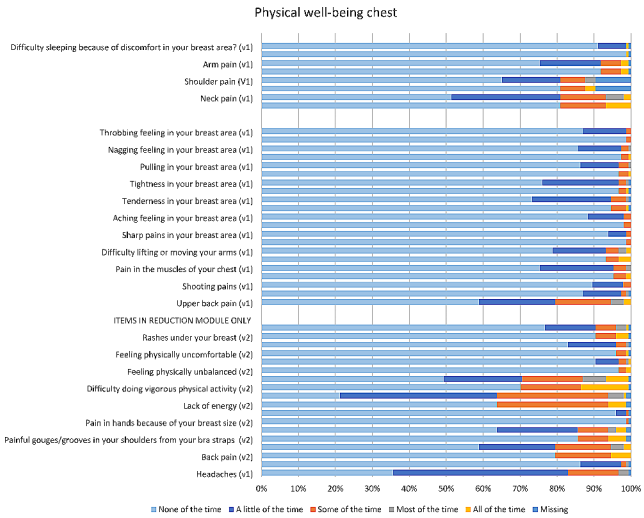

Fig. 4 Distribution of BREAST-Q scores for physical well-being chest, version 1 & 2

There are two versions of the modules. In the first version the responders are asked to consider the past 2 weeks and in the second version the past week. In the second version the response options for the physical well-being domain have been reduced from five to three. For the reduction/mastopexy module, two items have been categorized as stand-alone items and thus removed from the sum score of the domain. For the cancer/reconstruction module 6 items have been removed in the physical well-being domain: neck pain, upper back pain, shoulder pain, arm pain, rib pain, and shooting pains.

For this study, the versions with five response options and the perspective two weeks were used. However, for the domain where there is a considerable difference in items between the versions, the physical well-being domain, Q-scores were calculated for both version 1 and version 2, to enable comparison. To calculate version 2 Q-scores, the response options 1 and 2 and 4 and 5 were merged into two categories and the items described above were removed.

Use of BREAST-Q, authored by Drs. Klassen, Pusic and Cano, was made under license from Memorial Sloan Kettering Cancer Center, New York, USA.

Results

The satisfaction with breast/s domains have three items in common in the two modules. The cancer/reconstruction module has one additional item whereas the mastopexy/breast reduction has six additional items. The average scores are similar between the two domains; although, the ranges differ somewhat. For the median score, the difference between the two domains equals the distribution based minimal important differences (MIDs) for the cancer/reconstruction module, but is smaller than the MID for mastopexy/reduction module (Table 1).

The psychosocial well-being domains have five items in common in the two modules. The cancer/reconstruction module has five additional items and the mastopexy/reconstruction module four additional items. The differences between both the mean and the median scores are smaller than the MIDs for both modules (Table 1).

The first versions of the physical well-being domains have four items in common, whereas the second versions only have one item in common. In the first version, the domain of the cancer/reconstruction module has twelve additional items, whereas the second version has nine. The domain of the reduction/mastopexy module has ten additional items in both versions. In addition, the second version of the domain physical wellbeing chest, regardless of module, have a reduced number of response options, from five to three.

The sexual well-being modules have five items in common and the cancer/reconstruction module has one additional item. The additional item seems to affect the scores in a positive direction as the women score slightly higher on the domain of the cancer/reconstruction module than the reduction/mastopexy module, whereas the standard deviation is bigger in the module with fewer items in the domain. The differences between the domains are smaller than the MIDs for both modules (Table 1).

Discussion

The BREAST-Q modules cancer/reconstruction and reduction/mastopexy have four common domains; although, the included items vary to different extents between the two modules. This study shows that there are some differences in scores, when the modules are answered by the same normative population, illustrating that scores can be affected by how the items are worded, suggesting that it is questionable to use scores from different modules to compare different patients groups that have breast conditions treatable by plastic surgery [6]. Similarly, a clear difference could be seen in scores between version 1.0 and 2.0, contradicting that the scores are equivalent between the two versions [6].

The wording in the two modules vary because the items are based on qualitative research [7, 8] among stakeholders, including patients. The reduction/mastopexy module is answered by, and the items are created based on interviews with, women who wants a breast reduction/mastopexy and are dissatisfied with their breasts as they actively are seeking corrective surgery, whereas the cancer/reconstruction module is answered by women who are having or have had a mastectomy due to disease or to reduce the risk of disease, and who might be we very satisfied with their breast. The question is if whether the differences between the groups really warrant a different wording of the items. It cannot be presumed that all women who will have a mastectomy are completely satisfied with their breasts. Their satisfaction should be similar to that of the general population or possible affected by complex feelings towards their breast due to their own disease or that of close relatives.

Looking at the satisfaction with breast/s domain, a lot more items are included in the reduction/mastopexy module compared with the cancer/reduction module; for example, items on size, symmetry, shape, and normality are included, which also might be relevant to women who will have a mastectomy. The pre-operative cancer/reconstruction module is answered both by women who have had a mastectomy, waiting for a delayed breast reconstruction, and women who are planned for a mastectomy and an immediate breast reconstruction, that is women who still have both their native breast. Hence, it would be very relevant to know how satisfied the women who still have both their native breasts are with size, symmetry, shape, and normality pre-operatively to enable a reasonable evaluation of the outcome after reconstruction. Size, symmetry, shape, and normality are issues that are often complained about or commented on by women post-reconstruction and cited pre-operatively as reasons to have breast reconstruction [12]. Nonetheless, the scores do not differ much between the two modules, which might indicate item redundancy in the reduction/mastopexy module. To our knowledge, only post-operative Cronbach's alpha values, have been published for the BREAST-Q modules [8, 9, 13]. In other words, item redundancy has not been investigated in the pre-operative modules, that were used in the present study.

The psychosocial domains of the two modules have five items in common. The cancer/reconstruction module has five additional items and the reduction/mastopexy module four. However, the items that differ between the module do not seem to be condition specific. Feelings of being like other women and of normality might be an equally important to somebody with breast hypertrophy/ptosis as to somebody who have had cancer treatment.

The first version of the physical well-being chest domains had more items in common than the second version. In the second version, six items, all concerning pain, have been removed from the cancer/reconstruction module, whereas they remain in the reduction/mastopexy module. However, two pain related items regarding headache and pain in the chest area are re-classified as stand-alone items and excluded from the sum score of the domain but remaining in the questionnaire [6]. It is unclear why the items regarding pain have been removed as it might be part of breast-related health in women who will have mastectomy as well and it is definitively common in women who have had mastectomy [14], due to scarring and tissue damage. Hence, pain seems to be relevant to take into consideration in both categories of patients, pre-operatively.

Regarding sexual well-being, the items are identical, except for one additional item in the cancer/reconstruction module. The additional item is the only item in the domains concerned with the role of the breasts in the woman's sexuality. Therefore, it does not seem logical not to include it in the reduction/mastopexy module as well when breast-related quality of life is measured. Indeed, it might be warranted to discuss if more breast-specific questions should be included as it is breast-related sexual well-being that is measured.

Regarding general differences between version 1.0 and 2.0, these have several implications. Firstly, it is unclear why and how the items have been reduced in the different domains [6]. The method is relevant as the items of the first versions were developed by exploring what is important to stakeholders [7, 8] and a reduction of items therefor risks eliminating some aspects that are important to stakeholders. Secondly, the reduction of response options from five to three in the second version could make the floor/ceiling effects higher for the domains. Floor and ceiling effects have, to our knowledge, only been published for version 1.0 of the BREAST Q reconstruction domains Satisfaction with back appearance and Satisfaction with back and shoulder function. The ceiling effects were 37% and 14%, respectively, and the floor effects 0.8% for both domains [15]. In

validation studies, the threshold is often considered met at 15% [16–18] and thus indicating that the instrument not being able to discriminate between, for example, the satisfied/unsatisfied and the very satisfied/unsatisfied. Considering this, further studies regarding the floor/ceiling effects of the two versions of BREAST-Q are warranted. Thirdly, the differences in scores between versions 1.0 and 2.0 might suggest that it is not possible to compare results from the two versions. This should be considered when researchers chose version to use in their studies, to enable comparison with previous studies.

In summary, women from a normative population score slightly different on the domains satisfaction with breasts, psychosocial well-being, sexual well-being, and physical well-being from the cancer/reconstruction and reduction/mastopexy module, respectively. The differences in items between the modules are not always logical and necessarily relevant to the module specific conditions. This begs the question if the time has come for a comprehensive preoperative BREAST-Q domains that measure breast-related quality of life irrespective of any specific breast-conditions, making comparison between different groups possible. Moreover, there is a difference in scores generated by version 1.0 and version 2.0 of BREAST-Q, which might lead to difficulty when results from different studies are compared.

Authors' contributions All the co-authors have made a substantial contribution to the study, the writing process, and the final manuscript. The manuscript has been seen and approved by all co-authors.

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Data availability The datasets used and/or analysed during the current study are not publicly available due to General Data Protection Regulation laws but are available from the corresponding author on reasonable request and with permission from the Swedish Ethical Review Authority.

Declarations

Ethical approval The study was pre-registered at ClinicalTrials.Gov (identifier NCT04526561 and NCT05233891. The study was vetted and approved by the Regional Ethical Committee of Gothenburg (254 – 18) and the Swedish Ethical Review Authority (2021–03165 and 2022-06237-02) and conducted in accordance with the Helsinki Declaration and the Good Clinical Practice (GCP) guidelines.

Consent to participate All participants gave their informed consent to participation.

Consent for publication Not applicable.

Competing interests The authors have no relevant financial or non-financial interests to disclose.

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