Journal of Plastic Surgery and Hand Surgery

ISSN: 2000-656X (Print) 2000-6764 (Online) Journal homepage: www.tandfonline.com/journals/iphs20

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To cite this article: Linn Weick, Anna Grimby-Ekman, Carolina Lunde & Emma Hansson (2023) Validation and reliability testing of the BREAST-Q expectations questionnaire in Swedish, Journal of Plastic Surgery and Hand Surgery, 57:1-6, 315-323, DOI: 10.1080/2000656X.2022.2070180

To link to this article: https://doi.org/10.1080/2000656X.2022.2070180

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Published online: 09 May 2022.

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JOURNAL OF PLASTIC SURGERY AND HAND SURGERY
2023, VOL. 57, NOS. 1–6, 315–323
https://doi.org/10.1080/2000656X.2022.2070180

ARTICLE

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Validation and reliability testing of the BREAST-Q expectations questionnaire in Swedish

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ABSTRACT

Knowledge about preoperative expectations and how they affect satisfaction with breast reconstruction are key in improving care. A prerequisite for such studies are methodologically sound ways to define and measure expectations. The aims of this study were to translate and culturally adapt BREAST-Q Expectations for Sweden, and to perform a psychometric evaluation of the questionnaire. A cross-sectional study was performed. BREAST-Q expectations was translated according to current guidelines and sent to all patients on the waiting list for a breast reconstruction in our department. Internal consistency was assessed by Cronbach's α. Inter-item correlations were calculated, and convergent validity was evaluated using a subjective comparator. Bland–Altman plots were drawn to evaluate test–retest reliability. Floor and ceiling effects were calculated. The questionnaire was sent to 198 patients, of which 129 responded (65%). Internal consistency was acceptable for all domains (Cronbach's α 0.71–0.85) and all except one inter-item correlations were within the predefined intervals. Bland–Altman plots indicated that the agreement is variable. Ceiling effects were high for most domains. The results of the study support that the Swedish version of BREAST-Q expectations has a good content and face validity and internal consistency. Convergent validity and known-group validation cannot be adequately examined for expectations. Further studies are needed regarding test–retest reliability. High ceiling effects indicate that the instrument cannot discriminate between patients with high expectations and very high expectations. More studies are needed on how we can evaluate if expectations are realistic or not.

Trial registration: ClinicalTrials.gov Identifier NCT04714463, 19 January 2021

Patient and public contribution: All the data were generated directly from patients.

ARTICLE HISTORY
Received 12 January 2022
Revised 8 March 2022
Accepted 19 April 2022

KEYWORDS
Breast reconstruction; patient-reported measures; expectations; psychometrics; validity; reliability; health-related quality of life; plastic surgery; psycho-oncology

Introduction

A patient's preoperative expectations might affect their postoperative satisfaction with breast reconstruction [1]. However, the relationship could be complex as expectations are affected by a number of factors, including patient linked, cultural and disease related factors.

Patients linked factors include sociodemographic [2,3], body-image and investment [4], previous experiences [3,5] and individual adaptation to disease and cultural include health-care system/health policy, social norms, and the notion of equity [3]. Disease-related factors that might affect expectations on breast reconstruction encompass, for example, the quality and understanding of preoperative information given to the patient [6], timing of the reconstruction, if it is performed in conjunction with cancer treatment, several years later, or as a risk reducing procedure [7–9], and waiting time to treatment [10]. Moreover, expectations have several dimensions as they can be ideal/value-based (the preferred outcome), predicted/probability-based (the anticipated outcome), normative (the socially endorsed outcome), and unformed (when the patient is unable/unwilling to express his/her expectations) [3,11]. Nonetheless, some of these aspects are modifiable and therefore knowledge about expectations and how they affect satisfaction with breast reconstruction are key in improving care.

A prerequisite for studies on the effect of expectations on outcome are methodologically sound ways to define and measure expectations [3]. Suggested methods include retrospective questionnaires [6], prospective questionnaires [8,9], inferred expectations measured from the patients ranking of importance of different appearance aspects of the breasts [12], and retrospective interviews [13,14]. For breast reconstruction, only one standardised instrument that measures expectations has been described, the BREAST-Q expectations questionnaire [15]. It has never been validated outside North America and there are no previously published studies on measurement properties of the instrument.

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Standardised instruments make it possible to compare patient expectations across studies. However, the complexity and multidimensionality of expectations necessitate validated and cross-culturally adapted instruments.

The aims of this study were to translate and culturally adapt BREAST-Q Expectations for Sweden, and to perform a psychometric evaluation of the questionnaire in Swedish patients currently on the waiting list for a breast reconstruction in a university hospital.

Patients and methods

Protocol

This was a cross-sectional study to validate a PROM questionnaire for breast reconstruction. It is part of the Effects of Expectations and Body Image in Breast Reconstruction study protocol (ClinicalTrials.gov Identifier NCT04714463). The study was reviewed and approved by the Swedish Ethical Review Authority (2020-04729). The principles of the Helsinki Declaration were followed. All participants gave their written informed consent to participation in the study and to the publication of the results. Use of the BREAST-Q expectations questionnaire, authored by Drs. Klassen, Pusic and Cano, was made under license from Memorial Sloan Kettering Cancer Center, New York, USA.

BREAST-Q expectations

The domains and items of BREAST-Q expectations were developed in North America using qualitative technique [15,16]. The questionnaire includes individual questions, where the option the patient checks is her response. In addition, the questionnaire includes four domains with multiple items: Expectations of Support (Question (Q) 4), Pain (Q5), Coping (Q9) and Appearance (Q10). Hence, the instrument includes both treatment-related (outcome and process) and patient-related expectations. Each domain comprises four to six items that the patient rate on a Likert scale as 'unlikely' (1), 'somewhat likely' (2), 'very likely' (3) or 'don't know'. For each domain, the raw scalesummed score is transformed to Rasch-scores and then log-transformed into a score from 0 to 100. A higher score indicates higher expectations, that is greater support, more pain, better coping and a more satisfactory appearance. For missing data and answer 'don't know', the mean of complete items is inserted, if missing data are less than half of the items of the domain. If the missing data are more than half, the domain is not interpreted for that individual. The validation was performed on the four domains: Expectations of Support, Pain, Coping and Appearance. There are no previously published studies on validation and translation of BREAST-Q expectations.

Recruitment and participants

The study was performed in the Department of Plastic Surgery at Sahlgrenska University Hospital, Gothenburg, one of Sweden's seven university hospitals and departments of plastic surgery. The department currently perform about 350–400 breast reconstructions a year. The sample size was based on the number of patients currently on the waiting list for a breast reconstruction in the department. There were more patients on the list than the recommended minimum recommendations for validations studies, usually ranging from 50 to 200 [17]. All patients were consecutively asked to participate in a letter containing study information, the questionnaires, the consent form, and a stamped return envelope. A remainder was sent after two and four weeks. The first 60 patients who answered the questionnaire were sent a second questionnaire, two weeks later, to allow for analysis of test–retest reliability. Exclusion criteria were inability to give informed consent and insufficient Swedish language skills. The participants had the possibility to ask questions about the study, over the telephone, before enrolling, during, and after the study.

Cross-cultural adaptation

Translation

The questionnaire was translated according to established guidelines [18,19]. Two independent translations from the English original of the BREAST-Q expectations questionnaire into Swedish were performed by professional Swedish mother tongue medical translators. The researchers in the Department of Plastic and Reconstructive Surgery then created a single Swedish version, solving discrepancies with consensus. A back-translation from Swedish to English was performed by a professional English mother tongue medical translator. The authors of the original BREAST-Q expectations questionnaire reviewed the back-translated version to ensure that the meaning of the items was equivalent to that of the original and the Mapi Research Trust approved the final Swedish version of the questionnaire.

Content validity and face validity

A pilot test of the translated version was performed in five preoperative native speakers of Swedish (aged 46, 47, 47, 50 and 52 years). They were interviewed by a specially trained research nurse. A semi-structured interview guide, on how the participants understood and interpreted the items and if they found the items acceptable, was used. A summary of the process is given in Figure 1.

Examination of measurement properties and hypotheses

Measurement properties were examined according to the criteria proposed by Terwee et al. [20]. Continuous variables were described by mean (standard deviation) and median (minimum and maximum). All tests were two-tailed and a *p*-value of 0.05 was considered to indicate a statistically significant result. The analyses were performed on Breast-Q Rasch converted scores 0–100. Statistical tests were performed using SPSS, version 27, for Mac (IBM Corp, Armonk, NY). The function GKgamma in the R package vcdExtra (Bell Labs, Murray Hill, NJ) was used to calculate the 95% confidence intervals for the Gamma correlations (CRAN package, https://cran.r-project.org).

Internal consistency

Internal consistency was assessed using Cronbach's α [21] for the different domains and values ranging from 0.70 to 0.95 were considered acceptable [22]. A low Cronbach's α indicates a low interrelatedness among the items and consequently they should not be combined to a total score. A high Cronbach's α ($\geq$0.95) might indicate a redundancy of items.

Inter-item correlations between all items (raw scores) were calculated using Spearman's correlation (ρ). A ρ value of between 0.2 and 0.8 were considered to indicate a good consistency and $\rho > 80$ could indicate a redundancy of items.

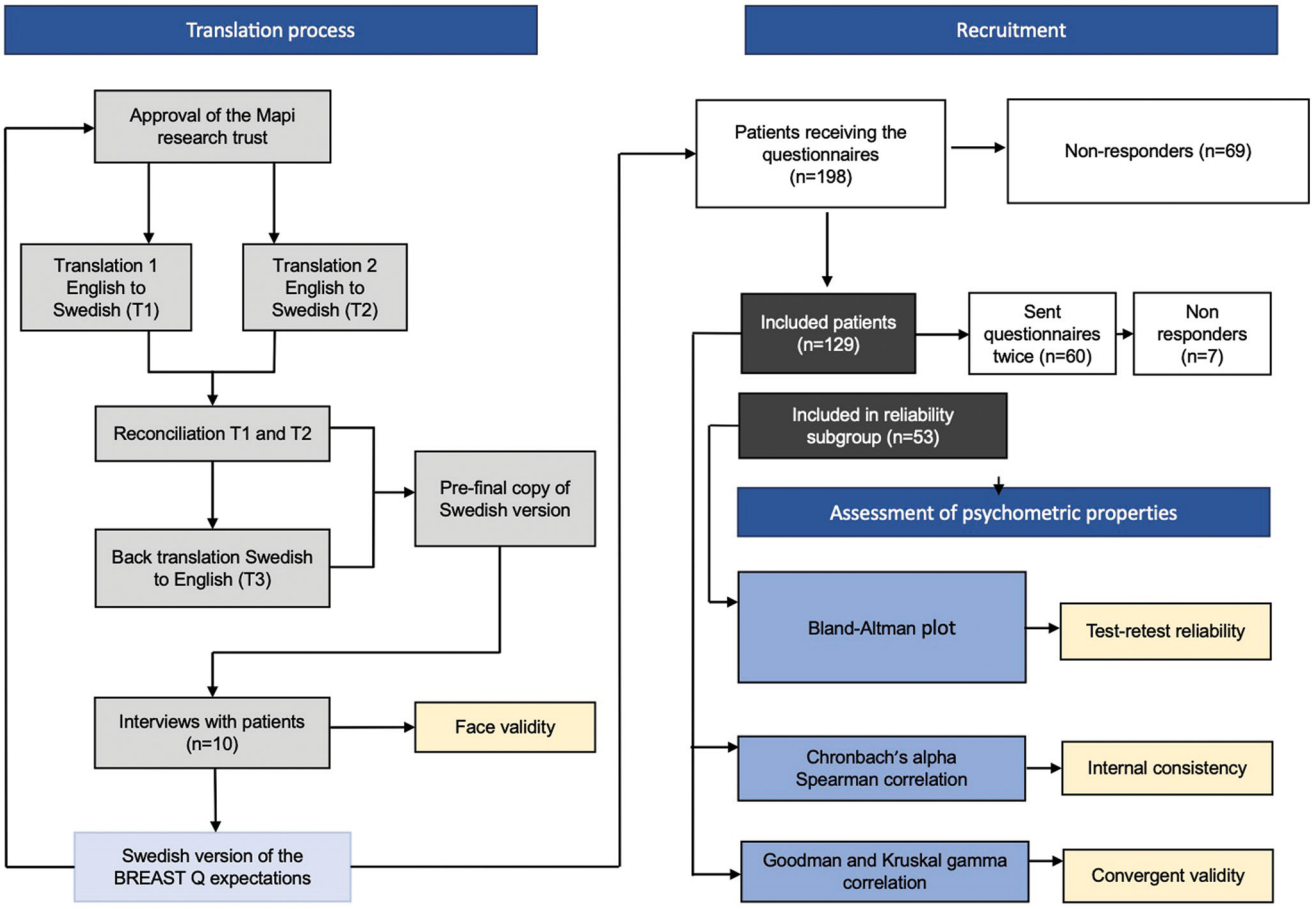

Figure 1. The course of the study. Figure created by Åsa Bell, medical photographer, Department of Plastic and Reconstructive surgery, Sahlgrenska University Hospital, Gothenburg, Sweden.

Test–retest reliability

Test–retest reliability was examined by letting a subgroup of 60 participants answer the questionnaire on two separate occasions, 2 weeks apart. Bland–Altman plots [23] of the individuals' two separate Rasch converted logits scores (0–100) were drawn.

Floor and ceiling effects

Floor and ceiling effects were calculated as the percentage of participants (with 95% confidence intervals) [24] who obtained the minimum and the maximum scores, that is 100 and 0 points. The threshold was considered met if more than 15% of the patients achieved the minimum or maximum scores [25].

Convergent validity and hypotheses

There is no gold standard for measuring expectations in breast reconstruction. In fact, there are no other validated instruments to measure them [1] . Consequently, a subjective comparator, six in-house constructed visual analogue scales (VAS) (Support, Pain, Coping, and Appearance) were used so the patients could rate their self-perceived expectations for different domains on 100-mm long horizontal lines, with two anchors. A higher score indicated greater support, less pain, worse coping and a less satisfactory result, respectively. Goodman and Kruskal γ and 95% confidence intervals for γ were calculated to examine if the scales were related. We hypothesized that there would be a positive correlation between BREAST-Q support and the corresponding VAS and a negative correlation between BREAST-Q pain, coping, and appearance and the corresponding VAS ($\gamma < -0.70$ or $> +0.70$), [20].

Results

Translation and pilot testing

During the discussions to produce a version that is conceptually equivalent to the original questionnaire, the main issue was whether items should be expressed 'det kommer att.' (e.g. det kommer att kännas ömt) or 'jag kommer att.' (e.g. 'jag kommer att känna mig öm'). The group decided that 'jag kommer att.' is the most idiomatic way to express it in Swedish. The cognitive interviews did not reveal any difficulties in interpretation and understanding of the items. All women found the items acceptable, although one woman remarqued that the questions made her worry more about the operation. Consequently, face validity was considered acceptable, and no changes were made to the questionnaire.

Participants and data completeness

The questionnaire was sent to 198 patients and 129 patients replied (65%). The majority of patients were waiting for an autologous delayed reconstruction and most patients had had a therapeutic mastectomy (Table 1). Demographics are given in Table 1. Most of the participants had answered all questions (Table 2).

Internal consistency

Internal consistency was acceptable for all four domains (Cronbach's $\alpha = 0.71–0.85$, Table 3), indicating that the items are adequate in number and in interrelatedness and can be combined to a score. Inter-item correlations indicated a good consistency for all four domains (Tables 4–7). Only one correlation fell outside the predefined acceptable interval ($\rho = 0.2–0.8$), that between the items 'Things will get better as time goes on' (Q9, Ia) and 'I will get back to my normal life' (Q9, Ie) ($\rho = 0.12$, Table 6).

Test–retest reliability

None of the patients were operated between the two measurements. The mean difference between score 1 and 2 was biggest for support (−6.8, *SD* 31) and for coping (7.7, *SD* 34) and smallest for pain (−0.4, *SD* 26) and for appearance (−1.6, *SD* 25). The overall assessment of the comparison of score 1 and score 2 shows that the direction of the mean is close to zero for pain (Figure 2) and appearance (Figure 3) and varies more for support (Figure 4) and coping (Figure 5). The extent of the limits of agreement indicates that the agreement is variable.

Floor and ceiling effects

The threshold for floor effect was not reached for any of the domains, whereas it was reached for the ceiling effect for pain (a lot of pain), coping (coping very well) and appearance (a very satisfactory appearance) and almost reached for support (great support) (13%) (Table 9).

Table 1. Demographics.

	Median (min–max): 53 (23–76) Mean (SD): 52 (10)	
Age, years	*N* (%total)	Response rate
Type of reconstruction		
Delayed DIEP flap	85 (66%)	64% (85/132)
Delayed latissimus dorsi flap	7 (5.4%)	58% (7/12)
Delayed implant based	20 (16%)	63% (20/32)
Immediate implant based	17 (13%)	77% (17/22)
TOTAL	129	65% (129/198)
Type of mastectomy		
Therapeutic	112 (87%)	64% (112/176)
Risk reducing	17 (13%)	77% (17/22)
	Rasch scores (1–100) (median (min–max)	Rasch scores (1–100) (mean (SD))
Breast-Q		
Support	54 (0–100)	60 (26)
Pain	80 (5–100)	78 (20)
Coping	100 (54–100)	88 (16)
Appearance	87 (10–100)	81 (20)
	1–100 (median (min–max))	
VAS		
Support	77 (8–100)	
Pain	30 (0–100)	
Coping	33 (0–98)	
Appearance	25 (0–93)	

Convergent validity

The correlations between the BREAST-Q domains and the in-house constructed VAS scales were week (Table 8) and not in accordance with our hypotheses, indicating that the two instruments do not measure similar constructs.

Discussion

Patients' expectations might affect the patient experienced outcome of surgery [1], which makes knowledge about expectations important. A prerequisite for studies on expectations are methodologically sound ways to define and measure expectations [3]. This study validates the BREAST-Q expectations questionnaire.

Methodological considerations

The raw scores from BREAST-Q instrument are ordinal categorical. According to the developers, the transformed standardized 0–100 is a continuous scale. When the Rasch analysis is performed, scores on the logit scale is the result. However, in case of the BREAST-Q instrument, the Rasch logits have been transformed to a standardised scale from 0 till 100. The logits have been calibrated based on minimum and maximum logits in a calibrated data and therefore the 0–100 scale has retained the metric properties achieved in the Rasch analysis. However, the 0 and 100 are not absolute limits, but low respectively high values based on the calibration data. The process of transforming raw scores to Rasch logits and then to 0–100 scale has been partly described for some of the BREAST-Q modules [26], but not for BREAST-Q expectations According to the BREAST-Q manual, the English version of the BREAST-Q expectations has been validated, but no reference or data on the validation are given.

The relative low response rate (65%) might have affected the results, if the sample does not fully represent the patient group. For example, participants who either had very low or very high expectations could have been more prone to answer the questionnaire. Looking at the ceiling effect in this study, a skewness toward high expectations is more probable. Most of the participants were waiting for an autologous delayed reconstruction, which could have contributed to high expectations and to the ceiling effect being reached for several areas.

There is no golden standard to measure patients' expectations. Therefore, a subjective comparator was used as a proxy in this

Table 3. Cronbach's α.

	Chronbach's α
Support	0.84
Pain	0.85
Coping	0.71
Appearance	0.85

Table 2. Missing data.

	Ia	Ib	Ic	Id	Ie	If
Support (Q4) ($n = 129$)	12 (9.3%)	11 (8.5%)	23 (18%)	22 (17%)	21 (16%)	
Pain (Q5) ($n = 129$)	4 (3.1%)	11 (8.6)	38 (29%)	25 (19%)	22 (17%)	11 (8.5)
Coping (Q9) ($n = 129$)	7 (5.4%)	6 (4.7%)	6 (4.7%)	4 (3.1%)	6 (4.7%)	
Appearance (Q10) ($n = 129$)	3 (2.3%)	7 (5.4%)	7 (5.4%)	14 (11%)	11 (8.5%)	

Table 4. The inter-item correlations of the Support domain.

	Ia	Ib	Ic	Id	Ie
Ia	1.00				
Ib	0.63**	1.00			
Ic	0.45**	0.57**	1.00		
Id	0.47**	0.49**	0.56**	1.00	
Ie	0.36**	0.42**	0.56**	0.69**	1.00

*p < 0.05 **p < 0.01 ***p < 0.001

Table 5. The inter-item correlations of the Pain domain.

	Ia	Ib	Ic	Id	Ie	If
Ia	1.00					
Ib	0.52**	1.00				
Ic	0.40**	0.63**	1.00			
Id	0.32**	0.52**	0.59**	1.00		
Ie	0.24**	0.39**	0.46**	0.61**	1.00	
If	0.47**	0.52**	0.49**	0.58**	0.39**	1.00

*p < 0.05 **p < 0.01 ***p < 0.001

Table 6. The inter-item correlations of the Coping domain.

	Ia	Ib	Ic	Id	Ie
Ia	1.00				
Ib	0.24**	1.00			
Ic	0.46**	0.53**	1.00		
Id	0.12	0.23*	0.49**	1.00	
Ie	0.30**	0.30**	0.32**	0.26**	1.00

*p < 0.05 **p < 0.01 ***p < 0.001

Table 7. The inter-item correlations of the Appearance domain.

	Ia	Ib	Ic	Id	Ie
Ia	1.00				
Ib	0.60**	1.0			
Ic	0.62**	0.63**	1.00		
Id	0.41**	0.51**	0.54**	1.00	
Ie	0.51**	0.46**	0.70**	0.61**	1.00

study. However, the weak correlations seen could be a consequence of the many dimensions of expectations [3,11] and an indication and they cannot be measured with a one-item scale. No conclusions can be drawn on the convergent validity of the BREAST-Q expectations instrument based on our analyses.

Another aspect that presently cannot be addressed is whether the BREAST-Q expectations instrument can discriminate between two groups that should have different expectations, so called known-group validity. It could not be examined in this study, as we know very little about the expectations of different groups of patients waiting for a breast reconstruction. For example, it cannot be assumed that older women have different expectations than younger women, or that women who have a therapeutic mastectomy have different expectations than women who have a risk reducing procedure.

Considerations regarding the results

Reliability of instruments measuring expectations in orthopaedic surgery has shown moderate reliability for some subscales [27,28], notably items involving emotions, rather than function, such as 'alleviate the fear of shoulder giving away' [28]. All the BREAST-Q expectations domains involve mainly items involving emotions and values, such as 'The surgeon will make me feel like I'm his/her only patient' (Q4, Id), 'I will feel uncomfortable' (Q5, Ib), 'I will think positively' (Q9, Ib), and 'I will look normal when I look in the mirror' (Q10, Id). The nature of these items reflects the aims of breast reconstruction, which include improving how the patient is feeling about herself and her sexuality, as well as enabling her to 'move on' from cancer [15,16]. These aspects are inherently emotional and value laden. Such effects are more difficult to quantify than for example how long distance you can walk before and after a joint replacement, which might explain the poor reliability of the BREAST-Q expectations instrument seen in this study. Moreover, it seems very difficult for a patient to predict what effect a breast reconstruction will have on her, as women tend to overestimate its effect on quality of life and on the reduction of stigma [2]. Reconstruction may improve some aspects of QoL, for example body-image, but

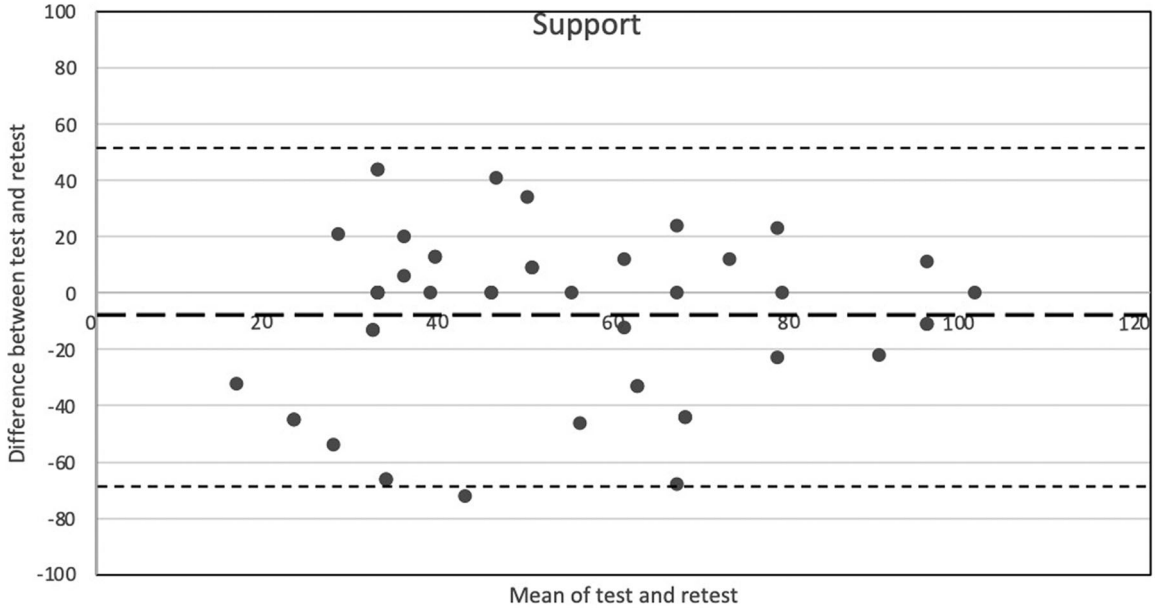

Figure 2. Bland–Altman plot for pain. Dotted lines are mean score 1 and score 2 (−0.4) and Limits of agreement (−52 and 51). Calculations are based on Rasch converted scores (1–100).

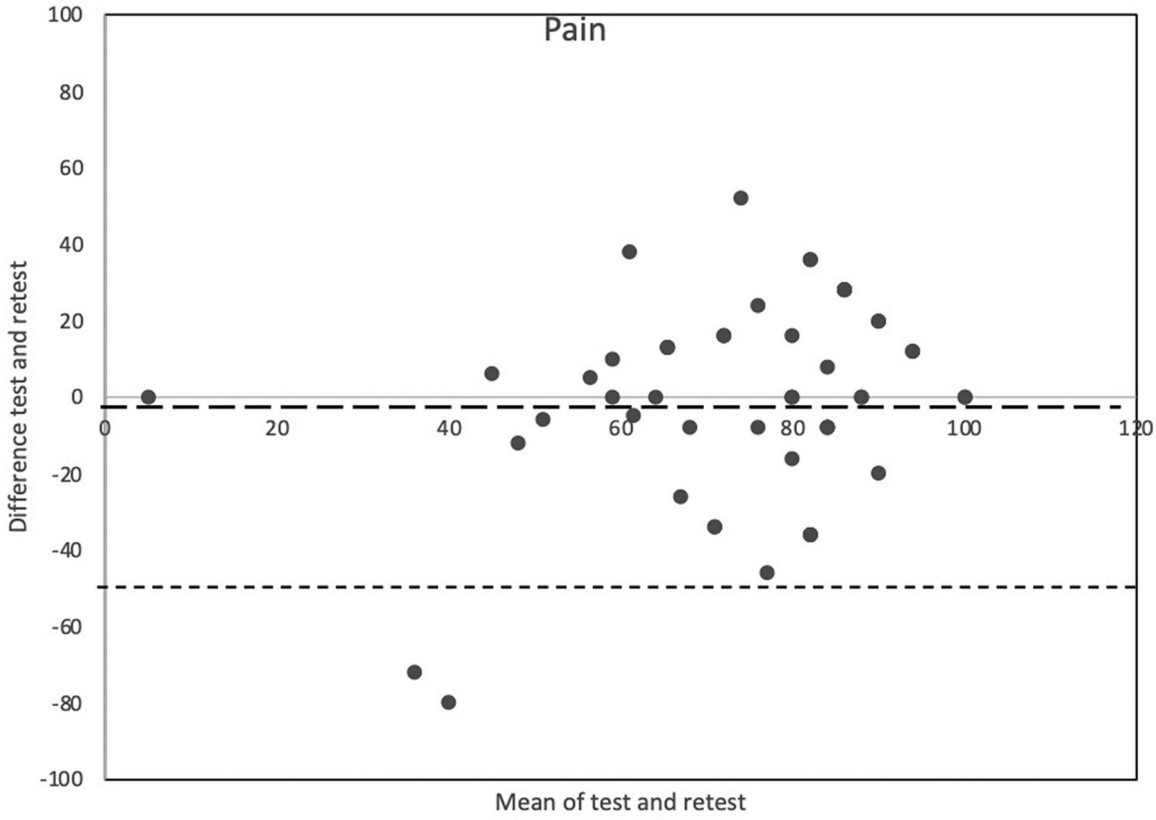

Figure 3. Bland–Altman plot for appearance. Dotted lines are mean score 1 and score 2 (−1.6) and Limits of agreement (−51 and 48). Calculations are based on Rasch converted scores (1–100).

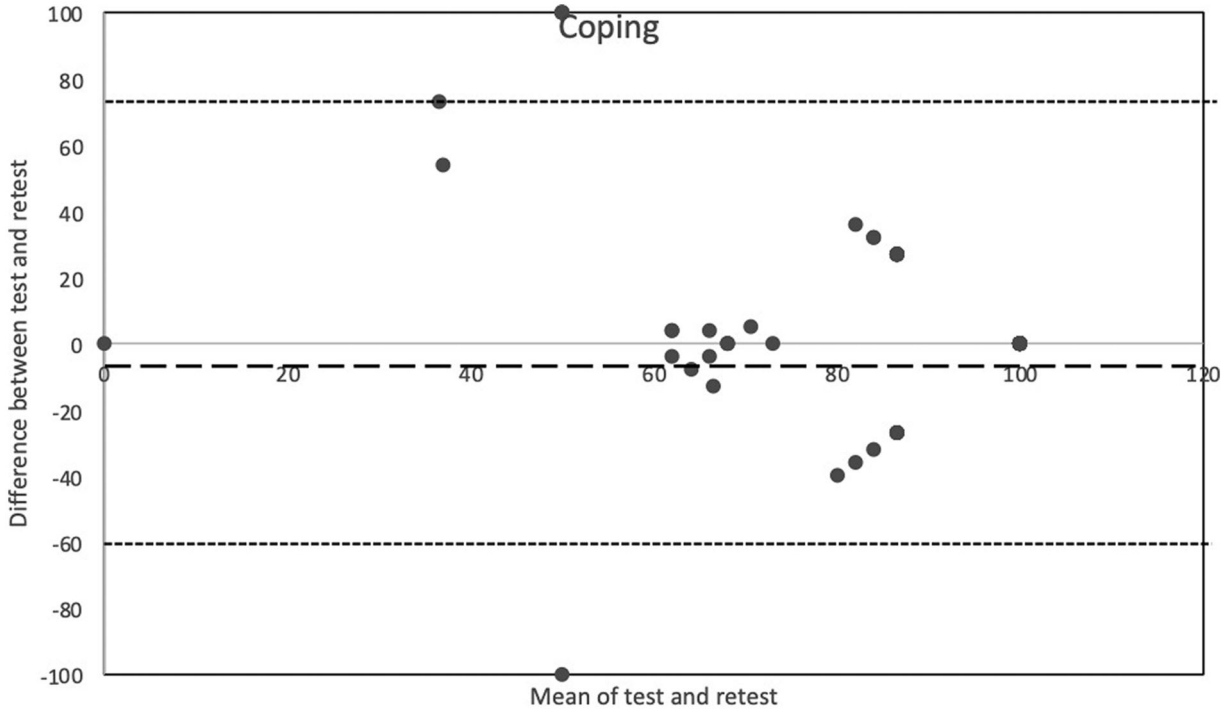

Figure 4. Bland–Altman plot for support. Dotted lines are mean difference between score 1 and score 2 (−6.8) and limits of agreement (−53 and 67). Calculations are based on Rasch converted scores (1–100).

not necessarily other aspects such as emotional distress caused by cancer and fear of recurrence [29].

It is likely that the participants interpreted the questions differently depending on whether they had their ideal/value, predicted/probability, or normative expectations in mind when answering [3,11]. Considering that the ceiling effect was reached for several areas, it is possible that there is a tendency for the instrument to capture the participants' preferred

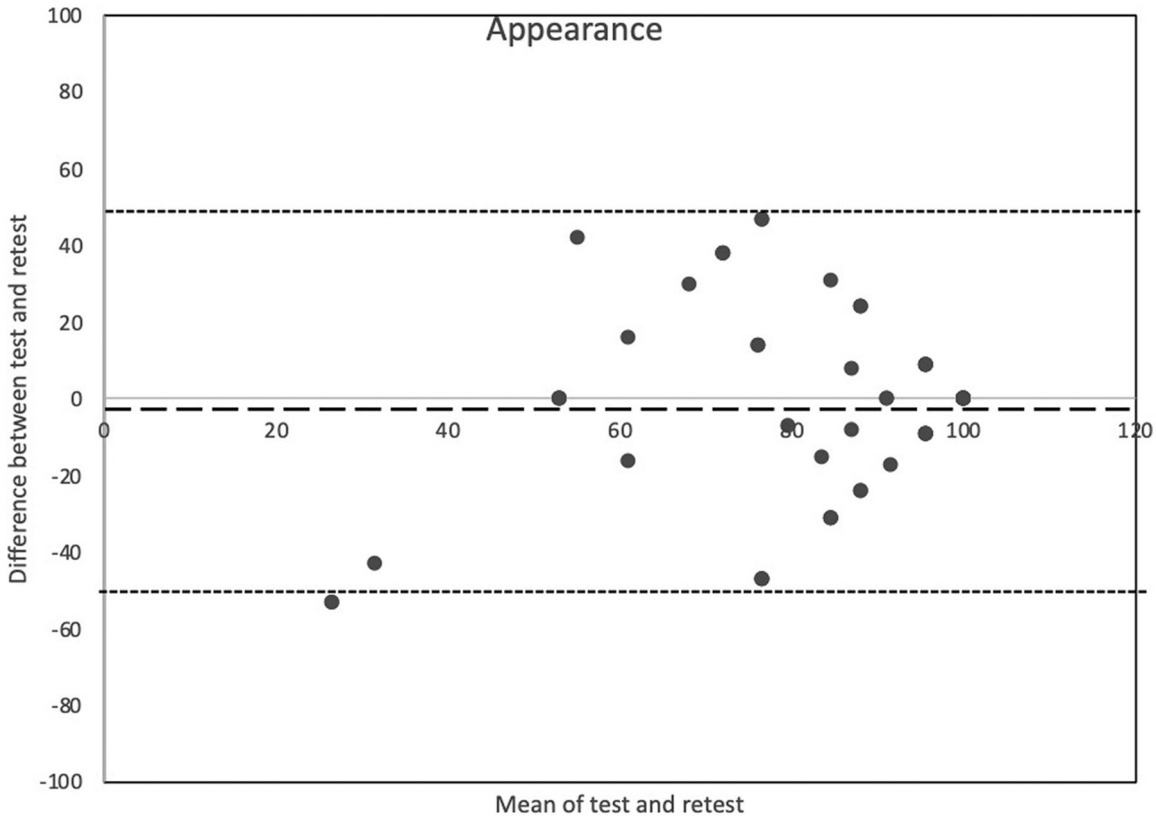

Figure 5. Bland–Altman plot for coping. Dotted lines are Mean score 1 and score 2 (7.7) and Limits of agreement (−60 and 75). Calculations are based on Rasch converted scores (1–100).

Table 8. Correlation between Breast-Q (0-100) and VAS.

	Gamma	95% CI
Support	0.058	−0.078; 0.195
Pain	−0.441	−0.564; −0.318
Coping	−0.196	−0.363; −0.030
Appearance	−0.313	−0.459; −0.166

Table 9. Floor and ceiling effects.

	Floor		Ceiling	
$N = 129$	n (%)	95% CI	n (%)	95% CI
Support	1 (0.8%)	0.14; 4.26	17 (13%)	8.4; 20.1
Pain	0	0.0; 2.9	34 (26%)	19.5; 34.6
Coping	0	0.0; 2.9	76 (59%)	50.3; 67.0
Appearance	0	0.0; 2.9	43 (33%)	25.8; 41.8

outcome rather than anticipated outcome. It has, for example, been found in previous research on patients' expectations for health care that realistic expectations in general are lower than ideal expectations [30]. More studies are needed on what type of expectations we are measuring with BREAST-Q expectations.

A breast reconstruction is a patient-chosen adjunct in breast cancer treatment. As a breast reconstruction is something the woman chooses to have herself, it is performed primarily to enhance quality of life and she invests time, discomfort and recovery efforts to have it, it can be assumed that expectations in general are high. Hence, it would be expected that more women reach the threshold for the ceiling effect, than for the floor effect (Table 9). Nonetheless, the high number of women reaching the ceiling threshold is suboptimal if the instrument is going to be used to identify patients with unrealistic expectations [15]. The high levels of ceiling effect (Table 9) could be an indication that there should be more items to enable the instrument to discriminate between high expectations and too high, unrealistic, expectations. More studies are needed on how we can evaluate if expectations are realistic or not.

Even if it could be assumed that expectations for positive outcomes in general are high due to the individual's investment and free choice to undergo breast reconstruction, it does not explain why there were high expectations for pain (having a lot of pain). There are probably many factors that contribute to a patient's expectation for pain, with the most obvious one being the preoperative information that patients receive from doctors regarding pain associated with surgery. Nonetheless, as already mentioned, it is likely that the instrument needs more items to better discriminate between high and too high expectations for pain. Unrealistically high expectations for pain could be particularly important to identify as they might influence an individual's perception and might be modifiable with the correct preoperative information [31,32].

Conclusions

The results of the study support that the Swedish version of BREAST-Q expectations has a good content and face validity, and internal consistency. Convergent validity and known-group validation cannot be adequately examined for expectations. Further studies are needed regarding test–retest reliability. High ceiling effects indicate that the instrument cannot discriminate between patients with high expectations and very high expectations. More studies are needed on how we can evaluate if expectations are realistic or not.

Acknowledgements

We are immensely grateful to the patients for completing the questionnaires. We also thank our colleagues, plastic surgeons Dr Fredrik Brorson, Dr Andri Thorarinsson, Dr Christian Jepsen, and associate professor Mattias Lidén for help in reconciling the two Swedish translations.

Ethical approval

The Swedish Ethical Review Authority reviewed and approved the study (2020-04729). All participants provided written informed consent to participate in the study.

Author contributions

LW made substantial contribution to the conception and design of the study, the analysis and interpretation of the data and drafted the work. AGE made substantial contribution to the analysis and interpretation of the data and revised the work. CL made substantial contribution to the analysis and interpretation of the data and revised the work. EH made substantial contribution to the conception and design of the study, the analysis and interpretation of the data and drafted the work. EH supervised LW. All authors read and approved the final manuscript.

Disclosure statement

No potential conflict of interest was reported by the author(s).

Funding

Open access funding provided by University of Gothenburg. The study was funded by grants from The Swedish Cancer Society [21 0279 SCIA-EH], the federal government under the ALF agreement [ALFGBG-724171 and ALFGBG-965161 -EH], The Percy Falk Foundation, Stockholm, Sweden (EH) for research into prostate cancer and breast cancer, and The Swedish Breast Cancer Association (EH). The sources of funding had no role in the design of the study and collection, analysis, and interpretation of data and in writing the manuscript.

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Data availability statement

The datasets generated and analysed during the current study are not publicly available due to patient confidentiality, but are available from the corresponding author on reasonable request and permissions.

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