

Trends in Emotional Functioning and Psychosocial Wellbeing in Breast Cancer Survivors

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Abstract

Purpose

A breast cancer diagnosis can threaten every aspect of a woman's wellbeing, including her mental health. With the growing number of breast cancer survivors, longitudinal studies addressing mental health in this population are of increasing importance now more than ever. Therefore, the current study investigated trends in emotional functioning and psychosocial wellbeing of breast cancer survivors, and the demographic and treatment characteristics that may influence these trends.

Methods

Prospectively collected data of women treated for breast cancer at the Erasmus MC was analyzed in this study. Emotional functioning was measured using the EORTC-QLQ-C30, while psychosocial wellbeing was measured using the BREAST-Q. Type of surgery, age, family status and employment status of study participants were retrieved from patient files. Multilevel analysis was performed to identify trends in emotional functioning and psychosocial wellbeing and to determine the relationship between aforementioned characteristics and these trends.

Results

334 cancer survivors were analyzed. Psychosocial wellbeing declined, but emotional functioning showed a steady improvement over time. Type of surgery was associated with changes in emotional functioning and family status with changes in psychosocial wellbeing: women who underwent breast reconstruction showed a steeper increase in their emotional functioning and women with no partner or children showed a greater decline in psychosocial wellbeing between baseline and 12 months after surgery.

Conclusion

These findings can be utilized by healthcare teams to identify breast cancer patients at risk for emotional problems and to provide adequate psychological support to those women who need help dealing with their emotions and self-concept in order to optimize clinical treatment.

Background

Breast cancer is the leading female malignancy and cause of death for women in both developing and developed countries [1]. It is the most common cancer diagnosis in women in the Netherlands [2]. Significant advancements in cancer diagnostics and treatment over the years have rendered the lifetime risk of breast cancer death to drop from 1 out of 22 women in 1990 and 1 out of 24 in 2000 to 1 out of 27 in 2010 [2]. However, the experience of cancer is known for its effects on mental health. Some studies

state that cancer and its treatment can be so traumatizing that the distress associated with cancer has been compared to the course and symptom structure of post-traumatic stress disorder [3–5].

Studies documenting the experiences of breast cancer survivors emphasize the transient nature of dysfunctions in wellbeing; they found that the pretreatment phase (phase between diagnosis and initial treatment) is marked by the most critical changes to one's self-concept and lifestyle [6–10]. Examining the trends in mental health and wellbeing can be vital to identifying potential points in the trajectory of breast cancer where women are most vulnerable to respond to adverse effects of breast cancer (treatment) with diminished levels of functioning.

Therefore, the current study aimed to find out how levels of emotional functioning and psychosocial wellbeing in breast cancer survivors change as a function of time. Based on the literature, it is expected that patients will follow a U-shaped trend: levels will first decline, then incline as a function of time by virtue of personal resources like coping and social support [6–11]. From these trends that emerge, the present study further aimed to identify factors or characteristics associated with these trends. Based on previous literature, we expect factors such as age, family status, type of surgery and employment status to influence trends in wellbeing [9, 12, 13].

Methods

The employed cohort study was conducted to explore the trends of longitudinally collected patient-reported outcome measures (PROMs). This study is part of an ongoing set of studies investigating the quality of life of breast cancer patients, which was approved by the Medical Ethics Review Committee of the Erasmus University Medical Center (MEC-2018-1015). All data, including baseline patient characteristics and PROMs, were derived from the “Zorgmonitor”. The Zorgmonitor is an institution-specific online database that contains various PROMs collected at different time points [14, 15]. PROMs are administered preoperatively (T0), three (T3, within the subset of patient treated with neo-adjuvant systemic therapy) and six months (T6) after surgery, a year (T12) postoperatively and yearly thereafter. As part of the routine care protocol, informed written consent was obtained from all the patients in this study during the administration of the initial questionnaires at T0 for storing their information in the “Zorgmonitor” and using it for research purposes thereafter. The date of data extraction was March 4th, 2019.

Demographic and Treatment Characteristics

Breast cancer patients (≥ 18 years) treated at the Academic Breast Cancer Center, Erasmus MC between October 2015 and March 2019 were included in this study. The demographic characteristics of interest were patient's age at the time of diagnosis, family status and employment status. Type of surgery was classified as “none” (if they had not yet undergone any surgery), “breast-conserving therapy” (BCT), “mastectomy”, and “reconstruction”. Family status was classified as “no partner/children”, “partner”,

“children”, “partner and children”, while employment status was categorized as “employed” and “unemployed”. Age was kept as a continuous variable.

Patient-Reported Outcome Measures

The PROMs used in this study were the EORTC-QLQ-C30 (The European Organization for Research and Treatment of Cancer Quality of Life Questionnaire) and the BREAST-Q [16, 17]. For this study, the subscales “Emotional Functioning” (EORTC-QLQ-C30) and “Psychosocial Wellbeing” (BREAST-Q) were analyzed.

EORTC-QLQ-C30

This questionnaire measures multiple dimensions of quality of life in cancer patients. It includes 30 questions categorized into five functional scales (physical, social, role, emotional and cognitive), three symptom scales (fatigue, pain and nausea/vomiting), a global health status scale, and additional single items which address common symptoms of cancer patients. The “Emotional Functioning” scale used in this study comprises four questions with respect to the emotional functioning of the respondent in the previous week: “Did you feel tense?”, “Did you worry?”, “Did you feel irritable?”, and “Did you feel depressed?”. Responses are measured on a 4-point Likert scale, and scores are standardized into a range from 0 to 100 with higher scores representing better functioning [18]. EORTC-QLQ-C30 is a strongly validated and reliable measure of QoL which has been translated into many languages [19–22]. The Dutch version of this questionnaire shows high internal consistency (Cronbach’s $\alpha = 0.86$) for the “Emotional Functioning” scale used in the study [22].

BREAST-Q

The BREAST-Q was developed to quantify the effect of different types of breast surgery on quality of life. It consists of six subscales, namely, “Psychosocial Wellbeing”, “Physical Wellbeing”, “Sexual Wellbeing”, “Satisfaction with Breasts”, “Satisfaction with Outcome” and “Satisfaction with Care”. The “Psychosocial Wellbeing” subscale used in this study comprises 10 items for breast conserving therapy (BCT), mastectomy and reconstruction modules with respect to how often the respondent felt the following things about her breasts in the previous two weeks: “Felt comfortable in a social situation”, “Felt capable of doing things you want to do”, “Felt emotionally healthy”, “Felt as worthy as other women”, “Felt confident”, “Felt feminine with clothes on”, “Felt that you have accepted your body”, “Felt normal”, “Felt like other women” and “Felt attractive”. Responses are measured on a 5-point Likert scale, and transformed into a range from 0–100 with higher values representing a better wellbeing [21]. The preoperative version was administered to all patients at baseline, while surgery-specific versions (breast-conserving therapy, mastectomy or reconstruction) were administered at follow-ups. This questionnaire has a good reliability with Cronbach’s $\alpha > 0.80$ for all subscales [23, 24]. The “Psychosocial Wellbeing” subscale shows high internal consistencies (Cronbach’s $\alpha = 0.95, 0.95, 0.96$) for BCT, mastectomy, and reconstruction modules, respectively [25].

Statistical Analyses

Longitudinal analyses were performed with multi-level regression analyses for both subscale scores. The covariance structures were determined with restricted maximum likelihood, while the fixed part of the models with ordinary maximum likelihood. 'Months since baseline' or 'm' was constructed as the difference between each patient's date of response to questionnaires at T0, T6, T12 and T24, and their registration date. To identify linear and possible non-linear changes in subscale scores, 'm' and the logarithm of 'm' were entered as fixed covariates. Each demographic and treatment characteristic were then separately entered as a covariate to the previous models, resulting in eight multilevel models. The predictor effects of each demographic and treatment characteristic were determined for subscale scores at T12. Data was analyzed using IBM Statistical Package for Social Sciences (SPSS) version 24.0 software [26].

Results

Sample Characteristics

The initial sample size was 345 patients. After data cleaning, participants were excluded if they had not completed the questionnaires at any time point (N = 9) or if they were duplicates (N = 2). 334 participants were ultimately analyzed. The CONSORT flow chart of dropout rates at each time point is provided in Fig. 1.

Table 1 shows that BCT was the most common surgery undergone by study participants. Most participants in this sample were employed and had both a partner and children. Average age was 52.7 years. However, women in the (mastectomy plus) reconstruction group were 14.6 and 14.5 years younger than those in the mastectomy (without reconstruction) and lumpectomy groups, respectively ($p < 0.001$), while employed women were 15.4 years younger than their counterparts ($p < 0.001$). The 4.2% of women who had not undergone surgery ("none" category) yet, consisted of women who either received neoadjuvant endocrine treatment for a longer time and had not received their surgery yet, or had distant metastases and went on palliative treatment.

Table 1
Baseline Demographic characteristics of the sample of breast cancer survivors (N = 334)

Predictors	Categories	N (%)	Mean age per group (years)	SD
Age			52.74	14.0
Type of surgery	None	14 (4.2)	44.4	14.4
	BCT	188 (56.3)	54.9	13.0
	Mastectomy	92 (27.5)	55.0	14.8
	Breast reconstruction	40 (12.0)	40.4	8.9
Family status	No partner/children	49 (14.7)	55.8	15.2
	Partner	104 (31.1)	55.2	14.6
	Children	15 (4.5)	57.6	11.2
	Partner and children	162 (48.5)	50.0	13.0
Employment status	Unemployed	125 (37.4)	62.5	12.6
	Employed	248 (61.1)	47.0	11.5
BCT: breast conserving therapy				

Trends in “Emotional Functioning” and “Psychosocial Wellbeing”

The changes in emotional functioning and psychosocial wellbeing at different timepoints are presented in Table 2, along with their effect sizes. The estimates of the multilevel analyses are displayed in Appendix A. These tables show that emotional functioning and psychosocial wellbeing both had comparable baseline scores and showed a significant non-linear trend. Emotional functioning of breast cancer survivors significantly increased since baseline (log time *est.* = 2.83, *SE* = 0.99, *p* = 0.004), while psychosocial wellbeing significantly declined until a year after surgery (log time *est.* = -5.37, *SE* = 1.94, *p* = 0.006). However, ‘estimated psychosocial wellbeing’ scores that were modeled based on the analysis (Fig. 3a) show that psychosocial wellbeing may show a slight increase one year after surgery.

Table 2

Estimates for Changes in “Emotional Functioning” and “Psychosocial Wellbeing” at different Time Points

	Time points	Emotional functioning			Psychosocial wellbeing		
		est.	d	p	est.	d	p
Baseline	T0	72.99			72.98		
Change	T6	5.28	0.29	< 0.001	-7.51	-0.41	< 0.001
since	T12	6.82	0.31	< 0.001	-7.90	-0.43	< 0.001
baseline	T24	8.23	0.45	< 0.001			
Predictor effects at 12 months							
Type of surgery							
BCT		8.22	0.54	< 0.001	-6.93	-0.38	0.001
Mastectomy		1.35	0.09	0.599	-9.03	-0.50	< 0.001
Reconstruction		13.08	0.87	< 0.001	-5.05	-0.28	0.126
Differences between trends in types of surgery at 12 months							
Mastectomy - BCT		-6.87	-0.46	0.025	-2.09	-0.12	0.512
Reconstruction - BCT		4.87	0.32	0.234	1.88	0.10	0.631
Mastectomy - Reconstruction		-11.74	-0.78	0.010	-3.97	-0.22	0.330
Family status							
No Partner/Children		3.00	0.14	0.391	-10.34	-0.56	0.008
Partner		6.94	0.31	0.002	-9.04	-0.49	< 0.001
Children		11.81	0.53	0.047	-5.31	-0.29	0.356
Partner & Children		7.28	0.33	< 0.001	-6.50	-0.35	0.002
Age							
At mean age		6.54	0.30	< 0.001	-8.01	-0.44	< 0.001
10 years older		4.45	0.20	0.007	-8.54	-0.46	< 0.001
Employment status							
Unemployed		5.72	0.26	0.010	-8.69	-0.47	< 0.001

**p* values = sig. of differences of time-point with baseline

***d* = Cohen's *d* effect size

Time points	Emotional functioning			Psychosocial wellbeing		
	est.	d	p	est.	d	p
Employed	7.56	0.34	< 0.001	-7.48	-0.41	< 0.001
* <i>p</i> values = sig. of differences of time-point with baseline						
** <i>d</i> = Cohen's <i>d</i> effect size						

Differences between groups and predictor effects on trends in emotional and psychosocial wellbeing

The results of multilevel analyses examining the predictor effects on trends in emotional functioning and psychosocial wellbeing are presented in Appendix B. Table 2 shows the predictor effects on changes in emotional functioning and psychosocial wellbeing between baseline and 12 months (i.e. difference between T12 and T0 for each category of predictor variable). T12 was chosen as the primary timepoint for comparing the groups because psychosocial wellbeing was not recorded at T24.

Predictor effects of surgery type show that while emotional functioning of the mastectomy group remained fairly stable between baseline and T12 (MAS *est.* = 1.35, *d* = 0.09, *p* = 0.599), BCT and reconstruction groups showed a significant increase in functioning, with reconstruction group showing the sharpest increase (BCT *est.* = 8.22, *d* = 0.54, *p* < 0.001; REC *est.* = 13.08, *d* = 0.87, *p* < 0.001). Psychosocial wellbeing showed a significant decline between baseline and T12 for BCT and mastectomy groups (BCT *est.* = -6.93, *d* = -0.38, *p* = 0.001; MAS *est.* = -9.03, *d* = -0.50, *p* < 0.001), but not for reconstruction (REC *est.* = -5.05, *d* = 0.28, *p* = 0.126). The differences in the trajectories in emotional functioning and psychosocial wellbeing for different surgery types are displayed in Fig. 2.

All family situations except the group with no partner or children showed a significant incline in emotional functioning. Psychosocial wellbeing declined for all family situations, but the decline was the greatest for the group with no partner or children. Employment status and age were not significantly related to trends either in emotional functioning or psychosocial wellbeing.

Discussion

The main goal of this study was to identify whether there were any trends in emotional functioning and psychosocial wellbeing in breast cancer survivors over time. The results showed that psychosocial wellbeing of our sample decreased over a period of one year. Hence, psychosocial wellbeing partly followed the pattern that is in line with findings for the first year in other studies [7, 8]. However, emotional functioning followed a different trend as it increased with time. Thus far, emotional functioning and psychosocial wellbeing have been grouped together and most studies on post-traumatic stress in breast cancer survivors have considered them to be very closely related [5, 6, 27, 28]. However, the diversification that was found in the trends between emotional functioning and psychosocial wellbeing in this study, as measured by common instruments like EORTC-QLQ-C30 and BREAST-Q, suggests that they may better be considered as separate outcomes.

The differences between the trajectories of emotional functioning and psychosocial wellbeing can be explained by looking closely at the differences between the emotional functioning subscale of EORTC-QLQ-C30 and the psychosocial wellbeing subscale of BREAST-Q. The emotional functioning subscale measures the general determinants of negative mood, such as anxiety, irritability, and depression [16], whereas the questions for psychosocial wellbeing are more specific and correspond to perceptions of self-worth and self-confidence, which are phrased with respect to the breasts [22].

A cancer diagnosis is marked by fears and uncertainty about treatment, stress, anger and depressive symptoms [29]. This could explain why the emotional functioning in this study was the lowest at baseline and consistently increased with time thereafter, a finding also reported by studies investigating different types of cancer patients [6, 9–11]. By contrast, the psychosocial wellbeing was the highest at T0. Considering that this measurement was taken before the participants had undergone any breast surgery, it might explain why psychosocial wellbeing with respect to their breasts is highest preoperatively [23–25]. The trajectory showed a dip in psychosocial wellbeing at 6 months after surgery, which persisted till one year postoperatively. This is in line with findings about the pretreatment phase [6–10], which is said to cause disruption to one's self-concept. Incorporating cancer into one's life and self-concept is a dynamic process of maintaining mental wellbeing and this data suggests that this process might take more than a year to accomplish.

Furthermore, it was found that the reconstruction group had both the highest increase in emotional functioning and an insignificant decline in psychosocial wellbeing between baseline and a year after surgery. This is in contrast to the findings from other studies, which found that women who receive breast reconstruction have more mood disturbances and distress than those who undergo mastectomy, up to twelve months after baseline [6, 12, 30–32]. Perhaps, the difference between previous research and the current study's findings can be accounted for by differences in practices regarding patient-centered care. Having unrealistic expectations about the outcomes of breast reconstruction can drastically reduce the emotional wellbeing of patients after surgery [33, 34]. However, over the past years, efforts have been undertaken to improve patient education by discussing these expectations extensively in the preoperative phase in our center, which may suggest that adequate patient-centered care moderates the influence of surgery on patient wellbeing [31, 32]. It was also found that women with no partner or children showed the most significant decline in psychosocial wellbeing and stable levels of emotional functioning. These findings corroborate with previous studies that highlight the importance of social support in the navigation and management of different phases of the cancer journey [7, 11–13].

The strength of this study lies in its prospective character. Past studies were retrospective in nature and collected data by asking the participants to look back on their journey, thereby confounding the results with recall bias [4, 9, 11]. Another important strength is the collection of baseline PROMs [4].

Study limitations

A shortcoming of this study is the inconsistency in questionnaire administration. Because the BREAST-Q was not administered at T24, in order to understand how psychosocial wellbeing changed after a year, the trajectory had to be modeled (see Appendix B). Data quality and value of these findings could have been enhanced when both questionnaires had been administered at the same time-points. Another limitation of the present study is that we did not control for whether women underwent systemic treatment. Systematic treatment may have an influence on the emotional and psychological outcomes of the patients. Therefore, it is recommended that future research includes this factor when exploring emotional functioning and psychosocial wellbeing in breast cancer survivors.

Clinical Implications and Conclusion

This study highlights the need for alertness on emotional and psychosocial problems in certain groups, particularly from diagnosis to the first 10–12 months. The diagnosis phase is the starting point of the cancer journey and is marked by distress associated with high levels of uncertainty [6–10], so the role of the professional here is to pay attention to the increased survival rates and the overall good treatment outcomes in terms of quality of life [2, 35]. One of the most significant decisions the patient makes in this phase concerns the type of surgery [34]. Hence, supportive care should facilitate an open dialogue between the patient and the professional about her preferences, expectations and the level of freewill in selecting a type of surgery [35]. While most women in this sample underwent breast-conserving therapy, reflecting national data, this option is not feasible for some patients for example in large, multicentric carcinoma, DCIS, or after previous radiation treatment [32]. If that is the case, and patients would have preferred this treatment option, patients should be given space and enough time to express disappointments, ask questions about other possibilities and process any loss of control. Breast reconstruction, on the other hand, is often a product of choice [12, 30–34]. However, the experience of women undergoing reconstruction may vastly differ based on the timing of reconstruction after mastectomy, type of reconstruction, and the occurrence of surgery-related complications [6, 12, 30, 31, 34]. Hence, apart from expectations, these factors must also be discussed in depth before a decision is made.

One of the most significant findings in this paper is the realization that emotional functioning and psychosocial wellbeing are not the same in breast cancer survivors. Especially, during the crucial time points of 6 months and a year after their surgery, their scores on PROMs should be screened carefully to identify significant deviations from baseline. In doing so, it is important to keep in mind that emotional functioning and psychosocial wellbeing are not necessarily (entirely) related to breast cancer treatment. It may be that there are other important life events affecting the patients' wellbeing [29].

In addressing deviations or high scores, it is important to have an open attitude and not refrain from asking how patients feel. Even though there may be adverse emotions related to breast cancer treatment, this is not a reason not to address it during the consultation. In fact, patients may benefit from an open and understanding conversation with their physician on their treatment outcome [36], especially if the patient perceives the outcome as disappointing [37, 38]. Physicians may be afraid that asking about mental health and wellbeing would elicit a strong, unpredictable reaction that may be hard to control or

time-consuming, but this fear turns out to be unfounded. Several studies have shown that patients highly appreciate an empathetic understanding from their doctor [36–39]. Moreover, it appears that such small gestures do add to their wellbeing and their treatment evaluation [36, 38, 39]. For patients for whom a conversation with the physician does not seem enough to address possible mental health issues, the physician may discuss referral to mental health team available in the hospital. Even then, it is advised that the physician inquires about a patient's wellbeing in the first place because otherwise a mental health problem, for which evidence-based treatment exists and is indicated, could have been missed. Therefore, a discussion of PROM scores offers the opportunity to further improve the quality of care.

Declarations

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Availability of data and material: The data that were analyzed during this study are available upon reasonable request from the corresponding author. The data are not publicly available due to privacy and ethical restrictions.

Code availability: Not applicable to this paper.

Authors' contributions: All authors involved in this publication have made substantial contribution to the study conceptualization and design, and have provided critical revisions to the text. Data acquisition was conducted by Sri K. Devarakonda, Arvind Oemrawsingh, and Inge Apon, and data analysis and interpretation were performed by Sri K. Devarakonda, Reinier Timman and Arvind Oemrawsingh. All authors have read and are in approval of this manuscript for publication.

Ethics approval: This study was granted approval by the Medical Ethics Review Committee of the Erasmus University Medical Center (MEC-2018-1015) and therefore, was performed in accordance with the principles of Declaration of Helsinki.

Consent to participate: Written informed consent was obtained from all the patients in this study.

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Appendix

Appendix A. Multi-level models

	Intercept			Linear time			Log time		
	Estimate	S.E.	<i>P</i>	Estimate	S.E.	<i>P</i>	Estimate	S.E.	<i>P</i>
Emotional Functioning									
Main	72.99	1.26	<.001	-0.04	0.14	.801	2.83	0.99	.004
Type of surgery									
BCT *	73.87	1.57	<.001	-0.06	0.17	.726	3.48	1.20	.004
Mastectomy †	-0.67	2.99	.822	0.32	0.38	.389	-4.20	2.47	.090
Reconstruction †	-6.88	4.14	.097	-0.49	0.46	.287	4.17	3.17	.189
Family status									
Partner & children *	70.51	1.82	<.001	-0.15	0.26	.562	3.55	1.67	.034
Partner †	5.06	2.91	.083	0.10	0.32	.304	-0.59	2.22	.791
Children †	5.20	6.27	.407	-0.21	0.98	.831	2.75	5.76	.634
No Partner/Children †	3.63	3.72	.329	0.74	0.65	.251	-5.14	3.76	.172
Age									
At mean age *	73.41	1.25	<.001	-0.03	0.14	.832	2.69	0.98	.006
Each year older †	0.41	0.10	<.001	-0.00	0.01	.980	-0.08	0.08	.336
Employment status									
Employed *	73.33	2.09	<.001	-0.24	0.28	.383	3.37	1.81	.063
Not employed †	-0.64	2.65	.808	0.27	0.33	.406	-0.55	2.17	.799
Psychosocial wellbeing									
Main	72.99	1.10	<.001	0.49	0.41	.237	-5.37	1.94	.006
Type of surgery									
BCT *	74.75	1.36	<.001	0.38	0.63	.543	-4.49	2.91	.123
Mastectomy †	-6.21	2.56	.016	0.20	0.92	.825	-1.77	4.32	.682
Reconstruction †	-1.54	3.51	.662	-0.14	1.10	.896	1.41	5.28	.790
Family status									

Partner & children *	70.53	1.59	<.001	0.64	0.59	.278	-5.54	2.78	.047
Partner †	4.84	2.51	.055	-0.61	0.91	.507	1.84	4.31	.670
Children †	2.26	5.46	.414	-0.48	1.80	.791	2.70	8.54	.753
No Partner/Children †	4.39	3.17	.166	0.63	1.34	.637	-4.46	6.22	.474
Age									
At mean age *	73.05	1.10	<.001	0.48	0.42	.260	-5.34	1.96	.007
Each year older †	0.08	0.08	.345	-0.01	0.03	.792	0.02	0.15	.902
Employment status									
Employed *	71.95	1.79	<.001	0.05	0.72	.947	-3.61	3.29	.273
Not employed †	1.45	2.27	.524	0.62	0.88	.484	-2.41	4.09	.555

*reference; †additional; S.E.= standard error

Appendix B is not available with this version.

Figures

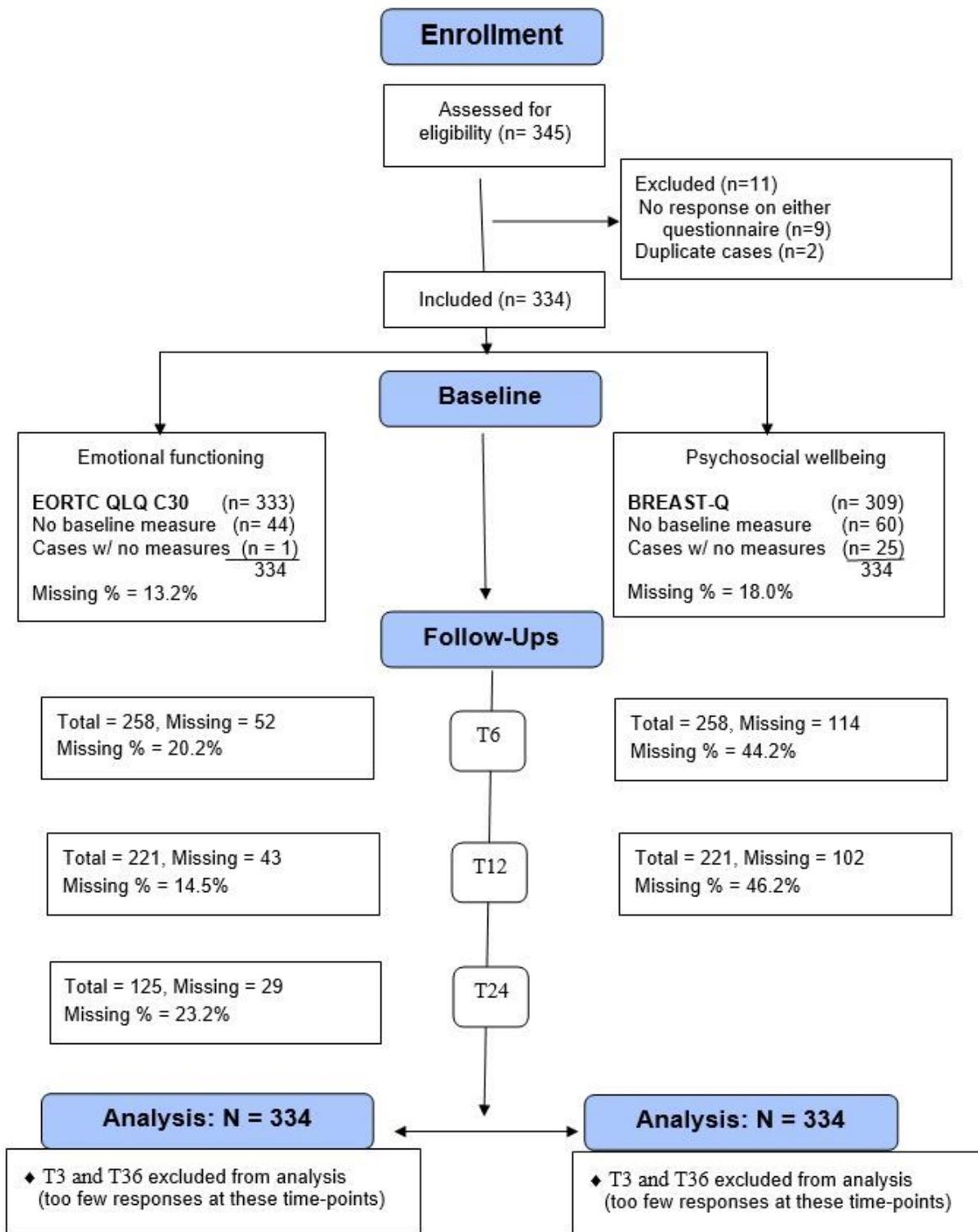


Figure 1

CONSORT Flowchart

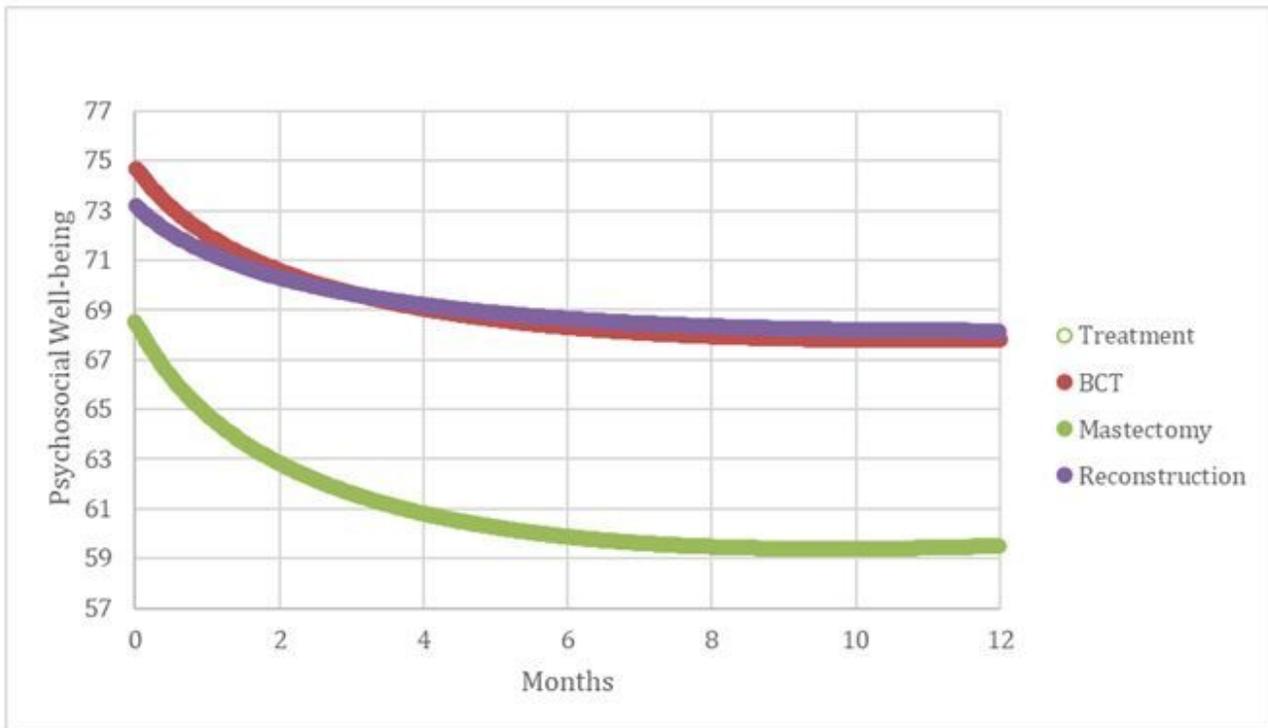
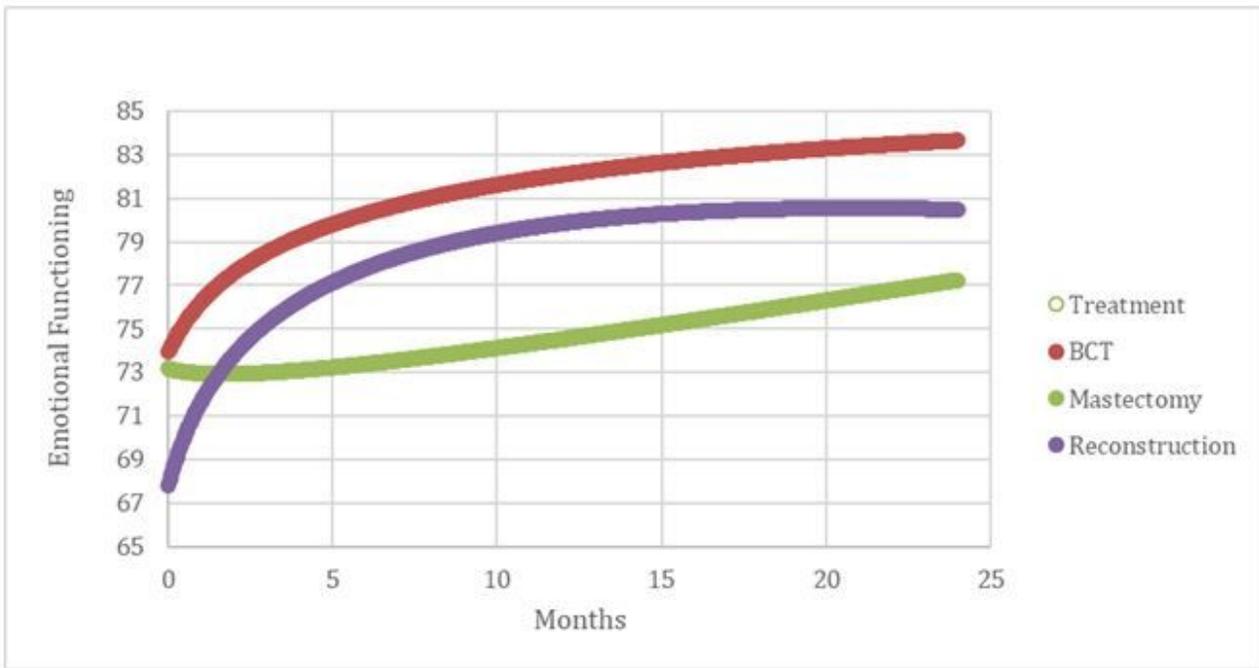


Figure 2

a Trends in Emotional Functioning b Trends in Psychosocial Wellbeing

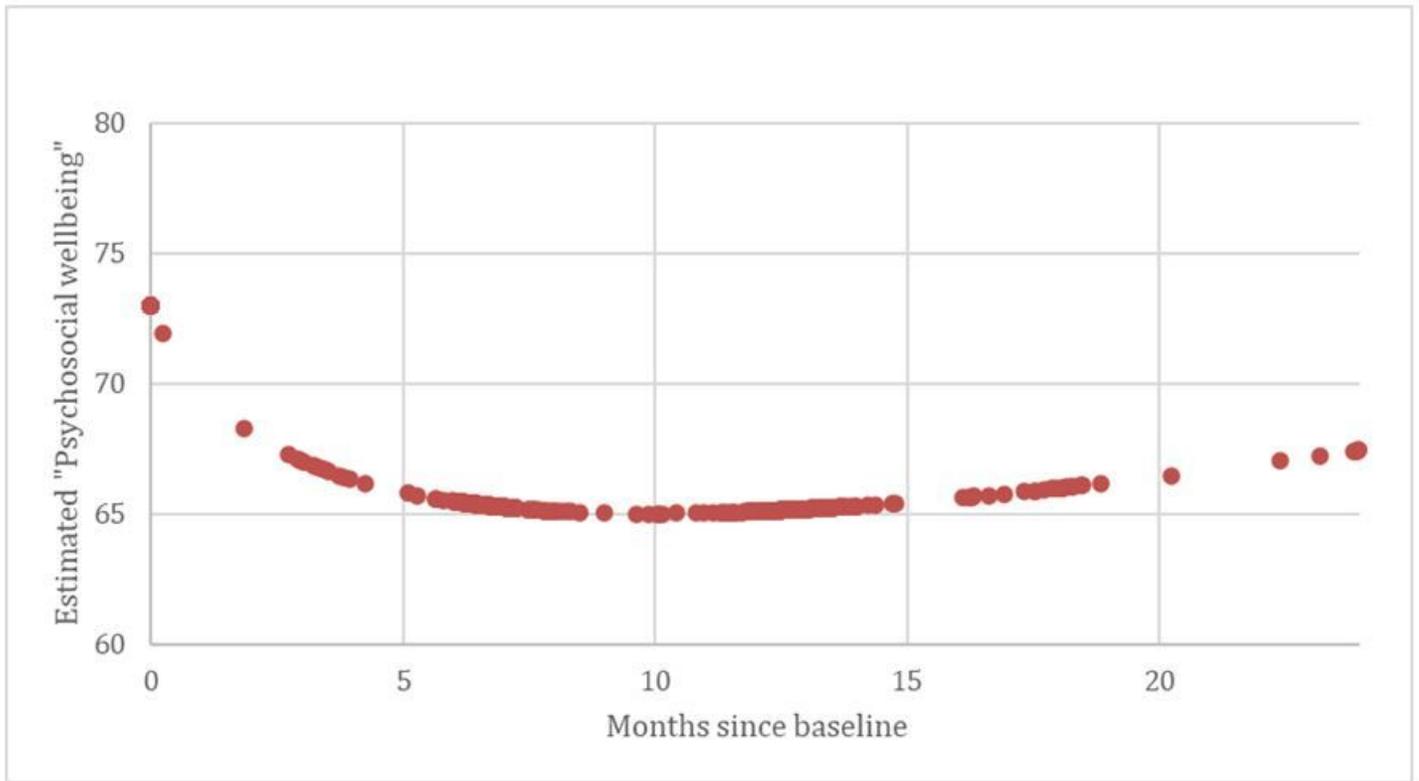


Figure 3

Trends in Estimated Psychosocial Wellbeing