

# Sexual well-being in patients with early-stage breast cancer at 1- and 2-year follow-up

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## Abstract

**Background:** Sexual well-being (SWB) is an important aspect of overall quality of life and should therefore be considered when measuring the effect of breast cancer on daily life.

**Aim:** To identify positive and negative predictive factors associated with change in SWB 1 year after diagnosis (T12; hereafter,  $\Delta$ SWB) and whether SWB changes the year after.

**Methods:** All data were derived from an online patient-reported outcome measure that included patients aged >18 years who were treated for breast cancer between October 2015 and March 2022 at the Erasmus University Medical Center. Multivariable linear regression was used to analyze the association between demographic- and disease-specific variables and change in SWB between time of diagnoses (T0) and one year after (T12) ( $\Delta$ SWB). For defining the clinical relevance of  $\Delta$ SWB, patients were divided into 3 groups based on their SWB score at T12: decreased, stable, and improved. Wilcoxon signed rank test was used to test the difference in SWB between T12 and T24 (2 years after diagnosis) in all 3 groups.

**Outcomes:** Outcomes included the associations between demographic- and disease-specific variables and  $\Delta$ SWB (T0 vs T12) and change in SWB the year after (T12 vs T24).

**Results:** An overall 204 patients were included, with a mean age of 51.7 years (SD, 12.8) and a mean SWB score of 64.3 (SD, 20.9) at T0. Body mass index >30 kg/m<sup>2</sup> at T0 had a significant negative association ( $\beta = -8.369$ ,  $P = .019$ ) with  $\Delta$ SWB. Reconstruction ( $\beta = 20.136$ ,  $P < .001$ ) and mastectomy ( $\beta = 11.157$ ,  $P < .001$ ) had a significant positive association with  $\Delta$ SWB vs lumpectomy. Change in psychological well-being had a significant positive relation to  $\Delta$ SWB ( $\beta = 0.349$ ,  $P < .001$ ). Patients with decreased SWB at T12 did not improve the year after ( $P = .376$ ).

**Clinical Implications:** By identifying the variables that are associated with decreased SWB during the trajectory of breast cancer treatment and by defining the clinical relevance of decreased SWB, patient groups can be targeted and offered extra support.

**Strengths and Limitations:** This study is one of the first to analyze the development of SWB, instead of sexual function, over time in patients with breast cancer, and it uses data over a longer period. However, only one-third of the patients responded to the SWB domains at both time points.

**Conclusion:** Type of operation, body mass index >30, and change in psychological well-being were associated with  $\Delta$ SWB. Patients with decreased SWB 1 year after diagnosis tended not to improve or normalize the year after, indicating that intervention is needed to restore SWB in this specific group.

**Keywords:** sexual well-being; BREAST-Q; breast cancer; patient-reported outcome measure; value-based health care.

## Introduction

Breast cancer is the most common cancer diagnosis among women. The incidence in the Netherlands is still increasing (103.4–153.2 per 100 000 women between 1990 and 2014).<sup>1,2</sup> Fortunately, improvements in treatment strategies have increased the survival rate and life expectancy. The risk of breast cancer death has decreased from 1 in 22 to 1 in 27 women,<sup>3</sup> which has resulted in an increasing number of women dealing with the consequences of breast cancer diagnosis and the life thereafter. Patients who have breast

cancer face difficult challenges throughout and after their trajectory of disease, which may compromise their quality of life (QoL).<sup>4,5</sup> Due to the increasing life expectancy, it becomes more important that day-to-day breast cancer care focus on improving the different aspects of QoL.

According to the World Health Organization, an important aspect of QoL is sexual well-being (SWB).<sup>6</sup> SWB is defined as a state of physical, emotional, mental, and social well-being in relation to sexuality; it is not merely the absence of diseases, dysfunction, or infirmity.<sup>6</sup> SWB is known to

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be negatively affected by breast cancer, causing a decreased QoL.<sup>7</sup> Currently, it is estimated that the majority of the breast cancer survivors report decreased SWB at some point after their diagnosis. This can be due, though not exclusively, to the side effect of received endocrine therapy or chemotherapy, which leads to a reduction in sexual desire, lubrication difficulties, and vaginal pain.<sup>7,8</sup> However, even patients who did not receive adjuvant therapy report decreased SWB due to psychological factors (eg, negative body image and disruption of survivors' intimate relationships).<sup>8,9</sup>

To date, however, studies about SWB are mainly cross-sectional and focused on sexual dysfunction instead of SWB as a whole.<sup>8,10–12</sup> Sexual dysfunction is limited to disorders of desire, arousal, orgasm, and sexual pain.<sup>13</sup> Examining the trends in SWB and identifying risk factors could inform and help patients and health care professionals in the process of shared decision making, thereby improving QoL. If impaired SWB does not resolve with time, it could be a target for intervention.

This study therefore aims to identify positive and negative predictive factors associated with SWB 1 year after diagnosis. Moreover, it aims to define whether patients with decreased, stable, and improved SWB 1 year after diagnosis improve 2 years after diagnosis without intervention. On the basis of the literature, we expect the following factors to influence SWB: endocrine therapy, age, body mass index (BMI), menopausal status, type of surgery (breast conserving, mastectomy, or reconstruction), change in psychological well-being (PWB), family status, and adjuvant or neoadjuvant chemotherapy.<sup>7,8,11,12,14–19</sup>

## Methods

### Study participants

Patients with breast cancer aged >18 years who were treated between October 2015 and March 2022 at the Academic Breast Cancer Center, Erasmus University Medical Center in Rotterdam, who gave informed consent for the Healthcare Monitor were included in this study. Only patients who were treated with curable intent were included. If disease progressed to metastasized disease where treatment goals changed to life prolongation, patients did not receive any more invitations.

### Data collection

All data, including demographic- and disease-specific information, were derived from the Healthcare Monitor, an institution-specific online patient-reported outcome measure (PROM; Erasmus University Medical Center). Data were collected via Gemstracker. The following demographic- and disease-specific variables were of interest and collected: age, menopausal status, BMI at baseline, type of surgery (breast conserving, mastectomy, or reconstruction), endocrine therapy, PWB (measured by the PWB domain of the BREAST-Q), family status (partner vs no partner), and adjuvant or neoadjuvant chemotherapy (yes/no). Mastectomy and reconstruction were mutually exclusive in this study, as cases with mastectomy without a reconstruction were labeled as *mastectomy* and those with mastectomy and reconstruction were labeled *reconstruction* and not included in the mastectomy group. Neoadjuvant chemotherapy is given before the operation, whereas adjuvant chemotherapy starts after the operation. The breast cancer-specific PROMS

were administered preoperatively and 3, 6, and 12 months postoperatively and yearly thereafter. For this study, the BREAST-Q score at T0 (at diagnosis) and at T12 and T24 (1 and 2 years after diagnosis) was derived from the Healthcare Monitor.

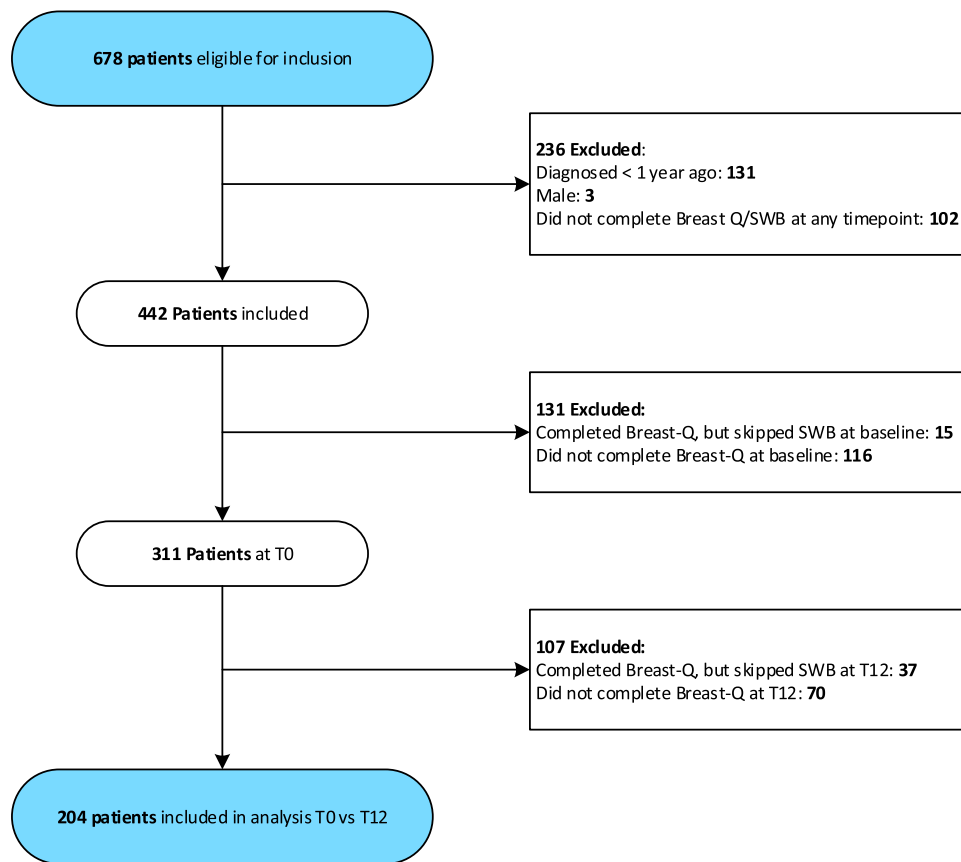
### BREAST-Q

The BREAST-Q is a validated, widely used, breast surgery-specific PROM that assesses patient satisfaction, health-related QoL, and patient experience in women prior and after different types of breast surgery to assess the effect of treatment on the domains.<sup>20</sup> The preoperative scale of the BREAST-Q contains 9 domains among SWB and PWB, each with several items that are scored on a Likert scale. Raw scores are converted per domain to a score from 0 to 100 by rasch measurement methods, where 100 represents the best outcome. Higher scores mean higher satisfaction of better health-related QoL. All scales showed high reliability (Cronbach  $\alpha > 0.80$ ).<sup>21–23</sup> The postoperative BREAST-Q is adapted by the type of operation and has different modules for augmentation, reduction, mastectomy, reconstruction, and breast-sparing surgery. They are developed in a way that overlapping domains can be compared among modules, without extra conversion of scores.<sup>20</sup> Only the PWB and SWB domains of the BREAST-Q were analyzed in this study. The latter is composed of 6 questions concerning body image, sexually confidence, and satisfaction. All questions within the SWB domain are the same across the preoperative module and the modules for mastectomy, reconstruction, and breast-sparing surgery, with the exception of 2 extra questions for the breast-conserving module. SWB is an optional domain and could be skipped by the patients. The PWB domain consists of 10 questions concerning emotional status, self-confidence in social situations, and feeling of equality with other women.

### Statistical analyses

Data were presented as count and percentage for categorical variables and mean and SD for continuous normally distributed variables. Skewness and kurtosis were used to test age and change in PWB for normality. Spearman rank correlation coefficient was used to determine the correlation coefficients of SWB at baseline, T12, and T24. The strength of correlation coefficients was defined as none ( $|\rho| \leq 0.2$ ), weak ( $0.2 < |\rho| \leq 0.4$ ), moderate ( $0.4 < |\rho| \leq 0.75$ ), and high ( $|\rho| > 0.75$ ). We did expect at least a moderate correlation between the SWB at baseline and T12 and that at T12 and T24. We also expected at least a weak correlation between SWB at baseline and T24, since these time points are further apart.

Multivariable linear regression was used to analyze the association between the change in SWB between T0 and T12 (hereafter,  $\Delta$ SWB) and the following: age, type of surgery, adjuvant and neoadjuvant chemotherapy, family status, menopausal status, endocrine therapy, and change in PWB ( $\Delta$ PWB; defined as the increase or decrease of PWB 1 year after diagnosis).  $\Delta$ SWB was defined as the SWB score at T12 minus that at T0, which results in a negative delta when SWB decreased over time and a positive delta when SWB increased over time. All variables were entered together into 1 model because we know from the literature that these variables are associated with SWB.<sup>7,8,14</sup> The residuals of linear regression were tested for homoscedasticity and normality. The variables were tested



**Figure 1.** Flowchart of patient selection. SWB, sexual well-being; T0, at diagnosis; T12, 1 year after diagnosis.

for multicollinearity, with all factors showing low probability for multicollinearity (variance inflation factor <5).

Patients who did not complete SWB at 1 of the time points, T0 or T12, were included in the nonresponder analyses. The independent *t*-test and the Fisher-Freeman-Halton exact test were respectively used for age and type of operation.

To see whether decreased SWB at T12 improved at T24 and if stable and improved SWB at T12 changed at T24, patients were divided into different groups based on a minimal important change of 4, as defined by Voineskos et al.<sup>24</sup> SWB at T12 and T24 were tested on normality, with *P* values rejecting the null hypothesis for all groups. Wilcoxon signed rank test was used to test differences in SWB between T12 and T24 in all 3 groups. Statistical analyses were performed with SPSS (version 28.0.1.0; IBM).

### Ethical considerations

The data for this article were collected from an ongoing prospective study investigating the QoL of patients with breast cancer, which was approved by the Medical Ethics Review Committee of the Erasmus University Medical Center (MEC-2018-1015). Informed consent from participants for storing and using information for research purposes was obtained during the first questionnaire, as part of routine care protocol.

## Results

### Study participants

On March 16, 2022, an overall 678 patients were eligible for inclusion: they approved to be part of the Healthcare Monitor,

and at least 1 clinical outcome or part of a PROM was registered. Of these, 131 received their breast cancer diagnosis <1 year ago and were therefore excluded, as there were no data available at T12. Males (*n* = 3) and patients who did not complete the BREAST-Q at any of the time points (T0 and T12) were excluded. As this study focuses on the change in SWB, patients without a response to the BREAST-Q and those who did not complete the SWB domain at T0 (*n* = 131) or T12 (*n* = 107) were also excluded (*n* = 238). A total of 204 patients were included for further analysis (Figure 1).

### Demographic variables

Among the 204 patients, the mean age was 51.7 years (SD, 12.8) and the mean SWB score was 64.3 (SD 20.9). The majority of the patients had a BMI <25 (50.5%) at the start of the treatment. Patients underwent a lumpectomy (110/204, 53.9%), mastectomy (57/204, 27.9%), or reconstruction (autologous or implant based; 37/204, 18.1%). Prior to surgery, 54 (26.5%) received neoadjuvant chemotherapy and 29 (14.2%) underwent adjuvant chemotherapy. Moreover 105 (51.5%) started endocrine therapy at some point during their treatment trajectory (Table 1). The mean age of patients undergoing lumpectomy, mastectomy, and reconstruction was 52.67 (SD, 12.36), 43.89 (SD, 11.32), and 54.89 (SD, 12.86) years, respectively. There was a moderate correlation between SWB at baseline and T12 ( $\rho = 0.444$ ; 95% CI, 0.323-0.551) and SWB at T12 and T24 ( $\rho = 0.661$ ; 95% CI, 0.543-0.753) and a weak correlation between SWB at baseline and T24 ( $\rho = 0.212$ ; 95% CI, 0.030-0.381]). The mean  $\Delta$ SWB at T12 was  $-17.17$  (SD, 22.06; range, 146) and that for  $\Delta$ PWB was  $-2.74$  (SD, 22.11; range, 145).

**Table 1.** Demographic variables (204 patients).

	Mean $\pm$ SD (range) or No. (%)
Age, y	51.70 $\pm$ 12.84
BMI, kg/m <sup>2</sup>	
<25	103 (50.5)
25-30	69 (33.8)
>30	32 (15.7)
Type of surgery	
Lumpectomy	110 (53.9)
Mastectomy	57 (27.9)
Reconstruction	37 (18.1)
Menopausal status	
Premenopausal	78 (38.2)
Perimenopausal	34 (16.7)
Postmenopausal	92 (45.1)
Family status: no partner	31 (15.2)
Neoadjuvant chemotherapy: yes	54 (26.5)
Adjuvant chemotherapy: yes	29 (14.2)
Endocrine therapy: yes	105 (51.5)
Psychological well-being	
T0	73.53 $\pm$ 17.30 (66)
T12	67.11 $\pm$ 19.37 (86)
Sexual well-being	
T0	64.31 $\pm$ 20.91 (100)
T12	47.14 $\pm$ 46.02 (100)
T24	46.42 $\pm$ 19.19 (100)

Abbreviations: BMI, body mass index; T0, baseline; T12, 1 year after diagnosis; T24, 2 years after diagnosis.

### Multivariable regression

The residuals were normally distributed. BMI >30 at baseline had a significant negative association ( $\beta = -8.369$ ,  $P = .019$ ) with  $\Delta$ SWB. The other demographic variables (partner, menopausal status, and age) at baseline were not significant predictors of  $\Delta$ SWB ( $P > .350$ ), when controlled for the other variables. Mastectomy ( $\beta = 11.157$ ,  $P < .001$ ) and reconstruction ( $\beta = 20.136$ ,  $P < .001$ ) had significant positive associations with  $\Delta$ SWB at T12 as compared with lumpectomy when controlled for the other variables. Other adjuvant and neoadjuvant treatments had no significant relation with  $\Delta$ SWB ( $P > .2$ ).  $\Delta$ PWB had a significant positive relation to  $\Delta$ SWB ( $\beta = 0.349$ ,  $P < .001$ ) when controlled for the other variables. Last, SWB at baseline was a significant predictor for  $\Delta$ SWB (Table 2).

### Nonresponder analyses

For the nonresponder analyses, we compared patients who were included ( $N = 204$ ) with patients who were excluded due to missing SWB at T0 or T12 ( $n = 238$ ; Figure 1). There was no significant difference in age or type of operation (Table 3).

### Analyses of SWB after 2 years

Seventy-seven patients did not complete the BREAST-Q at T24, from which 17 (22.07%) underwent surgery <24 months ago. Six patients did not complete the SWB domain at T24 (Figure 2). The remaining 121 patients were divided into 3 groups based on their  $\Delta$ SWB scores at T12: a decrease >4 points (out of 100), a stable score (between -4 and 4), and an increase >4 points. There was no significant difference between SWB at T12 and T24 for the patients with a decreased ( $P = .376$ ) or stable ( $P = .074$ ) SWB at T12. Patients with an improved SWB at T12 had a significantly lower SWB at T24 ( $P = .013$ ; Figure 3).

## Discussion

SWB is an important aspect of overall QoL and should therefore be considered when measuring the effect of breast cancer on daily life, especially since the life expectancy of women with breast cancer has increased.<sup>2,6-8,12</sup> Despite this, most research on sexual health has focused on sexual function, therefore missing other important factors that may influence sexual health. Moreover, as most studies have a cross-sectional setup, little is known about the long-term consequences of decreased SWB during the treatment trajectory.<sup>8,10-12</sup> The SWB domain of the BREAST-Q incorporates different parts of SWB, such as body image, satisfaction, and confidence. Most important, it focuses on the perceptions of the patients themselves and not solely on sexual function and its sensitivity for change over time.<sup>20,22</sup> For this reason, this study used the SWB domain of the BREAST-Q to assess factors associated with a change in SWB 1 year after diagnosis. Finally, it assessed whether patients with decreased SWB 1 year after diagnosis recovered 2 years after diagnosis.

This study showed an overall mean SWB of 64.31 at T0, which is slightly higher than norm values of the healthy Dutch population set by Clarijs et al.<sup>25</sup> Despite the fact that these norm values lack demographic variables to correct for, which makes a comprehensive comparison difficult, this could be seen as an indication for the baseline SWB, which is thus not evidently affected by the breast cancer diagnosis.

Regarding the results of SWB at T24 vs T12, it can be concluded that patients who showed a decrease >4 points at T12 did not improve 1 year later. This could be due to the fact no intervention or guidance for this subject was offered by a professional to the patients. This suggests that intervention is needed to restore SWB in this specific group. Interestingly, the patients who improved after 1 year showed, on average, a significantly decreased SWB the year after. This means that even people without a decrease in SWB should be counseled about the possible effects of breast cancer and its treatment on SWB.

Moreover, Clarijs et al did not find age to be a predictive factor for SWB, which is in line with the results of this study, when controlled for other variables in the multiple linear regression. While some studies have shown a significant association between age and SWB at any time point, the data are contradictory and the relatively small changes are making clinical relevance questionable.<sup>7,8,26</sup> The same accounts for having a partner. Our study showed no association between the presence or absence of a partner and  $\Delta$ SWB. However, the number of patients without partner is rather small, which makes it difficult to be conclusive about this variable ( $n = 31$ , 15.2%).

This study found a negative association between BMI >30 at baseline and  $\Delta$ SWB at T12. Weight problems, such as overweight and change in weight, are known to affect body image and SWB.<sup>27,28</sup>

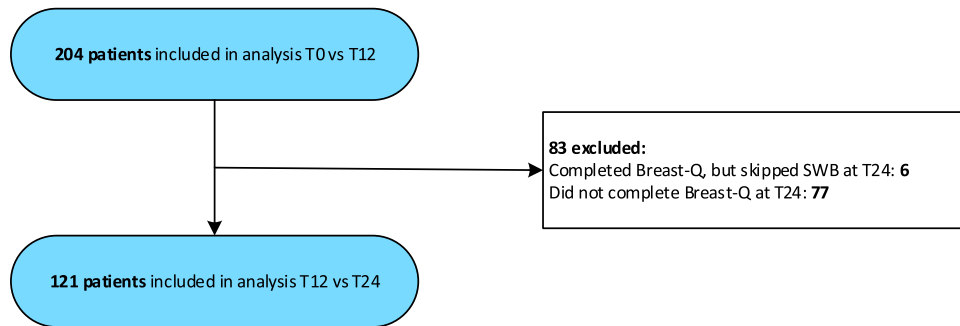
Menopausal status and endocrine therapy were not associated with a change in SWB, which is contradictory to most literature on sexual function.<sup>8,16,17,29</sup>

This could be explained by the fact that sexual function is not the same as SWB and women could adapt to sexual function symptoms such as vaginal dryness, atrophy, and decreased sexual desire. Also, some studies stated that the use of endocrine therapy does not worsen SWB even though it increases vaginal symptoms. It may indicate that the decrease

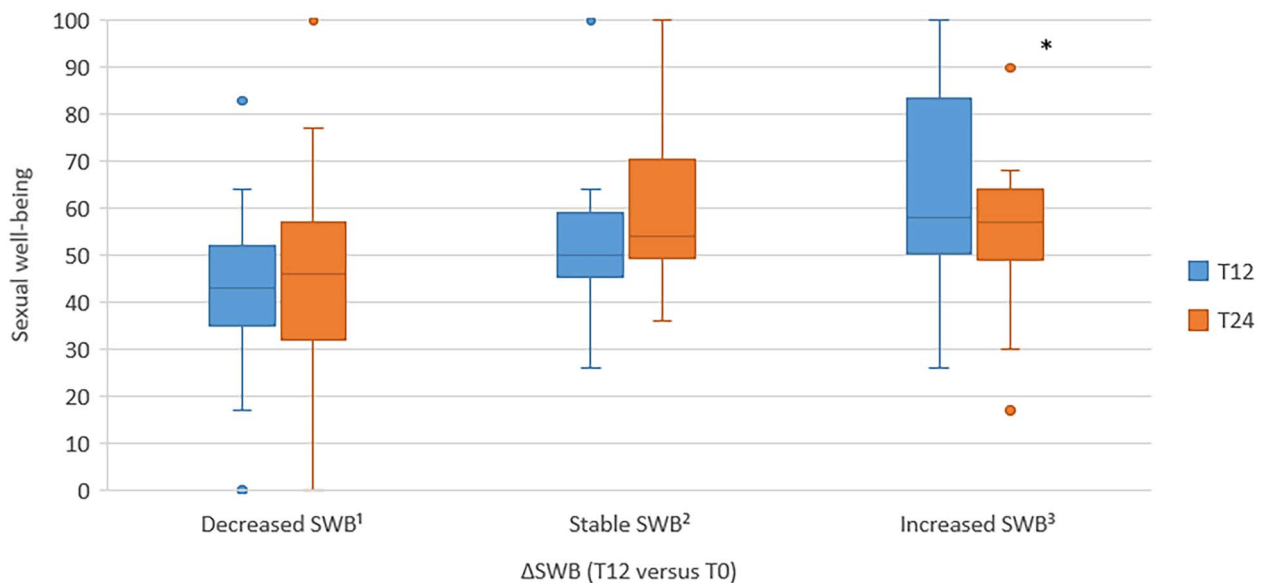
**Table 2.** Multivariable linear regression: ΔSWB (204 patients).

	$\beta$ (SE)	95% CI	P value
Age, y	-0.119 (0.159)	-0.433 to 0.194	.453
BMI, kg/m <sup>2</sup>			
<25	-2.363 (2.671)	-7.633 to 2.906	.377
25-30	Ref	—	—
>30	-8.369 (3.537)	-15.346 to -1.393	.019 <sup>a</sup>
Partner	2.753 (3.292)	-3.741 to 9.247	.729
Menopausal status			
Premenopausal	-2.293 (4.332)	-10.838 to 6.252	.597
Perimenopausal	3.284 (3.868)	-4.345 to 10.931	.397
Postmenopausal	Ref	—	—
Type of operation			
Lumpectomy	Ref	—	—
Mastectomy	11.157 (2.914)	5.408 to 16.905	<.001 <sup>a</sup>
Reconstruction	20.136 (3.297)	13.632 to 26.640	<.001 <sup>a</sup>
Endocrine therapy	-0.814 (2.346)	-5.442 to 3.813	.729
Neoadjuvant chemotherapy	-3.186 (2.940)	-8.985 to 2.614	.280
Adjuvant chemotherapy	-2.607 (3.564)	-9.638 to 4.424	.465
ΔPWB: baseline vs 12 mo	0.349 (0.065)	0.222 to 0.477	<.001 <sup>a</sup>
SWB at baseline	-0.502 (0.059)	-0.619 to -0.386	<.001 <sup>a</sup>

Abbreviations: BMI, body mass index; ΔPWB, difference in psychological well-being between T0 and T12; Ref, reference; SWB, sexual well-being; ΔSWB, difference in sexual well-being between T0 and T12; T0, at diagnosis; T12, 1 year after diagnosis. <sup>a</sup>P < .05.



**Figure 2.** Exclusion of patients for analyses at T24. SWB, sexual well-being; T0, at diagnosis; T12, 1 year after diagnosis; T24, 2 years after diagnosis.



**Figure 3.** Difference in sexual well-being at T12 and T24. ΔSWB categorized as follows: <sup>1</sup>Decrease >4 (minimal important change). <sup>2</sup>Maximum increase or decrease = 4. <sup>3</sup>Increase >4. ΔSWB, difference in sexual well-being between T0 and T12; T0, at diagnosis; T12, 1 year after diagnosis; T24, 2 years after diagnosis. \*P = .013.



**Table 3.** Nonresponder analyses.

	Mean $\pm$ SD or No. (%)		P value
	Responders	Nonresponders	
Age, y	51.70 $\pm$ 12.84	52.32 $\pm$ 13.51	.526
Type of operation			.411
Lumpectomy	110 (53.9)	118 (49.6)	
Mastectomy	57 (27.9)	79 (33.2)	
Reconstruction	37 (18.1)	37 (15.5)	
Missing	0 (0.0)	4 (1.7)	

in SWB due to endocrine therapy and postmenopausal symptoms could be overestimated, as it is associated with decreased sexual function but not with SWB.<sup>16,30</sup> This is supported by research stating that the majority of women with low sexual function do not report significant sexual distress, which is an important factor of sexual health.<sup>15</sup> For the same reasons, chemotherapy may not be associated with decreased SWB, even though it is the main cause, next to endocrine therapy, of premature menopause in patients with breast cancer.<sup>29,30</sup> However, data on possible alternative treatments or interventions, besides the care provided by the hospital, are lacking in our study. Patients with menopausal symptoms could have searched for treatments such as lubricant use or psychological support. This could have improved the outcomes of patients with side effects of the endocrine therapy and postmenopausal symptoms in this study, therefore not resulting in significantly decreased SWB.<sup>7,31</sup>

Very striking in our study were the positive significant effects of reconstruction and mastectomy as compared with lumpectomy on  $\Delta$ SWB. It was previously described that mastectomy without reconstruction can decrease SWB, probably due to lower body image and the feeling of being less feminine.<sup>10,11</sup> Lumpectomy, though, is known to be beneficial for body image and sexual health as compared with mastectomy.<sup>7,32</sup> However, our results could be explained by the fact that radiotherapy is known to affect body image and sexual health. Radiotherapy is a frequently used adjuvant therapy in patients undergoing lumpectomy.<sup>32</sup> Literature also states that patients undergoing mastectomy are less worried about recurrence of the disease, which is associated with decreased QoL and PWB, when compared with patients with breast-conserving therapy.<sup>33–35</sup> Yet, the exact influence on SWB remains uncertain as it has, to our knowledge, not been studied before. Unfortunately, data on radiotherapy and fear of recurrence are lacking in our study. Another explanation could be the lack of counseling on change in SWB in patients undergoing lumpectomy. Such patients may have higher expectations and therefore may experience more difficulties with adapting to the new situation, emphasizing the importance of good consultation. Literature shows that the majority of patients see information about SWB across stages of care very important.<sup>36</sup>

Last, change in PWB is an important predictor for  $\Delta$ SWB in this study. A previous study showed that even in women without cancer, worse PWB is associated with decreased sexual health.<sup>15</sup> Moreover, for a woman with breast cancer, reproductive health concerns and worrying about whether her partner wants to touch her operated breast can contribute to both decreased PWB and sexual distress.<sup>7,8,10</sup> This suggests an interplay between PWB and SWB, as supported by the fact that personality traits could influence overall QoL: patients with optimistic personality traits tend to score higher on psychosocial QoL domains.<sup>37</sup>

## Clinical implementations

This study contributes to a better understanding of the effect of breast cancer treatment on sexual health. Risk factors associated with decreased SWB 1 year after diagnosis could be discussed prior to treatment. In this way, patients know that this can occur during their trajectory, and they can take this into account during shared decision making. Supportive measures such as consultation with a sexologist could also be considered. Moreover, patients with a decrease  $>4$  points on the SWB score 1 year after diagnosis can be offered guidance, such as psychological consultation or education, especially because they will most likely not improve a year thereafter. Reese et al stated that only 30% of women were able to report a conversation with their oncologist about sexual difficulty.<sup>38,39</sup> Other studies showed that the majority prefer a health care provider to initiate the conversation.<sup>7,17</sup> We therefore encourage health care providers to discuss this topic with patients early in their disease trajectory as decreased SWB remains and does not resolve over time. Even in the group of patients where SWB initially improves first year of diagnoses, SWB decreases significantly the year after, indicating that most patients could benefit from good counseling about sexual health.

The results of this study suggest that solely discussing sexual dysfunction symptoms may not cover the complete concept of sexual health. Although the literature describes that menopausal status and endocrine therapy are associated with sexual dysfunction, our study did not show a similar association with SWB. This discrepancy may be explained by the fact that adequate coping or psychological interventions can improve SWB and consequently overall QoL, while the sexual dysfunction symptoms remain the same.<sup>7,31,39,40</sup> However, further research on this topic is needed.

## Limitations and further research

Several limitations were identified in this study. First, only one-third of the patients responded to the SWB domains at both time points, which might indicate that SWB is still a sensitive topic for patients and health care professionals. When SWB is not discussed in the consultation room, patients might not feel the need to complete the questions at the follow-up time points. This gives an indication that not every patient is willing to talk about it or does not feel free to discuss this with one's health care provider. More in-depth analyses are needed to find out why patients did not complete the SWB domain. Moreover, the Healthcare Monitor, an institution-specific online PROM, was one of the first PROM initiatives in the Erasmus University Medical Center after its implementation in 2015. In those years, little was known about the effects of breast cancer on QoL, making it difficult for health care professionals to put such outcomes into perspective. Due to the enormous growth in interest in PROMs and the increasing amount of literature published about the effect of breast cancer on QoL, more context is given to this concept. Ideally, this will result in more health care professionals reporting the findings to the patient in the consultation room. Also, all patients were invited to enroll in the Healthcare Monitor, even those who followed most of their treatment trajectories in a different hospital. A small number of patients may have underwent treatment in a hospital closer to home and therefore did not receive an invitation to complete the BREAST-Q. The nonresponder analyses did not find a significant difference

between the included and excluded patients in age and type of operation.

Second, we used the minimal important change of 4 based on a study of patients undergoing breast reconstruction.<sup>24</sup> To our best knowledge, such data have not been published for the BREAST-Q in patients after lumpectomy or mastectomy.

Third, it should be noted that some factors that are known to affect SWB, such as relationship satisfaction, education, and employment, are not included in our study. We know that low education level is negatively associated with SWB, as is relationship satisfaction.<sup>19,41,42</sup> This is also the case for mood disorders and SWB.<sup>19,42</sup> Even though we suspect that mood disorders are, to some extent, reflected in the PWB score, we did not take into account the presence of mood disorders.

For further research, we suggest investigating the effect of possible (psychological) interventions in patients with breast cancer, such as referral to a sexologist, to improve SWB, as little research is published on this topic. In other disease areas, psychological guidance is already proven to be effective for sexual health-related problems.<sup>43,44</sup> Next to this, little is known about possible barriers for health care professionals and patients to talk about SWB.<sup>39,45</sup> If we gain more insights in these barriers, effective training and/or education can help both stakeholders and improve the quality of care. Fortunately, more and more attention is given to this topic, resulting in initiatives such as the Pink Elephant (Roze Olifant), an educational project in the Netherlands.<sup>46</sup>

## Conclusion

This study showed the effect of patient- and treatment-related factors on the change in SWB over time in patients being treated for breast cancer. Type of operation, BMI > 30 kg/m<sup>2</sup>, and change in PWB were associated with a change in SWB 1 year after diagnosis. Menopausal status and endocrine therapy did not influence SWB. Patients with a decreased SWB score at 1 year after diagnosis tended not to improve or normalize the year thereafter, indicating that intervention is needed to restore SWB in this specific group and cannot be ignored.

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