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Body image in recently diagnosed young women with early breast cancer

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Abstract

OBJECTIVE—To assess body image concerns among young women following a breast cancer diagnosis.

METHODS—419 women with recently diagnosed stage 0-III breast cancer were surveyed following enrollment as part of a prospective cohort study of women age 40 or younger at diagnosis. Body image was assessed using three items from the psycho-social scale of the Cancer Rehabilitation Evaluation System (CARES). CARES scores range from 0–4, with higher scores indicative of greater image concerns. Mean CARES scores were calculated and compared between treatment groups using t-tests and ANOVA. Multiple linear regression models were fit to evaluate the relationship between physical and psychological factors and body image.

RESULTS—Mean time from diagnosis to completion of the baseline survey was 5.2 months. The mean CARES score for all women was 1.28. Mean CARES scores in the mastectomy-only group (1.87) and in the mastectomy with reconstruction group (1.52) were significantly higher ($p<0.0001$) compared to the scores in the lumpectomy group (0.85), indicating that radical surgery was associated with more body image concerns. Radiation ($p=0.01$), anxiety ($p=0.0001$), depression ($p<0.0001$), fatigue ($p=0.04$), musculoskeletal pain symptoms ($p<0.0001$), weight gain ($p=0.01$) and weight loss ($p=0.02$), in addition to surgery type ($p<0.0001$), were all associated with more body image concerns in the multi-variable analysis.

CONCLUSION—This analysis highlights the impact of treatment, along with physical and psychological factors, on body image early in the survivorship period. Our findings provide targets for potential future intervention and may aid young women in the surgical decision-making process.

Keywords

Breast cancer; oncology; young women; body image; mastectomy

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Introduction

A breast cancer diagnosis can have a profound impact on both short and long term quality of life (QOL), especially in young women. Recently, more attention has been directed toward medical and psychosocial outcomes among younger women with breast cancer. Ellsworth et al. [1] reported on an institutional series of women age 30 or younger who had reconstruction following mastectomy, highlighting the surgical choices made by this population, including a high rate of contralateral prophylactic mastectomy (CPM). In a retrospective analysis of a large national database, Freedman et al. [2] characterized treatment patterns among younger women, finding that those age 40 or younger were approximately twice as likely to report having had a mastectomy when compared to women aged 61–64. A recent comprehensive review by Howard-Anderson et al. [3] focused on a wide range of health and QOL issues affecting women diagnosed with breast cancer at age 50 or younger. This review, together with several earlier studies, are part of a growing body of evidence suggesting that younger women at increased risk for negative QOL outcomes compared to older women. [3–7].

Body image may be a particularly important issue in younger women: loss of a breast, surgical scarring, alopecia, weight changes, and lymphedema are all sequelae that can potentially impair quality of life in general, and body image in particular, in women treated for breast cancer. While many studies have found body image to be adversely affected both during and after treatment, the majority of these data were collected in older, post-menopausal populations [8–12]. To date, few studies have prospectively explored body image in young women (age ≤ 40) with breast cancer.

Using a large, prospective cohort study of young women with breast cancer, we sought to describe treatment-associated differences in body image concerns among young women. Theoretically, there might be factors associated with body image outcomes beyond treatment that may be amenable to intervention. We therefore wished to also identify whether certain physical and emotional side effects, were associated with body image independently of treatment type. This conceptual approach is similar to the framework presented by Ganz et al.[13] in their analysis of sexual functioning in breast cancer survivors, where it was hypothesized that several individual, disease-associated, and QOL factors might impact sexual functioning in women. Similarly, we anticipate that in addition to surgery type, side effects, including lymphedema, musculoskeletal symptoms, anxious/depressive symptoms, and weight change, will be related to body image in our analysis.

Patients and Methods

Participants

Beginning in November 2006, we enrolled women from ten sites into the Helping Ourselves, Helping Others: The Young Women's Breast Cancer Study, a prospective cohort study established to explore biological, medical, and QOL issues specific to young women with breast cancer. For the nine sites in Massachusetts, women were identified within six months of diagnosis using the Rapid Case Identification Core of the Dana-Farber/Harvard Cancer Center. Eligibility requirements included diagnosis with breast cancer at or under 40 years of age and less than six months prior to enrollment. Following enrollment and informed consent, women were mailed the baseline survey. The present analysis includes women who returned the baseline survey between December 2006 and March 2011. We excluded participants who did not respond to relevant questions on their baseline surveys (n=52), patients with stage IV disease (n=31) and patients with undocumented stage (n=9). In total, 419 women were eligible for inclusion in our analysis. This study was approved by

the Institutional Review Board at the Dana-Farber/Harvard Cancer Center as well as at other study sites.

Data and Instruments

Demographic, disease and treatment data—Age, race, ethnicity, and treatment information was self-reported by participants on the baseline survey. Medical record review was used to assess stage as well as reconcile missing treatment and socio-demographic data. Time from diagnosis was calculated using the interval between the date of diagnosis and the date the baseline survey was returned to study investigators. When the survey return date was undocumented (n=6), the date of the last menstrual period, which was asked on the baseline survey, was used as a proxy.

Dichotomous variables were created for the following treatment categories: chemotherapy (yes vs. no), hormonal therapy, i.e., treatment with tamoxifen, an aromatase inhibitor (AI), and/or medical or surgical ovarian suppression (yes vs. no), and radiation (yes vs. no). Primary breast surgery was divided into four groups: 1) mastectomy with reconstruction; 2) mastectomy only; 3) lumpectomy; 4) no surgery yet, e.g., women undergoing neo-adjuvant chemotherapy at the time of the baseline survey.

Assessment of body image—Body image was assessed using the Cancer Rehabilitation Evaluation System (CARES), a validated instrument that has been extensively used to evaluate QOL issues among individuals with cancer [14–16]. The CARES is composed of five summary scales: 1) physical function; 2) psycho-social function; 3) marital interaction; 4) sexual function; and 5) medical interaction [15]. The CARES body image sub-scale includes three items from the psycho-social scale: 1) I am uncomfortable with the changes in my body; 2) I am embarrassed to show my body to others because of my illness; 3) I am uncomfortable showing my scars to others. For these items, respondents are asked “How much does this apply to you?” on a 0–4 scale (0=Not at all, 1=A little, 2=A fair amount, 3 =much, 4=very much). The CARES body image score is calculated as the mean of the ratings for the three items. Scores range from 0–4, with higher scores indicating greater image concerns [14–16].

Assessment of other covariates—Depressive and anxious symptoms were assessed using the Hospital Anxiety and Depression Scale (HADS). The HADS scores range from 0–21 on the anxiety and depression subscales and a score greater than or equal to 11 on either is designated as representative of anxiety or depression, respectively [17]. Lymphedema, decreased range of motion (in the arm on the side that was operated on), general aches, joint pains, muscle stiffness, were evaluated using responses to selected items from the Breast Cancer Prevention Trial (BCPT) Symptom Checklist. Women were asked to report how much they were bothered by each symptom, with response options ranging from 0–4 (0=not at all; 4=extremely). Symptoms were grouped into the following two composite scales (BCPT Symptom Scales): musculoskeletal pain (general aches, joint pains, muscle stiffness) and arm symptoms (lymphedema, decreased range of motion) [18]. We also evaluated each BCPT item individually to appreciate how much each symptom contributed to its composite scale; any response ≥1 for an individual symptom was considered “symptomatic” vs. “asymptomatic” (response of 0) [19]. Fatigue/tiredness was assessed using the same scale (0=not at all; 4=extremely) and also analyzed as “symptomatic” (response ≥1) vs “asymptomatic” (response of 0).

Body mass index (BMI) was assessed from self-reported height and weight on the baseline survey. In addition, we calculated the change between pre-diagnosis body weight and body weight at the time of the baseline survey to account for potential differences in body image

that might be associated with either weight gain or weight loss during treatment. An increase or decrease of at least five pounds was categorized as weight gain or loss, respectively; any change less than five pounds was categorized as “no change.”

Statistical analysis

Frequencies and means were reported for categorical and continuous covariates, respectively. Unadjusted mean CARES scores were calculated and compared between groups using t-tests and one-way ANOVA. Multiple linear regression models were fit to control for potential confounding by stage, age, race, and time from diagnosis. All treatments were mutually adjusted for each other in the multivariable analyses. To assess the role of side effects, the final models included variables for depressive and anxious symptoms, baseline BMI, weight change, and the BCPT Symptom Checklist items/scales described above. All analyses were conducted in SAS version 9.2 (SAS Institute, Cary, N.C.).

Results

Study population characteristics

Table 1 includes demographic, disease, and treatment characteristics at the time of the baseline survey. Mean time from diagnosis to return of the baseline questionnaire was 5.2 months. The average time from diagnosis among patients who had undergone one of the 3 surgical treatment strategies was similar, with a mean of 5.1 months for lumpectomy, 5.6 months for mastectomy with reconstruction, and 5.7 months for mastectomy only. Women who had not yet had surgery at the time of the first survey were an average of 3.7 months post-diagnosis.

Mean age at diagnosis was 35.7 years; most women (90%) identified as white non-Hispanic (WNH). The majority of women (80%) had either a Stage I or Stage II cancer; 68% of all tumors were hormone receptor positive. At baseline, most women were receiving or had received chemotherapy (72%) but only a small proportion of women had commenced adjuvant endocrine treatment or reported ovarian suppression (22%). 38% of women reported having had both a mastectomy and reconstructive surgery. Only 12% had not yet undergone a definitive surgical procedure at baseline.

Body image and surgical treatment groups

The mean CARES body image score for all women was 1.28 (range: 0–4). Unadjusted and adjusted mean CARES body image scores for each treatment group are reported in Table 2. Type of surgery was significantly associated with differences in scores ($p<0.0001$). Women who had a lumpectomy had the lowest mean score, which indicated significantly fewer body image concerns compared to both women who had a mastectomy with and without reconstruction ($p<0.0001$). The mastectomy-only group had the highest mean score, which was borderline significantly higher than the mean score of the reconstruction group ($p=0.05$), even after adjusting for age, race/ethnicity, stage, time from diagnosis, and other treatment received. While hormonal/ovarian suppressive therapy was associated with a higher score in the unadjusted analysis ($p=0.009$), after controlling for other treatments, age, race/ethnicity, stage and time from diagnosis, the difference in scores was no longer significant ($p=0.17$). There was no significant difference in mean CARES body image scores between women who were treated with chemotherapy and those who were not ($p=0.11$).

Additional factors associated with body image

In order to assess how additional factors affected the treatment-body image association, we added covariates for anxiety, depression, weight change, fatigue, and the BCPT scales to the model that included only treatment, socio-demographic characteristics, stage, and time from diagnosis. In these analyses (Table 3), type of surgery remained associated with body image even after adjusting for the other covariates. Radiation treatment (data not shown) was the only other treatment variable that was significant (p=0.01) in the multivariable model.

Of the covariates we hypothesized might affect the treatment-body image association, musculoskeletal pain symptoms (p<0.0001) and both anxious (p=0.0001) and depressive (p<0.0001) symptoms were associated with poorer body image. When analyzed individually, among the musculoskeletal pain symptoms, only muscle stiffness (p=0.01) was significant. Additionally, both weight gain (p=0.01) and weight loss (p=0.02) were associated with greater body image concerns as measured by the CARES.

When we excluded women who had returned their baseline surveys more than 12 months after their diagnosis (n=8), the results did not change substantially (data not shown). Similarly, when we restricted the analysis to include only women who had surgery (n=368), the results were similar (data not shown), with the exception of weight loss, which was no longer significant (p=0.14).

Discussion

To the best of our knowledge, this study represents the largest analysis of body image concerns among young women with breast cancer. Our finding that women who had a breast conserving procedure have the fewest body image concerns is consistent with most prior studies [8–10, 20–25]. However, our results suggest that while women undergoing more radical surgery are at greater risk for body image concerns, reconstructive surgery appears to mitigate that impact to some degree, at least in the short term. This is inconsistent with findings from some prior studies of the impact of surgery on short-term body image, which have found reconstruction to negatively impact body image following surgery. Janz et al. [6] reported body image to be poorest among women who had a mastectomy with reconstruction and Collins et al. found that at six months post surgery, women who had undergone reconstruction had worse body image compared to those who only had a mastectomy, although this difference was no longer apparent one year after surgery [9]. In a study by Fobair et al. [12], women who were considering or had already undergone reconstruction had the most body image concerns during the first few months following diagnosis. As the majority of the women included in these prior studies were older than 40, it is important to consider that the divergent findings regarding the impact of reconstruction might be reflecting differences in body image perceptions in young women vs. older women. Alternatively, some of the women in our cohort who only had a mastectomy might have chosen reconstruction were it a viable option (e.g., immediate reconstruction is sometimes delayed in women who need post-operative radiation therapy). It is therefore plausible that body image would be poorest among this subset, since these women would have opted for reconstruction because of concern with their appearance. This reasoning is supported by evidence that women who are forced to delay reconstruction are at more risk for adverse psycho-social outcomes, including poorer body image [26–28].

While our results demonstrate that between group differences do exist in the early treatment period, findings from other studies that have assessed body image later in the survivorship period have been mixed. Several studies have reported that women who had breast conserving surgery continue to report fewer body image concerns relative to women with more radical surgery in longer follow-up [10–11, 25, 29–32]. Other studies, however, have

found no differences between surgical groups in the years following treatment [33–34]. Additional follow-up of our cohort will allow us to evaluate the trajectory of body image changes over time, as well as examine whether differences we identified in this analysis persist many years after surgery.

In contrast to our findings, some prior studies have suggested that body image may be adversely affected in women undergoing chemotherapy. This is generally attributed to alopecia, a common toxicity of many chemotherapeutic regimens [6, 12, 35]. It is likely that the lack of association between chemotherapy and body image in our analysis is due to the specific body image measure we used. The CARES body image items focus more on the consequences of surgery (i.e., uncomfortable showing scars, embarrassed to show body) than on image issues that might be more closely related to chemotherapy treatment.

While chemotherapy itself was not associated with body image, other sequelae often associated with adjuvant treatment were, including fatigue, which is consistent with findings from a recent study in which fatigue was negatively correlated with body image [36]. Similarly, weight gain is a well-documented side effect of adjuvant treatment [37–39]. Weight loss has not been as widely reported; our findings suggest, however, that in the short term, both weight gain and weight loss are important in predicting body image concerns among younger women. While Fobair et al. [12] found that concern with either weight gain or weight loss was associated with poorer body image, most studies in breast cancer survivors have focused exclusively on perceptions of weight gain, which occurs much more commonly than weight loss in this population [3].

Only a small proportion of women reported use of tamoxifen, an AI, and/or ovarian suppression on the baseline survey; we expect this number to increase upon longer follow-up when additional women will have started a course of adjuvant endocrine treatment. While there is little evidence that endocrine treatment impacts body image either in the short term or the long term, most studies that have examined this relationship have been conducted in post-menopausal populations [9, 12, 33]. Future follow-up among this cohort will allow us to answer whether this holds true in younger women.

Several studies have found lymphedema to negatively affect psycho-social well-being, although few of these report on the specific impact on body image [40–44]. While we did not find any association between body image concerns and lymphedema or other arm symptoms, a low prevalence (10%) of women reporting any bothersome symptoms from lymphedema may have precluded us from detecting any effect. One possible explanation for the low prevalence of lymphedema-associated symptoms is that almost half of the sample reported undergoing a sentinel node biopsy only, a procedure that carries a much lower risk of causing lymphedema than a full axillary dissection [45–46]. Alternatively, lymphedema (potentially exacerbated by weight gain and additional treatment including radiation therapy) could manifest at a later time, and therefore may be more likely to affect body image in the long term. Radiation treatment, which at baseline was only reported in 18% of women, was a significant predictor of poorer body image in the multivariable model. We expect that additional women (i.e., women who had a breast conserving procedure, but were still undergoing chemotherapy at baseline) will report having radiation at the 1 year mark. Subsequent analyses will help us identify whether radiation treatment remains significantly associated with body image concerns, as well as whether treatment side effects like lymphedema, are more important in relation to long term body image concerns.

Our findings suggest targets for future intervention to improve body image among young women with breast cancer, including medical and psychosocial factors. The fact that surgery type remained independently associated with body image after controlling for additional

covariates (e.g., depression, anxiety, fatigue, weight change, musculoskeletal pain) indicates that while several of these factors account for some of the variance in body image in this population, they are not explicit mediators of the treatment – body image relationship. It's likely these symptoms are, more generally, sequelae of a breast cancer diagnosis, and not side effects that primarily arise as a direct consequence of surgical treatment. While there is not enough evidence of a true mediating effect, our results do imply that the presence of certain symptoms, including fatigue, anxiety, depression, musculoskeletal pain, and weight change, in addition to type of surgical treatment, might help identify who might be at higher risk for experiencing body image concerns among young women.

Results from intervention studies of women undergoing treatment support the notion that body image is a QOL domain which can be successfully targeted. One trial found a favorable impact of exercise on self-esteem, and another reported improved perceptions of body image associated with participation in a weight training regimen, suggesting that promotion of physical activity during treatment can improve body image and other psychosocial outcomes [47–48]. There is also evidence that psycho-educational interventions, as well as exercise, can help women successfully manage symptoms of fatigue, anxiety, and depression, resulting in better QOL including improved body image [49].

Our findings also have important implications for surgical decision making. Women weigh multiple factors when deciding which surgical treatment is appropriate and should be informed of the potential for greater image concerns associated with more radical surgery. For the majority of women who have a choice when it comes to type of breast surgery, awareness that body image might be more compromised with mastectomy than lumpectomy in the months following surgery may be an important part of the decision making process. Future research evaluating surgical decision-making in young women and associated body image and psychosocial outcomes is clearly warranted, particularly given the increase in bilateral mastectomies in recent years in this population [50–53].

We acknowledge that this study has limitations. Because women are enrolled into this cohort study following diagnosis, we do not have any information about body image issues present prior to this time. Since pre-existing body image concerns might affect surgical decision making, and are likely associated with perceived body image during and following treatment, we cannot exclude the possibility of unmeasured confounding by pre-diagnosis body image. In addition, the underlying conceptual framework of this study assumes that the symptoms we assessed precede the emergence of body image concerns in this cohort of younger women. However, while it's possible that both anxiety and depression might actually be consequences rather than predictors, many of the symptoms we did evaluate (i.e., fatigue, musculoskeletal symptoms) are unlikely to be downstream effects of body image.

In our multivariable analyses, we simultaneously tested for the association between higher CARES body image score and several covariates. While we cannot exclude the possibility that some of the significant associations we detected might be due to chance (i.e., as a consequence of multiple testing) most of the associations we did find were fairly strong, and would have been statistically significant even with a more conservative significance threshold.

While many of the factors detailed in our analysis are consistent with findings from prior studies of body image conducted in breast cancer patients, it is still important to keep in mind that younger women have unique psycho-social circumstances surrounding their cancer diagnosis. This study highlights the importance of considering QOL, including body image, in the overall context of cancer care of younger women during the early phases of

treatment. Determining whether certain treatments are associated with improved psychosocial outcomes may ultimately better inform treatment decisions made by patients. Given that the initial period following diagnosis has been understudied in this population, identifying which factors are associated with negative QOL outcomes is essential for designing and implementing appropriate interventions to help young women cope with both the diagnosis and the consequences of treatment.

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Table 1

Study population characteristics at time of completion of the baseline survey (n=419)

	N (%)
Mean age, years (SD)	35.7 (3.9)
Range	17–40
Mean time from diagnosis, months (SD)	5.2 (2.4)
Range	1–16
Mean CARES Body Image (SD)	1.28 (1.1)
Range	0–4
Race/ethnicity	
White Non-Hispanic (WNH)	376 (90)
Non-WNH	43 (10)
Stage	
0	25 (6)
I	147 (35)
II	190 (45)
III	57 (14)
Estrogen and/or progesterone receptor status	
Positive	284 (68)
Negative	135 (32)
Chemotherapy	
Yes	300 (72)
No	119 (28)
Hormonal therapy/ovarian suppression	
Yes	93 (22)
No	326 (78)
Radiation	
Yes	77 (18)
No	342 (82)
Lymph node dissection	
Full lymph node dissection	96 (23)
Sentinel node biopsy	200 (48)
Unknown/No surgical lymph node evaluation yet	123 (29)
Breast surgery	
Lumpectomy	148 (35)
Mastectomy	59 (14)
Mastectomy with reconstruction	161 (38)
No breast surgery yet	51 (12)

Table 2

Mean CARES body image scores by treatment type at baseline[a]

		Unadjusted		Adjusted[b]	
	N	Mean CARES [c]	p-value	Mean CARES [c]	p-value
Chemotherapy			0.15		0.11
Yes	300	1.33		1.34	
No	119	1.15		1.12	
Hormonal and/or ovarian suppression therapy			0.009		0.17
Yes	93	1.54		1.43	
No	326	1.20		1.24	
Radiation			0.15		0.11
Yes	77	1.45		1.49	
No	342	1.24		1.23	
Breast surgery			<0.0001		<0.0001
Lumpectomy	148	0.90		0.85	
Mastectomy	59	1.90		1.87	
Mastectomy + Reconstruction	161	1.47		1.52	
No breast surgery yet	51	1.06		1.06	

[a]Mean time from diagnosis to completion of the baseline survey was 5.2 months.

[b]Adjusted for age (years), race/ethnicity (White non-Hispanic(WNH) vs. non-WNH) stage (0-III), time from diagnosis (months), and mutually adjusted for other treatments: chemotherapy vs. none; radiation vs. none; hormonal (tamoxifen, aromatase inhibitor) and/or ovarian suppression therapy vs. none; lumpectomy vs. mastectomy alone vs. mastectomy with reconstruction vs. no breast surgery yet.

[c]Higher mean CARES body image scores are associated with more body image concerns.

Table 3

Coefficients (β) and standard errors (se) for breast surgery and potential mediating factors of the surgery-body image association

Association between breast surgery alone and CARES body image scores		
	β (se)	**p-value**
Breast surgery[a]		
Lumpectomy	Reference	
Mastectomy	1.01 (0.18)	<0.0001
Mastectomy with reconstruction	0.67 (0.13)	<0.0001
No breast surgery yet	0.20 (0.19)	0.28
Association between breast surgery and CARES body image scores after accounting for potential mediators		
	β (se)	**p-value**
Breast surgery[b]		
Lumpectomy	Reference	
Mastectomy	0.82 (0.16)	<0.0001
Mastectomy with reconstruction	0.61 (0.12)	<0.0001
No breast surgery yet	0.28 (0.18)	0.11
Depressive symptoms	0.75 (0.19)	<0.0001
Anxious symptoms	0.41 (0.11)	0.0001
Fatigue	0.37 (0.18)	0.04
Weight change		
Weight change <5 lbs	Reference	
Weight gain of ≥5 lbs	0.30 (0.12)	0.01
Weight loss ≥ 5 lbs	0.29 (0.12)	0.02
Arm problem scale[c]	0.07 (0.08)	0.38
Musculoskeletal pain scale[d]	0.20 (0.05)	<0.0001

Note: Positive coefficients with a p-value ≤0.05 are associated with higher CARES scores, which indicates significantly more body image concerns

[a]Adjusted for age, race/ethnicity, stage, time from diagnosis, treatment (chemotherapy, radiation, hormonal treatment/ovarian suppression).

[b]Adjusted for age, race/ethnicity, stage, time from diagnosis, treatment (chemotherapy, radiation, hormonal treatment/ovarian suppression), BMI at baseline, and potential mediating factors included in table.

[c]The BCPT arm problem scale is composed of the following symptoms: lymphedema and decreased range of motion.

[d]The BCPT musculoskeletal pain scale is composed of the following symptoms: muscle stiffness, general aches, and joint pains.