



## Surviving breast cancer: Women's experiences with their changed bodies



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### ABSTRACT

In this study, we explored women's experiences with their bodies following treatment for breast cancer. Eleven women who had been treated for the disease ( $M_{\text{time since treatment}} = 4.45$  years) were interviewed. Data were collected and analyzed using interpretative phenomenological analysis (Smith et al., 2009). Four main themes emerged from the data: changing visibly and invisibly; experiencing intense thoughts and emotions; meaning of the body: a vehicle of health, well-being, and social expression; and managing and dealing with physical changes. Overall, the women experienced various physical changes that shaped, mostly in a negative way, their perceptions, thoughts, attitudes, feelings, and beliefs about their bodies. The women described attempts to make positive lifestyle behavior choices (e.g., diet, participate in physical activity), and used other strategies (e.g., wigs, make-up, clothes) to manage their appearances and restore positive body-related experiences. Based on these findings, it is important to be cognizant of women's body image concerns following breast cancer given the poignant and lasting effects they can have on their psychosocial and emotional well-being.

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### Introduction

Breast cancer is the most common cancer among women worldwide (Ferlay, Shin, Bray, Forman, Mathers, & Parkin, 2010). Early detection and advances in treatments have led to an increase in survival rates, whereby 90% of women in developed countries are expected to survive the disease for at least 5 years (Youlden, Cramb, Dunn, Muller, Pyke, & Baade, 2012). Despite the promising survival rates, undesirable appearance-related side effects, such as loss of breast(s), tissue damage, deformities in the breast(s), decreased range of motion, lymphedema, alopecia, weight gain, and muscle loss/weakness, are commonly reported (Collins et al., 2011; Frith, Harcourt, & Fussell, 2007; Irwin et al., 2005; Shapiro & Recht, 2001). These changes can affect women's valuation of their bodies (Fobair, Stewart, Chang, D'Onofrio, Banks, & Bloom, 2006; Helms, O'Hea, & Corso, 2008; White, 2000). Indeed, researchers have shown that a number of survivors experience poor body image and body dissatisfaction (Chen, Liao, Chen, Chan, & Chen, 2011; Moreira & Canavarro, 2010), and this can persist for years following diagnosis and treatment (Falk Dahl, Reinertsen, Nesvold, Fosså, & Dahl, 2010). These

experiences can impair women's quality of life (QOL) by stimulating the development of unhealthy behavioral patterns and spirals of negative emotions (DeFrank, Mehta, Stein, & Baker, 2007; Elmir, Jackson, Beale, & Schmied, 2010; Helms et al., 2008; Lam et al., 2012; Moreira & Canavarro, 2012). For these reasons, body image is recognized as a key aspect of women's QOL posttreatment for the disease (Bloom, Stewart, Chang, & Banks, 2004; Collins et al., 2011; White, 2012).

Although the construct of body image has received attention in the oncology literature in the last few decades, there remain several noteworthy limitations. A first limitation pertains to its conceptualization. Body image is defined as an "internal representation of your own outer appearance" (Thompson, Heinberg, Altabe, & Tantleff-Dunn, 1999; p. 4), and it consists of perceptual (i.e., accuracy of body size estimation relative to actual size), attitudinal (i.e., subjective (dis)satisfaction of the body), affective (i.e., feelings associated with the body), cognitive (i.e., investment in appearance beliefs about the body), and behavioral (i.e., compensatory behaviors such as avoidance of situations where one's body is exposed, dieting, physical activity) dimensions (Cash & Smolak, 2011). Endorsing this multidimensional conceptualization, White (White, 2000; White & Hood, 2011) developed a heuristic cognitive behavioral model of body image for oncology, which is rooted in the general principles of cognitive behavioral (Cash, 2011) and self-discrepancy (Higgins, 1987) theories. Based on this model, cancer can activate people's appearance-related schemas, and this will influence

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their investment in their appearances and self-evaluations. In turn, people may experience negative appearance-related assumptions, thoughts, beliefs and feelings, and engage in compensatory behaviors to improve their appearances (White, 2012; White & Hood, 2011). Although this model, as well as Cash's (2011) cognitive behavioral theory of body image, could both serve as frameworks to comprehensively understand breast cancer survivors' body-related experiences, many researchers in the oncology field have taken a more restricted view of body image by focusing their attention on the assessment of body image evaluation (i.e., body (dis)satisfaction). Further, few have examined the different dimensions of body image concurrently in studies among breast cancer survivors. Consequently, we have a limited understanding of the complexity of women's experiences with their bodies posttreatment. It is for this reason that researchers should integrate these frameworks into their studies in order to advance research on body image in oncology.

A second limitation relates to the methodological approach used by researchers. Qualitative methodologies offer an opportunity to gain multifaceted, in-depth insight into women's lived experiences, and thus can provide a better understanding of how women experience physical changes due to the disease and its treatment (e.g., Rasmussen, Hansen, & Elverdam, 2010). While qualitative studies have been published on this topic (e.g., Ashing-Giwa et al., 2004; Landmark & Wahl, 2002), the primary focus has often been on exploring QOL and/or psychosocial concerns more broadly. As a result, emergent themes pertaining to body image are commonly grouped together into a single theme reflecting 'body image-related concerns.' This only serves to suggest women are concerned about the changes to their bodies caused by cancer and its treatment, and it reveals an important gap in the literature. It is solely by understanding the different dimensions integral to body image described above that researchers can build comprehensive interventions that combine perceptual, attitudinal, affective, and behavioral components, which may be more effective than single-focus interventions. Therefore, more qualitative studies focused specifically on body image are needed to explore these issues in more depth.

A third limitation is the minimal exploration of positive body-related experiences (Salick & Auerbach, 2006). Cancer can alter women's presumptive worldviews, and may engender positive and negative experiences. Some researchers have challenged the notion that experiencing breast cancer is solely negative by showing that survivors experience psychological growth, positive identity shifts, and enhanced self-perceptions (Sabiston, McDonough, & Crocker, 2007; Tedeschi & Calhoun, 2004). On the basis of this work, it is likely that women may also report positive body-related experiences. Thus, studies exploring women's negative and positive body-related experiences are warranted to provide an unbiased account of breast cancer survivors' likely multidimensional and varied experiences with their bodies.

A final limitation is the philosophical underpinnings of existing research. Despite the use of qualitative methodologies, many researchers have anchored their studies in positivist or postpositivist research paradigms and have tried to provide an objective explanation that leads to the prediction of phenomenon (Creswell, 2003). While these approaches have helped to advance the science of body image, the findings may be prematurely prescriptive since we know very little about the 'what', 'why', and 'how' of experiences with cancer and the body from the perspectives of the survivors themselves (Rasmussen et al., 2010). Hence, it is important to build on the extant research by endorsing a constructivism–interpretivism paradigm, where the goal is to understand the lived experience from the point of view of those who live it (Schwandt, 2000). In this paradigm, researchers play an important role since participants' experiences are elicited through

deep reflection that is stimulated by interactive dialog with the researcher.

In order to address these limitations, we conducted a qualitative study that was anchored in a constructivism–interpretivism paradigm to explore women's experiences with their bodies posttreatment for breast cancer. The specific approach to inquiry we used was interpretative phenomenological analysis (IPA; Smith, Flowers, & Larkin, 2009) because of its theoretical cornerstones: phenomenology, idiography, and hermeneutics. In this way, IPA is both a philosophy and a research method that allowed us to explore women's accounts of their lived experience (i.e., phenomenology) through detailed analysis of each case before identifying similarities and differences between cases (i.e., idiography), which were discovered through a process of interpretation (i.e., hermeneutics; Clarke, 2009). Further, the interpretation of these experiences helped to make sense of the survivors' stories within a theoretical and empirical lens.

## Method

### Participants

In line with Smith et al.'s (2009) recommendation for homogeneous and purposeful sampling, women were invited to participate in the study if they were treated surgically for breast cancer and completed chemotherapy and/or radiation for the disease. Women who were treated for a first diagnosis of breast cancer, able to provide written informed consent and communicate in English, and willing to discuss their experiences with their bodies were invited to participate in this study. The criteria of a first diagnosis was important since women's thoughts, feelings, and experiences may be heightened following an initial diagnosis because of the novelty of treatment, which might not be the case following recurrence due to habituation or desensitization (i.e., decreased response to the physical side effects that result from the repeated exposure). Furthermore, it is common to have recurrences in secondary locations (e.g., lung, bone) that would present diverse treatment challenges, and we wanted to avoid this to ensure that women's accounts were focused on breast cancer.

Eleven women who met these criteria expressed interest in this study, which is a sample size deemed appropriate for an IPA study (Reid, Flowers, & Larkin, 2005). The 11 women were 47 to 70 years ( $M = 56.36$ ;  $SD = 7.74$ ) of age, and all self-identified as Caucasian. Forty-five percent of these women were overweight or obese (body mass index  $\geq 25$  kg/m<sup>2</sup>), 64% had a college or university diploma/certificate, and 50% were postmenopausal. All the women were either married or living in a common-law partnership, except for one (Bianca). Based on self-reported data, the women were treated for Stage I to III breast cancer between 1 and 31 years prior to the study ( $M = 6.46$ ,  $SD = 8.38$ ), with most (64%) having completed treatment less than 5 years prior. The women had undergone several treatments for breast cancer, including surgery (lumpectomy (66.7%), single or double mastectomy (33.3%)), chemotherapy (75%), radiation therapy (75%), hormone therapy (83.3%), and reconstructive surgeries (27%). Table 1 provides a summary of these women's characteristics.

### Materials

An interview schedule was developed to facilitate a comfortable interaction with the women involved in this study and obtain a detailed account of their experiences. It served as a guide, rather than as a rigid structure, and allowed for further probing of any areas of interest as they emerged in the interviews (Smith et al., 2009). In line with IPA (Smith et al., 2009) and as recommended

**Table 1**  
Participants characteristics (N = 11).

Pseudonym	Age (years)	Weight status	Cancer stage	Years since treatment	Menopausal status	Treatments
Kitty	50	Overweight	II	2	Menopausal	Lumpectomy, radiation, hormonal therapy
Fannie	54	Healthy	I	2	Postmenopausal	Lumpectomy, radiation, hormonal therapy
Mary	50	Healthy	II	6	Premenopausal	Lumpectomy, chemotherapy, radiation, hormonal therapy
Julia	62	Healthy	III	8	Postmenopausal	Mastectomy, chemotherapy, radiation, hormonal therapy
Sabrina	52	Healthy	II	2	Postmenopausal	Mastectomy, chemotherapy, reconstruction
Vienna	49	Overweight	III	4	Menopausal	Lumpectomy, chemotherapy, radiation, hormonal therapy, reconstruction
Rose	59	Healthy	II	4	Menopausal	Mastectomy, chemotherapy, hormonal therapy, reconstruction
Bianca	47	Overweight	I	4	Menopausal	Lumpectomy, chemotherapy, radiation, hormonal therapy
Kim	70	Healthy	I	2	Postmenopausal	Lumpectomy, radiation
Madeleine	67	Overweight	I	31	Postmenopausal	Lumpectomy, chemotherapy, radiation, hormonal therapy
Ginger	60	Obese	I	6	Postmenopausal	Lumpectomy, chemotherapy, radiation, hormonal therapy

Note. All women self-identified as Caucasian. Normal weight: Body Mass Index (BMI) = 18.50–24.99 kg/m<sup>2</sup>. Overweight: BMI = 25.00–29.99 kg/m<sup>2</sup>. Obese: BMI ≥ 30.00 kg/m<sup>2</sup>.

by Willig (2001), broad exploratory questions were initially used, followed by questions that were more thematic with supplemental probes for when responses lacked sufficient detail, depth, or clarity. Considering recent critiques pertaining to the use of structured interview schedules in IPA studies (Allen-Collinson, 2009), open-ended questions were prepared to facilitate free speech about body-related experiences, thoughts, feelings, and behaviors (see Appendix A). The predominantly open-ended nature of the interview schedule prevented any theoretical or personal preconceptions from the researchers from influencing the women's constructions of their experiences (Allen-Collinson, 2009). Prior to the interview, each woman completed a brief questionnaire that included information on their age, height, weight, marital status, menopausal status, self-identified ethnicity, and brief disease and treatment history for descriptive purposes.

## Procedure

The 11 women involved in this study were recruited using snowball sampling techniques, advertisements, and oncologist referrals from local medical clinics and hospitals once ethics approval was obtained. Data were collected using face-to-face individual interviews. In May 2010, the first author conducted a pilot interview with a woman who had been treated for breast cancer to test the content, length, and clarity of the interview schedule. The data from this pilot interview were not analyzed. Then, interviews with the 11 women were conducted from June 2010 through August 2010 by the first author, a 27-year old Caucasian woman of healthy weight at the time of data collection. The interviews took place in a location of the women's choice (e.g., private room at the university, their own homes), were digitally recorded, and lasted between 41 and 108 min ( $M = 77.36$ ,  $SD = 24.03$ ).

## Data Analysis

Each interview was transcribed verbatim and reviewed for accuracy by the first author. The verbatim transcripts were used as the raw data for the study and were managed using NVivo software. The first author analyzed the transcripts following Smith et al.'s (2009) heuristic framework for IPA studies. This initially involved an idiographic approach, and then moved to generalizations. Specifically, the first transcript was read multiple times to obtain a sense of the woman's 'whole story', which involved highlighting informative sections and locating contradictions. Second, a comprehensive and detailed set of notes was created to record potentially interesting passages, insights on similarities/differences, language used, and conceptual thoughts relevant to the purpose of this study. Third, emergent themes were developed by clustering related initial notes that reflected women's words and the author's interpretations. Fourth, interrelated and connected emergent themes were

grouped together under super-ordinate themes. Fifth, a master table of super-ordinate themes and emergent themes for this first transcript was created to represent the resulting structure of the themes. Then, steps one through five were repeated for each subsequent transcript so that each transcript was analyzed individually to maintain IPA's idiographic stance (Smith et al., 2009). Finally, the results from the master tables were examined to look for patterns across women's accounts, yielding a table of key super-ordinate themes that reflected the main emergent themes for the whole sample. After all transcripts were analyzed, the first author re-read each interview to ensure that all relevant data were coded and categorized into the emergent themes. Then, an external researcher trained in qualitative research re-read two transcripts to ensure all themes were grounded in the data and coded consistently. In cases of disagreement, the first author and the external researcher returned to the original transcripts and discussed the coding until a consensus was reached.

Yardley's (2008) four principles for demonstrating validity in qualitative research (i.e., sensitivity to context, commitment and rigor, transparency and coherence, impact and importance) were followed during each stage of this study. Specifically, the first author's initial analysis was followed by an independent review by an external researcher, a semi-structure interview schedule was used to ensure a consistent approach to interviewing, raw data are presented in the form of quotations to demonstrate the transparency of the data, and all emergent themes were checked against the original transcripts. Furthermore, an audit trail that documented all research choices, decisions, and insights was maintained to facilitate review of the reasoning process. Also, the primary researcher (i.e., interviewer, data analyst, interpreter, first author) constantly reflected on the way in which her own values, experiences, interests, assumptions, and preconceptions may have influenced the collection, analysis and interpretation of the data (Finlay & Gough, 2003). She did this by recording her personal experiences and expertise in the area of the physical self, as well as her subjective impressions and observations, throughout the study to preserve the voice of the women and minimize the influence of her beliefs and assumptions on the data collection and analysis (Smith et al., 2009). Nevertheless, she acknowledges that she was an informant of this study, and that her lived experiences and worldviews could have influenced the research process. Most notably, she had never been diagnosed or treated for the disease. However, she had previously worked closely with women treated for breast cancer, and indirectly observed some of the challenges these women might have experienced. This experience facilitated her understanding of the phenomenon under investigation and enhanced her ability to establish trusting relationships with the women involved in this study. These endeavors helped ensure that the essential structures of women's experiences would be observed (Allen-Collinson, 2009).

## Results

All of the women experienced changes to their bodies as a result of the treatments they received for breast cancer. Their encounters with the disease caused them to reflect on their bodies, and their accounts of their body-related experiences can be summarized by the following four super-ordinate themes: (i) changing visibly and invisibly; (ii) experiencing intense thoughts and emotions; (iii) the meaning of the body: a vehicle of health, well-being, and social expression; and (iv) managing and dealing with physical changes. These themes, which were expressed by all the women, are described and accompanied with representative quotations from the interviews in the following sections. In the quotations, [...] indicates omitted text. All names were replaced with pseudonyms and any other identifying information were removed to maintain anonymity of the women.

### Changing Visibly and Invisibly

The women experienced short- and long-term changes to their bodies as a result of having been treated for cancer. They discussed these changes as being both visible and invisible. The visible physical changes included hair loss, altered hair texture, loss of skin elasticity, being “lop-sided” and “disfigured.” In the words of Julia: “Your hair falls out, your pubic hairs fall in the shower. . . You go to put on your mascara one day and go ‘Oh! I don’t have any eyelashes.’” For Kim, and others like her, her experience with breast cancer resulted in obvious asymmetrical breasts: “One breast was always just a little smaller than the other, but it’s become more noticeable.” As well, changes in muscle definition and weight were discussed. Kitty said “During some of these surgeries and stuff, I’ve lost some muscle definition. . . and like I said there was a weight gain issue after my treatments. . .” Further, the discourse the women used to describe these physical changes made it obvious they were still trying to manage the lingering effects of cancer. As described by Fannie: “I’m still battling that self-image, that whole ‘Look at you gained all this weight!’”

Other changes the women experienced were perceived as being invisible to others, such as cessation of menstruation, hot flashes, numbness in the fingers and toes, tenderness in the breast(s), difficulty sleeping, and being constantly tired. Living with these ‘invisible changes’ was difficult for the women. Kitty explained:

“Like on top of all this now, I have the hot flashes and some of the side effect things, and again, one more thing. It’s not like it’s a big thing, it’s just after you’ve been through something that has been so life changing the little things can build up.”

Mary’s experience with invisible side effects such as fatigue and a lack of energy led her to feel that her body was not functioning as it did before: “I find that ever since the cancer, I get tired very easily even just going up a flight of stairs. . . by the time I’m there I’m out of breath, I’m tired. I don’t have as much energy as I used to.”

Overall, the women described important body-related changes as a result of having been treated for breast cancer. The changes left the women believing that their bodies no longer looked and functioned the same way as it did before they had cancer.

### Experiencing Intense Thoughts and Emotions

The women’s experiences with their changed bodies were shaped by strong emotional reactions and thoughts. They shared intense experiences of dissatisfaction toward their bodies, including negatively valenced emotions and thoughts, though the discussions peripherally touched on some positive body-related experiences.

The women’s experiences of body dissatisfaction were connected to their perceptions that their current bodies and/or specific body parts were discrepant from their past or ideal body. For Fannie, dissatisfaction with her body was experienced as a result of focusing on her perceived imperfections, namely on her missing breast and weight gain in the abdomen. She magnified these specific imperfections using metaphors:

“I’m missing mass on one side, so I don’t like that. And I don’t like the kind of extra bit that’s around my middle. It’s like poofed out and when I wear tight jeans, I get this muffin top. I never had a muffin top before. And geez, it’s developed into more of a cake top, its way huge.”

Vienna also experienced a sense of dissatisfaction toward her body. In her case, she expressed displeasure about her body as a whole: “Now I’m a 2 on the scale of satisfied. That’s like 10 being the best and 1 being the worst. . . I’m not satisfied at all. . . I don’t like anything about my body now. . . I don’t like my arms, my thighs.”

In light of the pessimistic views the women held toward their bodies posttreatment, they experienced an array of negative feelings and thoughts that were a direct result of their experience with breast cancer and these lingered well beyond the treatment phase. They felt “not happy”, “not comfortable”, “disappointed”, “angry”, “depressed”, “worried”, “like crap”, “shitty”, “bothered”, “pissed off”, “upset”, “negative”, “inadequate”, “damaged”, “insecure”, “conscious”, “envious”, “sad” and “ugly”. For instance, Ginger’s negative feelings consisted of anger and distress: “It really makes me angry, and it still pisses me off, and it makes me upset. . . I’m not happy with my body.” Fannie echoed Ginger’s feelings of continued anger and disappointment. She also felt alienated from her body:

“You know post-surgery and post-radiation, the initial feeling was disappointment with my body. . . I think the disappointment has been replaced by sort of anger. I mean it’s not a violent anger, it’s there just under the surface and it will probably remain there, um, for the next few years. . . Now, I’m not happy with the way I feel. . . It’s very disturbing. . . I’m not comfortable in my, in this body right now because I don’t feel like I own it. It [my body] was high-jacked by this little white pill I had to take everyday. . . I think the biggest thing is that all of a sudden my body wasn’t mine.”

For Vienna, the effects of the treatments for breast cancer also led to feelings of discomfort and estrangement from her body: “After I lost my hair, I just felt ugly. . . Also, as I started gaining weight, that’s when I felt ugly. . . Now, I just don’t feel good in myself. Like before I started, before I was diagnosed, I felt good in myself.”

For Sabrina, these negative feelings affected her desire for interpersonal interactions and made her feel depressed. She shared: “When I would look at myself, I felt very negative. You don’t feel like going out, you just feel depressed. . . You are not inspired because this is the person you see everyday. You see it several times in the mirror a day and it wasn’t myself.” In contrast, Kim explained how the changes in her body affected her on a more intrapersonal level since they made her feel insecure and self-conscious: “I’m a bit insecure in a way. . . I’m very conscious of my body.” Madeleine further noted that the changes in her body had a negative influence on how she felt about her body in relation to her sexuality and appearance: “For sexual attraction and physical attraction, I find I can’t get excited about myself, whereas when I was a full breast and slimmer and not so baggy skin, then you know. . . I feel inadequate now. . .”

The women’s negative thoughts and emotional experiences were closely tied to their body composition, and experiencing a lack of control or ability to change this aspect of their bodies further

contributed to their negative reactions and engendered experiences of disappointment and anger. Fannie exemplified this: “I was really disappointed in myself that I had achieved a lot in my life, but I couldn’t control my weight now.”

Although the women primarily expressed dissatisfaction and negative emotions, four of them also recounted positive body-related experiences. They did this by describing their bodies as objects that functioned well and that were strong—aspects that extend beyond appearance. Madeleine reflected on the strength and development of her body, and this helped her appreciate it: “I guess what I like about my body is that it’s strong. . . It’s like everything is more or less growing and doing what it’s supposed to do so I guess I like that about my body.” Sabrina viewed her body as courageous and felt she was able to rely on it throughout her illness: “My body actually was very brave, and this is what I think about it, it supported me.” Thus, a positive lesson that resulted from these women’s experiences with cancer was their ability to value their bodies differently (i.e., beyond appearance), and in a more meaningful way.

In addition, ‘surviving’ breast cancer changed some of the women’s worldviews and gave rise to feelings of self-acceptance and self-realization. Rose shared: “I’m accepting. . . After a while, you know, you’re just happy with what you are.” Julia also had optimistic views about being alive and offered that the changes she experienced did not define her: “It’s not the end of the world, it’s just a breast. It doesn’t make you a woman. . . The important thing was and is being alive.”

In general, the women experienced a sense of dissatisfaction toward their posttreatment bodies, which resulted in negative thoughts and emotions that continued to pervade throughout their lives. Despite this, positive thoughts were experienced based on four of the women’s accounts, such as satisfaction and self-acceptance. However, this was mainly regarding the strength of their bodies (as an object), how it functioned, and the realization that they still had their life, which is in contrast to the negative experiences which focused primarily on appearance.

### **The Meaning of the Body: A Vehicle of Health, Well-Being and Social Expression**

The women valued their bodies for both personal and social reasons. For instance, the women reported that health concerns were a central driving force behind their preoccupations with their bodies. They were aware that being overweight was unhealthy, which led them to place importance on losing weight. Rose described: “I read a lot about breast cancer and they say overweight is not good and all that, so I try taking care of myself.” The women also understood that carrying around extra weight would put them at higher risk for life-threatening illnesses: “It’s because it brings up concerns. For example, some individuals pay attention to their weight because they are afraid of health concerns and that goes through my mind too” (Vienna), and “I would like to weigh less. I think that’s important because, you know, your heart. You’ve got to think about what’s happening inside” (Madeleine).

In addition, embodying and displaying a desired body had a bearing on their emotional state and affected their overall self-worth as the women discussed the importance of looking good in order to feel good. Vienna recounted: “Maybe I sound superficial, but I don’t know, it makes me feel good, looking good. You know, I’ve always been that way really, but I guess more now.” Bianca also explained: “So it’s for me, I want to feel good about me. . . You do it for yourself. It makes you feel better, you feel lighter.”

The women also described the importance of the external representation of their bodies since it provided them with a way of transmitting how they felt inside to others. In a way, they perceived their bodies as vehicles of social expression. Kim stated: “I think it’s

a sign to others of being well too, if you are looking good and feeling good, you automatically look good. . . I think it’s a reflection of what’s inside if you look good and are feeling good.” Moreover, the women wanted to portray their bodies a certain way to control others’ reactions to them and make sure they would not be treated differently by others. As articulated by Sabrina: “I see that other people’s reaction are very different when you are well dressed, have make-up on, your hair done. And because you feel good, they treat you different, absolutely different. . .” In a similar vein, the women attempted to manage the appearance of their bodies to appear “normal.” It helped them negate public attention and protected them from social judgements and potential stereotypical remarks associated with looking different as a result of cancer. Fannie illustrated this when she said:

“To me it’s extremely important to just look normal. Just to look like anyone else on the street. It’s just to fit in with everybody else, not look any different. You can feel different inside, but just to look like everybody else because you are just like everybody else. You just carry this emotional scar and that’s why it’s important to look like everybody else.”

Overall, the significance and meaning the women attached to their bodies were complex. The physical changes the women experienced as a result of having been diagnosed and treated for breast cancer caused them to reflect on the importance of their bodies and question why it was important to them. Based on the women’s accounts, “looking good” had health implications and it greatly affected how they felt about themselves, as well as how others perceived them.

### **Managing and Dealing with Physical Changes**

In light of the women’s negative experiences with their bodies and ensuing adverse thoughts and emotions, they spent time, energy, and resources to try to ‘camouflage’ the changes they experienced (e.g., hair loss, scars), reduce the discrepancy between their post- and pretreatment (or ideal) bodies, and regulate their negative emotions. Wearing make-up, prosthetics, wigs, and scarves helped the women conceal the visible changes. For Rose, wearing a wig was important to hide the loss of her hair: “As soon as they told me, I went out and got a wig. I had it styled.” She also avoided wearing low cut shirts to cover the scar on her breast: “You see the scar and you know the breast is never the same. I never wore low cut clothing, but now I’m much more conscious of it.” Clothing was also used by the women to cover up aspects of their bodies they disliked: “I just try to dress according to my weight. I try not to accentuate whatever I don’t like about myself” (Vienna), and “I don’t like to wear sleeveless [shirts]. I always want to not show this part [mid area]. . . and a long dress hides a lot of things!” (Madeleine).

Canceling social engagements and deliberately avoiding social interactions were strategies used by the women to cope with the negative thoughts they experienced about their bodies. Vienna explained: “When I am not feeling good about my body, I just close myself at home and watch TV and I try to stay away from people.” The fact that Vienna isolated herself and withdrew from others reflects her desire to cope with her emotions on her own, possibly because she felt she should be able to manage her negative experiences.

In addition, the weight the women gained acted as a catalyst for behavior change since the women’s accounts revealed a desire to adopt a healthy lifestyle to lose weight and improve body composition. Engaging in physical activity and modifying one’s eating behavior (e.g., dieting, restricting food intake, eating well, and habitual food monitoring) were strategies used by the women. Sabrina said: “There is no other way on earth so far that you can take away your weight problem. There is no other way, just food and be

active. I know this from experience.” However, while the women wanted to make or maintain these lifestyle changes, mixed beliefs regarding confidence to do this were apparent in the women’s narratives. For example, Bianca wanted to control what she ate, but she experienced self-doubts in regards to her ability to do so in certain situations: “I find it very difficult because I love to eat . . . I realize how difficult it is to lose [weight]. . . . When I go out with friends, I just lose track.”

Being active at levels required to lose weight was also difficult to achieve. There was a definite feeling that the long-term and late-appearing treatment side effects affected their physical form and ability. Fannie commented that day-to-day activities were more effortful and less enjoyable than before her cancer, ultimately reinforcing the physical and psychological challenges the women experienced: “I’m tired because I have insomnia now so I don’t feel like doing a bunch of stuff. I don’t feel like walking the dog, and I don’t feel like doing my stairs and the things I normally do to stay physically active.” Another reason offered by the women for their inability to lose weight was their past failures to lose weight. Ginger expressed it like this: “I’ve tried it [to lose weight] a couple times and it didn’t work.” Regardless of the reasons the women offered, their experiences reflected a constant tug-of-war. Bianca illustrated this when she stated: “I try on a daily basis, but sometimes it’s difficult. . . . It’s an ongoing struggle. . . . I had tried to lose a bit of weight and stuff like that. I fluctuate. I go up and down, and up.”

Overall, the changes the women experienced to their bodies following treatment for breast cancer, and the negative reactions to these changes, led them to use various strategies to help them reconcile with their changed bodies and reduce the discrepancy between their post- and pretreatment (or ideal) bodies. Apparent in the narratives was that wearing make-up, prosthetics, wigs, scarves, and clothes to camouflage the visible changes that resulted from their cancer treatment, and adopting a healthy lifestyle, were means to help the women manage their negative reactions and lose weight. Moreover, the women continued to use the strategies to deal with the negative experiences and for self-enhancement long after treatment ended, which suggests that passage of time does not erase the ‘damage’ caused by breast cancer.

## Discussion

Despite a growing number of studies on body image in oncology, an in-depth understanding of women’s body-related experiences following treatment for breast cancer is lacking. In this study, we drew on IPA to explore women’s experiences with their bodies in the aftermath of breast cancer. The women reflected on the meaning of their bodies, and described perceptual, cognitive, affective and behavioral components of their experiences.

Similar to previous quantitative studies (Collins et al., 2011; Frith et al., 2007; Irwin et al., 2005; Shapiro & Recht, 2001), the women experienced undesirable changes to their bodies that were both visible and invisible to others. This is also consistent with previous qualitative research with breast cancer survivors (Beatty, Oxlad, Koczwara, & Wade, 2010; Rasmussen et al., 2010), as well as younger cancer survivors (Snöbom, Friedrichsen, & Heiwe, 2010). However, we discovered that changes in body composition were of central importance to the women in our study. This is not surprising since nearly 80% of older women report negative attitudes about their weight (Hurd, 2000), and body size dissatisfaction is a common struggle in women’s life (Liechty, Freeman, & Zabriskie, 2006). A possible reason why the women focused on their body shape, size, and weight posttreatment might be because they have been taught that women are largely valued based on their appearances, and “the way women’s bodies look bears greatly on how

other people relate to them and is directly connected with women’s economic value in society” (Brown & Jasper, 1993; p. 19). They might have also internalized weight-based stereotypes that hold that people are personally responsible for their weight (Tiggemann & Rothblum, 1997), and therefore feel that their weight gain is a matter of personal responsibility that denotes failure of control. In fact, women treated for breast cancer can feel a loss of control over their bodies (Hefferon, Grealy, & Mutrie, 2010; Sabiston et al., 2007). Finally, the women might recognize that overweight and obese women in Western societies are often perceived as unattractive, undesirable, and unhealthy (Degher & Hughes, 1999), which could also explain why these changes were of particular concern to them. These possible explanations warrant further investigation.

In line with self-objectification theory (Fredrickson & Roberts, 1997), the women reflected on themselves from an outsider’s perspective. That is, they described themselves as an object to be viewed, and saw their bodies as a means to show others how they felt inside and control how others perceived, evaluated, and treated them. Further, the external representation of their bodies was critical to the women in terms of social acceptance since they believed that people hold assumptions and prejudices about others based on appearance, which supports the tenets of the sociocultural theory of body image (Thompson et al., 1999). Thus, it could be said that self-presentation motives underpin, in part, the women’s attention toward the appearance of their bodies.

In keeping with past work (Brink & Ferguson, 1998; Hurd Clarke, 2002), the women also cited health as a reason for monitoring the changes in their bodies, especially their weight. Compared to normal weight counterparts, obese women have a 1.5–2.5 greater risk of recurrence and death following treatment for breast cancer (Chlebowski, Aiello, & McTiernan, 2002; Cleveland et al., 2007; Kroenke, Chen, Rosner, & Holmes, 2005). In light of the increased awareness of these disease outcomes, weight control was important for the women. Similarly, other researchers have indicated that cancer survivors report heightened motivation to lose weight for health reasons, and have termed this phenomenon a ‘teachable moment’ (Demark-Wahnefried, Aziz, Rowland, & Pinto, 2005). Based on these findings, developing strategies to help women manage their weight after treatment should be a research priority.

In accordance with body image theories (Cash, 2011; White & Hood, 2011), appearance management was integral to the women’s psychosocial and emotional state, such that women’s negative experiences with their bodies were inextricably related to a wide range of negative states and emotions. Even though it has been documented that negative body image and physical self-perceptions relate to higher depression, anxiety, and poorer quality of life (Collins et al., 2011; Falk Dahl et al., 2010; Lam et al., 2012; White, 2012), it is notable that the women in our study experienced other body-related reactions, such as disappointment, anger, sadness, and envy. Recently, McHugh et al. (2008) coined the term ‘web of emotion’ to reflect the range of body-related emotions young women experience, and concluded that body-related experiences cannot be reduced to a single emotion. Although our sample differs from McHugh et al.’s (2008) sample, our results indicate that the women’s body-related emotional experiences may be similar to other groups of women who experience changes to their bodies that can be considered inconsistent with the social standard of physical attractiveness (e.g., slimness). Thus, health care providers need to be aware of women’s negative body-related emotional experiences that linger well beyond the treatment phase of cancer.

Although researchers have traditionally focused on the negative consequences of breast cancer, there has been a shift in recent years to move beyond this one-sided view and examine positive aspects given the contention that people can experience positive changes in their lives following traumatic events and illness (Hefferon et al., 2010; Stanton, Bower, & Low, 2006; Tedeschi & Calhoun, 2004).

In support of this shift and existential frameworks of posttraumatic growth (Tedeschi & Calhoun, 2004) and previous research (Hefferon et al., 2010), a few of the women in the current study experienced an opportunity to re-evaluate themselves and grow from their struggle with the disease. While Lindwall and Bergbom (2009) reported that women felt as though their 'bodies had let them down', a few of the women in our study saw their bodies in a different light, a process referred to as cognitive reframing, and focused on its strength as they faced the risk of death. This reflects women's ability to change their self-views by focusing on less esthetics aspects of their bodies. Further, it supports the notion that individuals can gain an appreciation for life and strength following illness (Stanton et al., 2006; Tedeschi & Calhoun, 2004), and a new identity (Sabiston et al., 2007). In light of these findings, these overlooked facets of body-related growth should be explored in future research to provide a more comprehensive understanding of women's experiences with their bodies after breast cancer.

In addition to growth, a few of the women experienced self-acceptance and self-compassion toward their bodies in spite of enduring negative experiences of breast cancer. This finding supports previous findings of greater acceptance of oneself with age (Halliwell & Dittmar, 2003; Hurd, 2000). Also, these positive experiences mirror Avalos, Tylka, and Wood-Barcalow's (2005) concepts of positive body image, namely those of favorable opinions of the body, acceptance, and respect, and are consistent with Neff's (2003) notion that humans are capable of feeling compassion for themselves when they experience perceived inadequacies, failures, or general suffering. Based on Neff, Kirkpatrick, and Rude's (2007) work showing that self-compassion is related to life satisfaction, optimism, and positive affect, more research is needed to understand how to best promote self-acceptance and self-compassion in this population.

The women's negative emotions and thoughts acted as an impetus for them to take action to help themselves reconcile with their new physique and reduce the discrepancy between their posttreatment and desired bodies. This supports existing cognitive behavioral theories (Cash, 2011; White & Hood, 2011), and other findings showing that wearing make-up, prosthetics, wigs, and scarves are conscious strategies used to manage the physical changes following treatment for breast cancer (Harcourt & Frith, 2008; Rasmussen et al., 2010). Similar to Heffron et al.'s (2010) findings with mixed cancer survivors, the women in the current study also restricted the amount of food they ate, avoided certain foods, and viewed physical activity as means to manage their weight and obtain a toned, fit body. However, given that successful weight control can be challenging, developing effective long-term weight management programs, which rely on dietary and physical activity, is an important research priority.

This study has limitations that need to be acknowledged. We categorized the women's experiences into key super-ordinate and emergent themes, and this might have taken away from their own lived experience by thwarting the full picture of their experience or limited higher level interpretation. Also, the findings may have been influenced by the researchers' personal experiences and understandings. Thus, the findings represent only one of a number of possible interpretations. Moreover, as with other qualitative studies, women who were comfortable discussing sensitive issues related to their bodies volunteered to participate in our study. Emergent themes might be different for groups of women who did not volunteer because they were uncomfortable discussing these issues. Last, although we aimed for sample homogeneity as recommended for IPA studies (Langdrige, 2007; Smith et al., 2009), it would have been informative to interview women of different racial backgrounds, diagnosed with a recurrence, and/or not involved in a relationship since it is possible that the experience is different for these women. In light of these limitations, we encourage

researchers to further explore if the findings in our study are transferable to more diverse samples of breast cancer survivors.

In summary, this study adds to the understanding of women's perceptual, cognitive, affective, and behavioral body-related experiences following treatment for breast cancer. We lend support for the multidimensional view of body image (Cash & Smolak, 2011), and suggest that body image encompasses more than general concerns about appearance for women with a history of breast cancer—it was connected to their health. In addition, we provide a holistic perspective on women's body-related experiences by showing that women have both negative and positive body-related experiences following treatment for breast cancer. These findings could be used to extend existing body image models and guide future research so as to include positive characteristics of body image. Finally, given that experiences of body dissatisfaction induced debilitating negative emotions and thoughts, intervention strategies that reduce negative body-related self-perceptions, cognitions, emotions and behaviors, and promote positive ones, should be developed and evaluated in order to enhance women's psychosocial and physical health and well-being during cancer survivorship.

### Conflicts of interests

The authors have no conflicts of interest to report.

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### Appendix A.

#### Core questions

- Tell me about what is different about your body since your cancer treatments have ended.
- Describe your thoughts and feelings about your body since your cancer treatments have ended.
- How has your cancer diagnosis and the treatments you received influenced these thoughts and feelings?
- Describe your level of satisfaction/dissatisfaction with your body (e.g., weight, shape, and appearance) since your cancer treatments have ended.
- In your opinion, why are you concerned with looking a certain way *nowadays*?
- Tell me about some of the strategies you use to change your body size, shape, weight and appearance since your cancer treatments have ended?
- Is there anything else that I should know about being a breast cancer survivor and how that influences how you feel about body? Its size, shape, weight and appearance?

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