



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; Elmira, 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 ≥ 25 kg/m²), 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

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