



## “I’m still who I was” creating meaning through engagement in art: The experiences of two breast cancer survivors

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### A B S T R A C T

#### Keywords:

Art  
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Embodiment  
Interpretative phenomenology  
Meaning

**Purpose:** The aim of this feasibility study was two-fold: i) develop lifelike torsos of two breast cancer survivors using innovative sculpting material and; ii) shed light on the meaning women give to the experience of breast cancer after viewing their sculpted torsos.

**Methods:** This collaborative initiative between nurse researchers and artists was situated within phenomenological inquiry. Two breast cancer survivors shared their bodies, as models, and stories of their cancer journey and the experience of modeling to create life-sized torsos of their bodies.

**Key results:** The participants articulated embodied knowing as each shared experiences of connectedness and relationship which culminated in the emergence of four core themes: *The Landscape of Breast in Cancer*; *Red Shoes: The Re-claiming of Self*; *Liberation: towards an embodied self*; and, *Scars: Re-authoring Life*.

**Conclusions:** Active engagement in art through the use of one's body has the potential to open the door to healing, the generation of meaning and a reaffirmation of self.

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### Introduction

The use of art as a mechanism to visualize, understand and make meaning from illness and disease is not a recent phenomenon. The depiction of pathology through the paintings of Raphael, Reuben and Rembrandt (Espinel, 2002; Grau et al., 2001; Hayakawa et al., 2006) as well as Michelangelo's sculptures (Stark and Nelson, 2000; Strauss and Marzo-Ortega, 2002) have provided a unique interpretation of artists' conceptualization of disease, its manifestation and historical evidence of the existence of certain diseases such as cancer (Espinel, 2002). Frieda Kahlo, one of the world's most important 20th century artists, directly expressed her own personal pain, suffering, and alienation through her art; “her work is the best illustration of her life, thoughts and diseases” (Budrys, 2006, p10). The use of performance art such as *Handle with Care: Women living with metastatic breast cancer* (Gray et al., 2000), poster art (Sharf, 1995), and art therapy (Collie et al., 2006; Ponto et al., 2003; Reynolds and Prior, 2006) offer alternatives to traditional research as a way of enhancing our understanding of the impact diseases such as cancer have on the psychosocial health

and well-being of cancer survivors. Further, the use of art as a therapeutic intervention to support meaning-making, self-identity, and healing or as a medium for increasing awareness about cancer can be found in some health care settings (Deane et al., 2000).

Although the literature is limited on the therapeutic role of viewing art, many patients and artists have begun to describe the benefits and usefulness of engagement in art-related activities in creating meaning from the experience of illness (Ponto et al., 2003; Timmons and Macdonald, 2008). Building on the need for research to support the benefits of art, as well breast cancer survivors' comments about the need for answers to what they would look like after treatment for breast cancer (Sabo et al., 2007), a two-pronged feasibility study was undertaken to assist in determining whether it was possible to generate torsos of breast cancer survivors following treatment that visually and tactilely were similar to the human body. Second, with a paucity of research exploring the role of viewing art (self-depiction), it was important to explore what approach and questions would be beneficial in explicating the experience of viewing life-sized torsos and, subsequently, the generation of meaning for breast cancer survivors. A full-scale exploration of the role viewing life-sized torsos of breast cancer survivors has on the creation of meaning, femininity and body image is planned. What follows is a presentation of the reflections of two breast cancer survivors who participated as models in the feasibility study. Their stories highlight how, not only engaging in

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the production of art but the viewing of the finished product, informed the re-authoring of life's narratives and its ability to generate meaning out of the chaos of cancer.

### Breast cancer and body image

An exploration of the psychological literature highlights a significant body of work focused on the challenges faced by women diagnosed and treated for breast cancer. Challenges include decision-making, adjusting to an altered body and struggles around self-identity. The lasting effects from breast cancer may be reflected most powerfully in the autobiographical accounts of visual artists, poets and writers (Manderson and Stirling, 2007). The implications do not end with completion of treatment; rather, the visual reminder in the form of scars, partial or absent breasts serve as a legacy, a reminder of the disease, and the potential for recurrence or metastases (Thomas-Maclean, 2004).

The process by which a woman adjusts to a diagnosis and treatment for breast cancer is complex, influenced by multiple factors (Brennan, 2001). Issues related to body image, defined as "the mental picture of one's body, an attitude about the physical self, appearance and state of health, wholeness" (Fobair et al., 2006, p.580) play a significant role in this adjustment (DeFrank et al., 2007; Helms et al., 2007) and are frequently considered more difficult to cope with than secondary symptoms associated with treatment (White, 2000). The way in which a woman experiences her body, its femininity and wholeness is largely influenced by social interaction (Kaiser, 1997; Shilling, 2003). The media portrayal of attractive, feminine women as possessing two firm, rounded and healthy breasts reinforces difference and diminished value by virtue of scarring or absence of this socially constructed asset (Paff Ogle and Ullstrup, 2006; Ogden and Lindridge, 2008). Such unrealistic depictions of the female body impact how women perceive and/or think about their bodies. Further, when breast cancer survivors draw on socially constructed images of femininity and beauty, they may find themselves lacking resulting in depression, poor self-esteem and social anxiety (White, 2000).

### Art, illness and disease

A review of literature reveals no universally accepted definition of art. However, art is generally conceptualized as a form of creative expression and communication that conveys messages among people. As a medium of expression, art allows an individual to receive another person's expression of feelings and experience and, in turn, may feel those same emotions and thoughts (Hoshiko, 1985; Mohr, 1995; Thomas et al., 2004). If art serves as a vehicle for shared expressions, feelings and experiences, then it would seem reasonable to draw on it as a mechanism for change, informing perceptions of self, body image and femininity within the context of breast cancer.

Although the literature is limited on the therapeutic role of viewing art, many patients and artists have begun to describe the benefits and usefulness of art in creating meaning out of the illness experience (Ponto et al., 2003). Exhibitions of visual, performing and literary arts are now being used to educate the public about breast cancer and to advocate for a more realistic understanding of the breast cancer experience. The mediums used range from poster art and photographs to sculptured torsos and poetry. A Google search of breast cancer and art found the use of art as a common vehicle for increasing awareness of breast cancer and social injustice, as well as dispelling socially constructed myths about breast cancer.

Artist, activist, performance artist and breast cancer survivor Matuschka has sought to spread breast cancer awareness through the use of controversial photographs, such as *Beauty out of Damage*.

This photograph was a self-portrait of the artist wearing a gown that was cut away to reveal her mastectomy scar. Many women with breast cancer were excited about the media portrayal of this image as it depicted a woman that looked like them; the photograph presented the reality of breast cancer and breast cancer treatment in a positive light (Malchiodi, 1997). Another image was *Vote for Yourself* which presented a positive representation of a torso that had undergone breast surgery; this image was created to convey the underlying issues of self-esteem, self-confidence, and empowerment (Malchiodi, 1997). The majority of artwork created by Matuschka encourages discussion of personal empowerment, body image, and society's ideals of women. In a similar vein, it is hoped that the findings and images from this feasibility study may serve as a point of inspiration, a re-claiming of one's life, for women diagnosed with breast cancer as well as a stepping off point for researchers interested in exploring the role of viewing art as a mechanism for meaning-making within the context of cancer.

### Aim

The aim of this study was two-fold: i) develop lifelike torsos of two female bodies using innovative sculpting material and; ii) shed light on the meaning women give to the experience of breast cancer after viewing their sculpted torsos. Since the sculptors were using innovative new material to replicate the feel of skin, a decision was made to create the prototypes prior to submitting a full-scale grant application exploring the role of viewing art in supporting decision-making, generating meaning, re-conceptualizing body image and femininity. Narratives would be elicited from the two participants about their cancer experience and how viewing their sculpted torsos informed this experience.

### Methodology

#### Design

This study was situated within a qualitative paradigm informed by an interpretative phenomenological approach which sought a greater understanding of how meaning is created out of the everyday 'life world' (van Manen, 1997). Interpretative phenomenology provides a mechanism for explicating human experience. The notion of understanding, of what came before (pre-understanding), what is in, and what is behind statements, is at the core of interpretative phenomenology (Heidegger, 1962, 2005). To understand what it means to be in the world required an examination of shared aspects of the *life world* of the participants' experiences of cancer and art. This exploration included: i) how the women situated themselves past and present; ii) their embodied understanding of cancer and modeling; iii) their connections to the taken-for-granted cultural and social norms, beliefs, values of cancer, femaleness and health; and, iv) the interconnectedness of individual and world.

Collaborations between artists and social scientists offer unique opportunities for crossing inter-disciplinary boundaries, expanding and creating innovative new approaches to research as well as transcending barriers inherent in traditional modes of dissemination (Cole and Knowles, 2008; Gray and Sinding, 2003; Kontos and Naglie, 2006). In this feasibility study, art became both outcome and research methodology through which experiences of body image, self-identity and meaning-making following treatment for breast cancer were explored.

#### Data collection, participants & analysis

Following ethics approval from the Research Ethics Board of a large District Health Authority within Nova Scotia, a call for

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