



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

Brenda M. Sabo^{a,b,*}, Catherine Thibeault^a

^a Dalhousie University, School of Nursing, 5869 University Avenue, Halifax, NS, Canada B3H 3J5

^b Nova Scotia Cancer Center, Psychosocial Oncology Team, 5780 Dickson Building, Victoria General Hospital, Halifax, NS, Canada B3H 1V7

A B S T R A C T

Keywords:

Art
Breast cancer
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.

© 2011 Elsevier Ltd. All rights reserved.

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

* Corresponding author. Dalhousie University, Room 109, Forrest Building, School of Nursing, 5869 University Avenue, Halifax, NS, Canada B3H 4R2.

E-mail addresses: Brenda.Sabo@Dal.ca (B.M. Sabo), Catherine.Thibeault@Dal.ca (C. Thibeault).

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

participants was placed at the regional Cancer Center through posters, as well as through an on-line breast cancer support network. The collaborative study between two university departments (nursing and fine arts) was a unique endeavor intended to expose the complexity of interpretations residing within the breast cancer experience. The study comprised two phases: i) the generation of life-size sculpted torsos of two breast cancer survivors and, ii) interviews with the two women about their experiences of breast cancer following the viewing of their sculpted torsos. Photographs of the process of creating each woman's torso were taken by a graphic designer on the research team. The photographs served as a methodological approach by providing the two participants with an opportunity to view their bodies and the emergent sculpted torsos. In turn, re-examining their bodies through art provided a unique opportunity to reflect on their cancer experiences, gendered selves and embodied meaning.

The participants were between 35 and 45 years of age, married with young children. One woman opted to undergo concurrent reconstruction following her mastectomy. The second woman elected the removal of a healthy second breast with no reconstruction.

Consent was obtained from the participants to audiotape and photograph the casting sessions. Consent was also obtained to audiotape the face-to-face interviews. The interview guide was composed of open-ended questions consistent with phenomenological inquiry. Examples of questions included, but were not limited to: i) tell me what it was like for you to model for an art project on breast cancer. Tell me your thoughts and feelings about the experience; ii) what was it like to view your sculpted torso; iii) tell me about your cancer experience. Tell me about your thoughts, feelings and emotions as this experience unfolded. Each woman's interview lasted approximately 2 h. Thematic analysis based on the work of van Manen (1997) and Benner (1994) was used to illuminate the core themes from the narratives. Further, the graphic designer on the team interpreted each theme creating visual representations adding depth by moving beyond text.

Results

Art became a powerful medium exposing both the research team and participants to the visceral reality of the female body following cancer treatment. Although the sculptors had previous exposure to breast cancer through family or friends they had not been involved in the creation of art through intimate contact with the bodies of cancer survivors. One of the sculptors noted,

It was a bit intimidating. It felt intrusive to handle their body like a regular model but with a delicate touch... it [the process of casting] is neither elegant nor clean.

She (sculptor) felt a desire to protect and honor the women whose bodies she was working with. Placing the casting material on the participants' bodies heightened her sense of intrusion. She felt as if she was entering into a space reserved for lovers and family not for strangers. Further, the experience highlighted for her how her hands became instruments that brought forth pain, suffering and beauty, laying bare the physical and emotional scars of the two women.

In order to achieve a perfect casting, the sculptors required each participant to remain still for several hours. As the process unfolded for one participant, it became apparent to one of the authors that the initial discomfort associated with exposure quickly receded into the background to be replaced by the physical pain of immobility. Intuitively, the sculptor responded to this shift, her touch became more of a caress, working quickly to complete the mould and end the participant's suffering. In that moment, this author felt

as if the artist's intention to create became fused with her intention to care. The process of creating art forged a bond between sculptor and participant that went beyond the superficial. Through touch, space was opened to negotiate meaning in the sharing of this intimate connection.

Themes

Participants spoke of a sense of space and time as they shared their experiences. They articulated an embodied knowing through connectedness and relationship. Four core themes emerged from this study. We came to refer to the themes as: i) *The Landscape of Breast in Cancer*, ii) *Red Shoes: The Re-claiming of Self*, iii) *Liberation: towards an embodied self*, and iv) *Scars: Re-authoring Life*. Although each theme may stand as distinct, the reality is one of an interwoven multiplicity of context encompassing the private, social and spiritual.

The landscape of breast in cancer

The use of the word landscape suggests a geo-spatial view of terrain or topography. Metaphorically breasts form a human landscape for the body akin to mountain ranges. Mountainous landscapes are synonymous with place, space and time, holding a sense of beauty and wonder: a geographic formation that is born of earthly change, but that maintains its essential shape despite the forces of nature that prevail upon it. Similarly, the female breast has come to reflect another form of beauty and wonder that captures our attention. Socially constructed, the breast represents more than a physical attribute, a source of nourishment. The breast has become a sexual accoutrement, its size and shape dictated by the vagaries of modern socio-cultural values and beliefs. What happens when cancer intrudes necessitating the removal of a body part - the breast? How do women respond to image-related issues when disease challenges appearance and one no longer conforms to normative conceptualizations? Their landscape has been changed; the mind's eye beholds a terrain that is scarred, reshaped and distorted (Fig. 1).

Self-titled *Voluptuousness*, this sculpture reflects the first of two participants' views of the body's landscape. For Diane¹, reconstruction meant a *sense of modified wholeness* within a new beginning and a *new normal*. She believed it was important to retain her breasts. Her decision was not about her partner or ex-husband's wishes but about her own personal identity. She spoke of

want[ing] breasts. I want two of them! Having breasts is not about femininity, it is about 'femaleness'.

Diane saw her breasts as that part of her physical landscape that identified her as female. Yet her need to maintain two breasts came with a price. Although she perceived her newly constructed breast as voluptuous, as sensual and full, it was embodied as separate and distinct – a modified wholeness. She spoke of becoming a *gallery*, a living canvas for her surgeon's work.

I would go for checkups and the way he would look at it [the reconstructed breast] or touch it or photograph it, I had the impression that it was something he had created out of raw material from another part of my body. So, in a sense, I am the gallery for this plastic surgeon's work only I get to keep it for my whole life.

¹ The names of both participants have been changed to protect their identity thus ensuring anonymity and confidentiality.



Fig. 1. Voluptuousness.

Her landscape had been altered, reshaped. Externally, the differences appeared minimal. Diane spoke of the surgeon's work, which had fashioned more than a new breast; it had fashioned a new sense of self. Diane was no longer the owner of the breast but the holder of the surgeon's breast.

In contrast, the landscape for Betty was remarkably different. Titled *Liberation*, she saw herself as freed from the encumbrance of a socially constructed notion of femaleness (Fig. 2).

They are what made me look female to the outside world but to me, I'm still who I was. My breasts never made me who I was. They were a part of me but they never, ever made me who I was.

Her sense of self was altered and re-formed. Betty spoke of her ability to re-fashion her sense of self in the same way her body had been re-formed. The new terrain of her body, marked by the absence of breasts, had prompted her to draw a new map of herself. Betty's breasts did not define her; they were but a part of a larger organic whole. Initially, Betty spoke of feeling pressure to conform to stereotypes and socially constructed images of the female form – two round firm breasts. Prostheses were purchased and a semblance of socially constructed normalcy emerged. Very quickly her attitude changed, and was replaced by what she referred to as the *liberated* survivor of cancer.

For Betty, the experience of liberation was more than acceptance of her own physical non-conformity; rather, she chose to adopt her non-conformity as a badge of honor, as scars in a battle for selfhood, often and proudly repeating during the casting session, *I have cancer, but cancer doesn't have me*. She experienced her new breast-free body as a cancer-free body. Not only had she liberated herself from socially constructed physical normalcy, she had liberated herself from the grip of a powerful and destructive force: the illness of cancer.

Red shoes: the re-claiming of self

The intrusion of a life altering illness such as cancer irrevocably changes self-identity. How one perceives the self, meaning of the experience, goals and dreams must be reconceptualised. Images and narratives of the self are reviewed, parts re-claimed and others discarded as no longer a fit. The theme of *Red Shoes* became a metaphor symbolizing a re-claiming of life, living and self (Fig. 3). It was about challenging difference, of non-conformity. It became a vehicle calling people to look *at* not *away from* the survivor. *Red Shoes* was about making a statement – look at me, see me, do not hide me away. I am vibrant. I am me, not cancer.



Fig. 2. Liberation.

In the following example, one of the women spoke of receiving news that she was now cancer free after having successfully completed treatment for breast cancer. This marked a watershed in her life and required acknowledgment.

I was on my way home and I said, "I am going to get a new pair of shoes". I stopped in and saw these when I walked in the store. I immediately saw these pair of red patent-leather shoes and I thought to myself, "I need those shoes!" And I wore them home. I put them on my feet in the store and I wore them home. They have become MY RED SHOES, my trademark. I've got my red shoes on now and they're long and obnoxious and bright red. And they scream, here comes Betty with her red shoes. They are a symbol that I am alive. I will never wear them to the point I have to throw them in the garbage, they are that important.*

In the process of challenging expected norms concerning cancer and cancer patients, red shoes became an expression of Betty's activism. She goes on to talk about how she used the metaphor of *red shoes* as a tool for activism in her attempt to increase awareness about the reality of breast cancer. She had been asked to provide pictures from her experience for a talk she was giving on breast cancer survivorship. The metaphor became a powerful statement:

They showed a picture of me bald. They showed a picture of my husband and I and my son. They showed a picture of the day I found out I didn't have cancer. There is a picture of me wearing my red patent leather shoes on a big red chair. They didn't want to show the other pictures [with no breasts]. The pictures were pornographic in their minds. One lady thought the pictures were disgusting and another thought they were horrific and never should have been taken. I told them to take their heads out of their ... and face reality. This is WHAT it is!

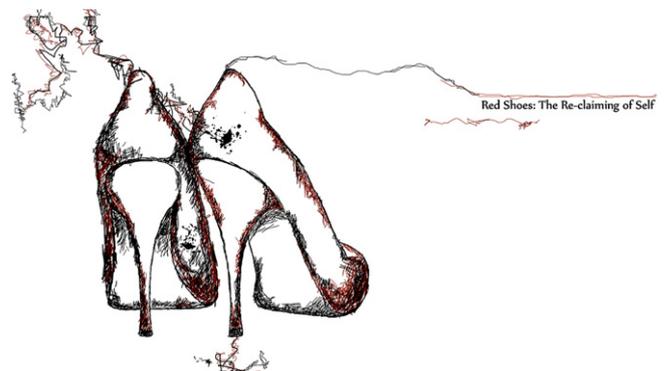


Fig. 3. Red shoes: the re-claiming of self

Many women with breast cancer face the prospect that they will live out their lives with significantly altered breasts, or with no breasts at all. Negative views only serve to further stigmatize and label the survivor as no longer normal. In this story, Betty spoke of how many audience members wanted to look away, and were unable to confront the reality of the breast cancer experience so viscerally portrayed by the absence of her breasts. Betty's red shoes symbolized her desire to command the attention of others, and communicate the distinct and sometimes jarring reality of breast cancer. For Betty, the reality of breast cancer was akin to wearing red shoes: a presence that was powerful and unmistakable, a symbol of blood that had been shed, and an expression of a new identity new life, of vibrancy and being truly alive.

Liberation: towards an embodied self

The theme, *liberation* came to personify strength and freedom for both women (Fig. 4). It reflected a freeing of the self from socio-cultural myths surrounding constructions of conformity and non-conformity, of how life should be lived in the presence of cancer and of ownership of the body. Ownership implied the capacity to make decisions about the body, in this case, to live as a survivor with a reconstructed breast or without breasts. Within the process of decision-making came acceptance of difference. Betty first spoke of how being photographed and cast helped her to come to the realization that she was comfortable with how she looks.

It means different things for different people. Being able to photograph it [her body] or cast it or whatever, it's a big thing. I told my mother what I was doing with the modeling and she said, "Are you really okay with that?" I said, "I am fine with that". I don't care, quite frankly, who sees me. I am doing that as a 39 year old woman. "Some of them [breast cancer survivors] haven't accepted the fact that it has happened to them. They talk about breast cancer like it is a disease, a dirty disease that somebody else had.

Diane spoke of becoming comfortable with her body as a large woman, of being proud of her decision.

I like the idea of being able to say to women, "Look, you know, it is okay. It doesn't matter what you look like. If you have breast cancer, if you are big, you are small, it doesn't matter". My body consciousness changed a lot during my breast cancer journey. I think it would be encouraging for women to actually see a larger woman who has had reconstruction and say, you know, "wow, I

could look like that!"...There was a period of time when, if I ran into someone with breast cancer or was related to someone with breast cancer or had questions about breast cancer, I would say, "I just had a great reconstruction. You want to see it?" and I would pop it out and show it off!

In the process of being cast to create their sculpted torsos, both women demonstrated beauty in difference. For Betty, acknowledgment and acceptance came through art and photography. This was her reality and she was proud of who she was. For Diane, liberation came with the realization that she was the canvas for her surgeon's work. This was further reinforced as she embodied living art. For both Betty and Diane, the result became a peaceful co-existence between mind and body, between sense of self and the sensate self. Difference became the new norm, embodied in their language of acceptance.

In the following anecdote, Betty spoke of how engaging in the creation of art and its viewing led to a new sense of self. She was no longer something to be stared at; her body was not horrific. She felt the artists gaze as caring, rendering her fragile and delicate. The sculptors treated her with respect; not someone to be shunned or hidden away; the missing breasts covered up. They captured the unique landscape of her body down to the tiny heart-shaped mole. She found the process of being viewed by the artists and their rendering of her body as the finished torso to be liberating.

It was worth being tired, being sore. It was fascinating when it [cast] came off. That mole, here on my chest- the tiny little details of my mole that is actually heart-shaped. I always joke and say it is the only one I own. It's heart-shaped and you could actually see the ridge detail...it is amazing to watch the whole process...People are wondering, "is it okay to touch her". I mean, I was fine with that. It was liberating. It was liberating to see that people are interested in what this is, what this looks like. I took my shirt off in front of strangers and they weren't horrified. This isn't a horrific thing that happened to me – it happened. It sucks, but it's okay... Being able to look at it from the outside, not just look down and look in the mirror, but being able to actually look at the physical shots was difficult but it helped me to accept this is who you are now.

In this anecdote Betty articulates a shift in her identity; her bodily self has been changed, altered, and freed from social conformity through the experience of modeling. *This is who you are now*, she told herself. She is saying that her body mediates her existence: she has shifted from a bodied to embodied self.

This expression of embodiment differed from Diane who stated that her body did not constrain her selfhood

I identify less with my body as being who I am. It is more like my body is a vehicle for the soul, to get through life, for a life that has been given to it [body]...

For Diane, her soul, reflected as the innermost sense of being that truly defined her, was given a separate identity. She perceived her body as a *vehicle*, a container for her soul. Diane was not suggesting that her body was a mere vessel; in fact, she stated that her body *had been given* a spiritual embodiment of life. Perhaps the best way to understand Betty and Diane's experiences is to recognize that both participants' stories pointed toward liberation of meaning; that is, each participant uncovered a new understanding of her embodied actions.

Scars: re-authoring life

The final theme that emerged was referred to as *scars: re-authoring life* (Fig. 5). Life after a diagnosis of cancer became more than what was reflected in the physical – a breast without a nipple



Fig. 4. Liberation: towards an embodied self



Fig. 5. Scars: Re-authoring life.

or white lines and puckered skin. It was not only about the visible but about the invisible. Scars also encompassed the emotional devastation associated with stigma through labels such as “dirty”, “diseased”, “horrific” and “disgusting”. It was about emotional pain arising out of interactions with a medical system that continued to harbor paternalistic attitudes about women’s bodies, decision-making and the assigning of blame or shame.

In the following example, Betty spoke of her encounter with a system unwilling to accept her decision to have her second breast removed. She attributed the failure to accommodate and accept her decision to a medico-centric philosophy and the patronizing views of her physician who seemed incapable of understanding Betty’s need to have both breasts removed. It was not about appearance but about survival. In feeling devalued and dismissed, Betty became angry; her anger served as a catalyst to push back, to reclaim her sense of self.

I saw the surgeon the following Tuesday and there began the battle of, you know, “no I am not taking your other breast. I am not taking your health breast. We can do mammograms, we can do ultrasounds, we can do biopsies, we can do anything to monitor you...She [surgeon] said, “you’ll battle depression within 6 months. You will never forgive yourself for doing it. You will be sorry that you did when you wake up.” I haven’t experienced any of that and I said to her, “If I battle depression, then I can take a pill. If I am dead, we can’t fix that.”...

Taking control of her decisions as well as ownership of her body was an important component of Betty’s re-authoring of her life story. She penned her story; it was not her surgeon’s or cancer’s story.

In the next example, physical scars became the focal point of fascination for Betty’s friends and family. At the same time the scars became a constant reminder of her personal cancer experience. Scars challenged any pre-conceived ideas she may have held about what her body would look like. In the end, her story was rewritten; it wasn’t as bad as expected.

When I first went back to work everybody’s fascination was with the scars. It was difficult; it wasn’t what I expected to look like. I don’t know what I expected but I expected worse than it looked like. I didn’t know exactly what to expect. It is literally two straight white lines and that is all. Initially it was difficult to see because it is a huge change from what I saw every day for 38 years to all of sudden look completely different, but it wasn’t nearly as horrific as I expected.

In the following anecdote, Betty’s scars served as a reminder of non-conformity, of residing outside mainstream socio-cultural values and beliefs.

For me it was a simple as showing other people because you don’t look like the mainstream. It is okay to look different. It is okay to be

different. I always looked like everybody else; now I don’t and I am perfectly fine with that. I think other people struggle more with something they are not used to seeing. If we can raise awareness that this is what happens to people, and they can survive it, go through it and come out the other end; be happy, be proud of who they are and proud of what they look like.

For Betty, scars became a grounding force, a mark of survival and acceptance. She was able to use art, in the form of her sculpted torso, to bring her scars to the forefront. It afforded her an opportunity to confront the devastation cancer may leave and shape new meaning out of the experience. Further, the scars were not merely physical, situated in the post aftermath of surgery, but a reminder of what preceded. For Betty, difference became the pivotal point for personal acceptance as well as an opportunity to demonstrate that survivorship comes in many shapes, all worthy.

It’s not so much the scars are who I am. It’s what I went through that produced the scars. It was facing the fear, trusting my intuition, deciding what I wanted. Allowing myself to have what I wanted.

In this anecdote Diane did not perceive herself as defined by her scars. Rather, her re-authored story emerged out of facing fear and uncertainty. Her scars became a symbol of strength and courage – a reflection of her ability to trust in herself. Diane went on to highlight how facing her scars amplified her insight and the new knowledge gained about this new self.

Growth can be painful, but it is ultimately fruitful. If we are willing to give it the time it takes and make the space to observe all the facets of it and not just what might appear on the surface. To me it is not like “oh my God. Thank God I got rid of the cancer”. It is more like, “oh my goodness. Look how much stronger I am now. Look at how it’s changed my relationships with myself and to the people around me and in my life”. It takes a willingness to ask questions, to sit in silence, to sit in fear. It is being willing to sit with what is unknown for a time and can become known in time.

Initially, the loss of a breast(s) may result in a loss of self. The loss sparked a new quest; Betty and Diane, as survivors, sought to find who they were as individuals. Their scars highlighted the loss of the Betty and Diane, before cancer, but these same scars became a touch point guiding them forward to create a new map for self-hood. Where *red shoes* symbolized activism, compelling others to look *at* rather than look *away*, the theme *scars* was a more personal and private act of reflection focused on re-conceptualization and re-authoring their life narratives.

Discussion

As I stood covered in petroleum jelly, Christian began applying wet plaster gauze to my torso giving me a new, tight hard skin that I found strangely comforting. I felt safe and protected, like a giant bug with all my squishy bits tucked inside my exoskeleton. (Dalziel Cruze, 1998, p. 402)

Research literature supports the premise that life threatening illness, including breast cancer, is a frequent cause of personal re-evaluation, reflection and changes in life perspectives (Sherman et al., 2010; Ganz et al., 1996; Thomas-Maclean, 2004; Collie and Long, 2005; Arman and Rehnsfeldt, 2002). One form of self-actualization leading to the generation of meaning following illness may take place through creative expression. For Dalziel Cruze, the experience of having her body sculpted, as well as the intimate viewing of it, although disturbing initially, led to the emergence of a new embodied self, a beautiful temple not unlike the butterfly emerging from its chrysalis. Viewing her body as

a work of art was “honest, simple, comforting, quiet, strong, peaceful and filled with beauty” (p. 402). Dalziel-Cruze’s depiction of her sculpted torso was not unlike Betty and Diane who saw their sculptures as a source of beauty, strength, and an opportunity for change.

Initially the therapeutic efficacy of art was attributed to the art therapist and art; it has now been relocated to lie within the individual and their capacity for creative expression (Boal, 1992). Whether expressed through visual, auditory or tactile senses, artistic expression has been integrally linked to the psyche (Stickley et al., 2007). Some of the most powerful images challenging our perceptions, values and beliefs have come through art. Whether these images take the form of art as self-image (Malchiodi, 1997) or drama depicting the life event (Gray and Sinding, 2003), all afford the viewer an opportunity to “channel or deeply connect with the original [author of life’s narrative]” (Rossiter et al., 2008, p.281).

Visual depictions such as paintings, sculptures or film, can be affirming or stigmatizing. The context within which visible difference marginalizes, marks and stigmatizes an individual includes: ability to conceal or hide the difference; progression of an ongoing condition; aesthetic qualities of the condition; disruptive nature of the condition on communication with the individual; origin of the condition (is the person perceived to be have caused or influenced the condition); and, risk to the person exposed to the affected other (Jones et al., 1984). For Betty, the aesthetic quality of her condition marked her as different. The removal of both breasts hinted at failure given the minimum standard of acceptability, two firm round breasts. Although the removal of a breast or breasts may be concealed through the use of prostheses, the viewing of self as part of one’s day-to-day routine, serves as a constant reminder and point of comparison that one is marked, falling outside of socially defined norms.

Theories abound reflecting the processes of reinforcement and social conditioning which emphasize and pressure groups and/or individuals to conform to socially defined norms (Rumsey and Harcourt, 2005). Appearance-related norms are defined and perpetuated through the media’s almost constant bombardment of images about how one should look and behave (Zimmerman, 2008). A diagnosis of breast cancer not only challenges these socially constructed norms related to femininity and femaleness by removing and/or scarring the body, but it has the potential to threaten all aspects of women’s lives including how they experience, perceive and think about their bodies as gendered selves (Paff Ogle and Ullstrup, 2006).

Many patients with cancer examine and re-examine the meaning of self and embodied self through a lens colored by social norms associated with body image. For a woman marked as different through the loss of a breast, a significant problem lies in the “management of tension produced by the identify gap that defines stigma and the parallel question for social acceptance” (Paff Ogle and Ullstrup, 2006, p.232). As a methodological approach, art may be instrumental in eliciting a new understanding of self by bridging the gap between stigma and social acceptance. For Betty, social acceptance came through the creation and viewing of her body as art - *this is WHAT it is!* Art pulls one in, reshaping thoughts, perceptions and spitting out a new reality. Art transcends boundaries, forges connections, pulling the viewer into the intimate, visceral world of its creator, the breast cancer survivor. It may well be that integrating art, as a methodology and outcome, provides a mechanism for moving women beyond the passive construction of breast cancer treatment, such as ‘I lost a breast’ or ‘they took my breast’ to actualizing the series of events through intentionality (Manderson and Stirling, 2007). For Betty, intentionality was embodied in the metaphor of *red shoes*, which reflected her desire to advocate for change about how the bodies of breast cancer survivors are perceived.

In contrast, Diane embraced the female body as consistent with social norms. The decision to undergo reconstruction was hers alone, neither her husband nor her surgeon’s decision. Yet, her breast was embodied as her surgeon’s breast. This is not inconsistent with findings in the empirical literature. In a review of breast cancer as an embodied life event, Paff Ogle and Ullstrup (2006) noted that a reconstructed breast is simply that, a reconstructed breast consisting of a rounded mound of tissue, which feels and looks different from the pre-cancer breast. Further, the new breast often lacks a nipple. The reconstructed breast serves as a reminder to the woman that it is but a replacement for the one lost through mastectomy (p.229). At the same time, the new breast helped Diane reaffirm herself as womanly, female and sexually attractive.

The integration of the cancer experience and its meaning results in a re-authoring of one’s life story (Borgman, 2002). This was clearly articulated by both Betty and Diane as they sought to make sense of the cancer experience, integrate this new meaning into their life and reshape self-identity. The development of such meaning gives rise to self-awareness and self-transformation (Reynolds and Prior, 2006). Where Diane’s experience brought her face-to-face with her innermost being, her soul and the resultant transformation, Betty’s experience was more visceral, reflected in activism, “pushing back” and freeing herself of the medico-centric and culturally constructed perceptions of a typical breast cancer patient. As stories become trafficked through the viewing of their torsos, identity is reconstructed, re-affirmed and re-claimed (White, 2000). According to Ferris and Stein (2002), the cultivation of the imagination and attention to inner emotional experiences allows cancer patients and survivors to experience a deeper sense of self and an exploration of the meaning of their lives.

The ability to successfully cope with the stress of breast cancer appears to be associated with how women relate to their own bodies as well as how they relate to others; possessing the capacity to integrate body image and bodily function following treatment underlie successful coping. This capacity may also be influenced by cultural beliefs and perceptions linking breasts to sexuality, motherhood and caring, as well as, attributes of femininity and femaleness (Fobair et al., 2006; Manderson and Stirling, 2007; Paff Ogle and Ullstrup, 2006). For Diane, coping first came as a form of exhibition - the showing off of her newly constructed breast. It subsequently shifted to self-identity in the form of femaleness rather than femininity. Betty was able to cope effectively after successfully navigating the tension between private and public beliefs and perceptions. She broke with conformity and in so doing reinforced her belief that breasts do not make the person. In viewing their torsos Betty and Diane were afforded an opportunity to reflect on their body in a disembodied manner before re-embodiment of the self.

Study limitations

Both women came into this study with healthy images of their self. Whether this was a reflection of their personal qualities such as resiliency, philosophical beliefs about life and purpose, or that time had afforded them an opportunity to adjust is not clear. Neither participant appeared to exhibit a rejection of their former way of life or expressed dissatisfaction with their pre-cancer self. Instead, both women were able to integrate the familiar identity with the newly established identity of cancer survivor. In might be said that they built on earlier strengths and qualities to re-create meaning. This finding is consistent with that of Reynolds and Prior (2006).

A review of the extant literature on the role of viewing art in facilitating the generation of meaning within the context of breast cancer highlighted a general lack of studies in this area. Given the novelty of this feasibility study, there is a need for further research

on how the viewing of art can support self reflection, healing and the creation of meaning and purpose from the cancer experience.

Implications for research and nursing practice

The use of creative arts within research provides an alternative to empirical ways of knowing. It does not depend upon prescriptive or reductionist ways of analysing and explaining data such as coding, statistical analyses and/or categorizing. Instead, the value of the aesthetic lies in its capacity to not only engage with the data differently but to see and interpret the data differently (Simons and McCormack, 2007). Artistic expression is also an effective means of bridging the gap between the individual and universal experience through connections. In viewing art, space is opened wherein people not only look at the artist's rendering of a subject, for example the torso of a breast cancer survivor, but interpret the work, integrate and assign meaning to that experience. This, in turn, informs future experiences or interactions and may be beneficial in the reduction of pre-conceived, socially constructed stereotypes of the female body, femaleness and femininity. Although there has been an explosion of arts-based educational research (Mullen, 2003), its relevance and use has yet to be fully explored within health-based, or more specifically, oncology based research.

If, as Simons and McCormack suggest, "we are able to capture meanings of experience and illuminate the values of a program through artistic expression, it makes sense to also communicate that understanding to others creatively and through artistic forms" (Simons and McCormack, 2007, p.305–306). To fully understand the meaning of cancer within the context of the lived experience of the cancer survivor requires stepping outside the box of traditional research and educational approaches. The use of art as a critical analytic and evaluative tool should be included within core curriculum on education, research and program evaluation. Educational theories that facilitate reflective practice and evaluation of creative and artistic practice in health care (Johns, 1993, 1995; Schon, 1983; Titchen, 2004; Stephens et al., 2004) as well as promoting novel creative approaches to research that include multiple qualitative data, interpretation and evaluation may provide a more robust comprehensive understanding of the cancer experience. In turn, evidence garnered from such research and enlightened education may provide the foundation for increased funding, program development and enhanced patient centered care delivery.

Conclusion

Engaging in the creation of art provides an opportunity for breast cancer survivors to re-experience the landscape of their bodies through the visual and tactile senses. Such sensory exposure, in the form of art pushes the individual towards self reflection and the re-authoring of the life narrative. Further, the intimate connection between model and artist provides a source of strength facilitating the model's capacity to see beyond culturally dominant and medico-centric stereotypes of what a breast cancer patient should be including conceptualizations of behavior and the female body. Although the project was not intended to provide generalizations, it contributes to our understanding of the potential therapeutic role engaging in art may have on the creation of meaning from the breast cancer experience.

Conflict of interest

The authors (B. Sabo & C. Thibeault) do not have any conflicts of interest to declare.

Acknowledgment

Funding for this project was received from the Canadian Breast Cancer Foundation: Atlantic Chapter. We extend our appreciation to the following individuals who helped this project become a reality: Ms. Kim Morgan, Ms. Tammy Worthington, Mr. Thierry Delva, and Ms. Gayle Hughson (graphic art and photography).

A special thank you to the two women who gave of their time to help us understand the experience of breast cancer within the context of art.

References

- Arman, M., Rehnsfeldt, A., 2002. Living with breast cancer—a challenge to expansive and creative forces. *European Journal of Cancer Care* 11, 290–296.
- Benner, P., 1994. *Interpretive Phenomenology: Embodiment, Caring, and Ethics in Health and Illness*. Sage Publications, Thousand Oaks, CA.
- Boal, A., 1992. *Games for Actors and Non-Actors*. Routledge, London.
- Borgman, E., 2002. Art therapy with three women diagnosed with cancer. *The Art in Psychotherapy* 29, 245–251.
- Brennan, J., 2001. Adjustment to cancer: coping or personal transition. *Psycho-Oncology* 10, 1–18.
- Budrys, V., 2006. Neurological deficits in the life and work of Frida Kahlo. *European Neurology* 55, 4–10.
- Cole, A., Knowles, G., 2008. Arts-informed research. In: Knowles, G., Cole, A. (Eds.), *Handbook of the Arts in Social Science Research: Perspectives, Methods, Examples and Issues*. Sage, Los Angeles.
- Collie, K., Bottorff, J., Long, B., 2006. A narrative view of art therapy and art making by women with breast cancer. *Journal of Health Psychology* 11, 761–775.
- Collie, K., Long, B., 2005. Considering 'meaning' in the context of breast cancer. *Journal of Health Psychology* 10, 843–853.
- Dalziel Cruze, P., 1998. The portrait of breast cancer and Raphael's La Fornarina. *Lancet* 360, 402.
- Deane, K., Fitch, M., Carman, M., 2000. An innovative art therapy program for cancer patients. *Canadian Oncology Nursing Journal* 10, 147–151.
- DeFrank, J., Mehta, C., Stein, K., Baker, F., 2007. Body image dissatisfaction in cancer survivors. *Oncology Nursing Forum* 34, 625–631.
- Espinell, C., 2002. The portrait of breast cancer and Raphael's La Fornarina. *Lancet* 360, 402.
- Ferris, B., Stein, Y., 2002. Care beyond cancer: the culture of creativity. *Illness Crisis & Loss* 10 (1), 42–50.
- Fobair, P., Stewart, S., Chang, S., D'onfrio, C., Banks, P., Bloom, J., 2006. Body image and sexual problems in young women with breast cancer. *Psycho-Oncology* 15, 579–594.
- Ganz, P., Coscarelli, A., Fred, C., Kahn, B., Polinsky, M., Petersen, L., 1996. Breast cancer survivors: psychosocial concerns and quality of life. *Breast Cancer Research and Treatment* 38, 183–199.
- Grau, J., Estapé, J., Diaz-padrón, M., 2001. Breast cancer in Rubens paintings. *Breast Cancer Research and Treatment* 68, 89–93.
- Gray, R., Sinding, C., 2003. Standing ovation: performing social science research about cancer. *Qualitative Research* 3, 284–285.
- Gray, R., Sinding, C., Ivonoffski, V., Fitch, M., Hampson, A., Greenberg, M., 2000. The use of research-based theatre in a project related to metastatic breast cancer. *Health Expectations* 3, 137–144.
- Hayakawa, S., Masuda, H., Nemoto, N., 2006. Rembrandt's Bathsheba, possible lactation mastitis following unsuccessful pregnancy. *Medical Hypotheses* 66, 1240–1242.
- Heidegger, M., 1962. *Being and Time*. Basil blackwell, Oxford.
- Heidegger, M., 2005. *Introduction to Phenomenological Research*. Indiana University Press, Bloomington.
- Helms, R., O'HEA, E., Corso, M., 2007. Body image issues in women with breast cancer. *Psychology, Health & Medicine* 13, 313–325.
- Hoshiko, B., 1985. Nursing diagnosis at the art museum. *Nursing Outlook* 33, 32–36.
- Johns, C., 1993. Nuances of reflection. *Journal of Clinical Nursing* 3, 71–75.
- Johns, C., 1995. Framing learning through reflection within Carper's fundamental ways of knowing in nursing. *Journal of Advanced Nursing* 22, 226–234.
- Jones, E., Farina, A., Hastorf, A., Markus, H., Miller, D., Scott, R., French, R., 1984. *Social Stigma: The Psychology of the Marked Relationship*. Freeman and Company, New York.
- Kaiser, S., 1997. *The Social Psychology of Clothing: Symbolic Appearances in Context*. Fairchild, New York.
- Kontos, P., Naglie, G., 2006. 'Expressions of personhood in Alzheimer's': moving from ethnographic text to performing ethnography. *Qualitative Research* 6, 301–317.
- Malchiodi, C., 1997. Invasive art: art as empowerment for women with breast cancer. In: Hogan, S. (Ed.), *Feminist Approaches to Art Therapy*. Routledge, New York.
- Manderson, L., Stirling, L., 2007. The absent breast: speaking of the mastectomized body. *Feminism & Psychology* 17, 75–92.
- Mohr, W., 1995. Integrating esthetics into nursing: literature as a suggested modality. *Archives of Psychiatric Nursing* 9, 365–372.

- Mullen, C., 2003. Guest editor's introduction: 'A Self-Fashioned Gallery of Aesthetic Practice'. *Qualitative Inquiry* 9, 165–181.
- Ogden, J., Lindridge, L., 2008. The impact of breast scarring on perceptions of attractiveness: an experimental study. *Journal of Health Psychology* 13, 303–310.
- Paff Ogle, J., Ullstrup, K., 2006. Breast cancer as an embodied life event: a synthesis of research and theory and directions for interventions and future work. *Illness, Crisis & Loss* 14, 223–244.
- Ponto, J., Frost, M., Thompson, R., Allers, T., Will, T., Zahasky, K., Thiemann, K., Chelf, J., Johnson, M., Sterioff, S., Rubin, J., Hartmann, L., 2003. Stories of breast cancer through art. *Oncology Nursing Forum* 30, 1007–1013.
- Reynolds, F., Prior, S., 2006. The role of art-making in identity maintenance: case studies of people living with cancer. *European Journal of Cancer Care* 15, 333–341.
- Rossiter, K., Gray, J., Kontos, P., Mkeightley, M., Colantonio, A., Gilbert, J., 2008. From page to stage: dramaturgy and the art of interdisciplinary translation. *Journal of Health Psychology* 13, 277–286.
- Rumsey, N., Harcourt, D., 2005. *The psychology of appearance*. Open University Press, Berkshire.
- Sabo, B., Saint-Jacques, N., Rayson, D., 2007. The decision-making experience among women diagnosed with stage I & II breast cancer. *Breast Cancer Research and Treatment* 102, 51–59.
- Schon, D., 1983. *Educating the Reflective Practitioner*. Jossey-Boss, London.
- Sharf, B., 1995. Poster art as women's rhetoric: raising awareness about breast cancer. *Literature and Medicine* 14, 72–86.
- Sherman, A., Simonton, S., Latif, U., Bracy, L., 2010. Effects of global meaning and illness-specific meaning on health outcomes among breast cancer patients. *Journal of Behavioural Medicine* Epub Ahead of Print.
- Shilling, C., 2003. *The Body and Social Theory*. Sage, Thousand Oaks.
- Simons, H., McCormack, B., 2007. Integrating arts-based inquiry in evaluation methodology: opportunities and challenges. *Qualitative Inquiry* 13, 292–311.
- Stark, J., Nelson, J., 2000. The breasts of "night": Michelangelo as oncologist. *The New England Journal of Medicine* 343, 1577–1578.
- Stephens, G., Titchen, A., McCormack, B., Odell-Miller, H., Sarginson, A., Hoffman, C., Francis, S., Petrone, M., Philipp, R., Naidoo, M., Mcloughlin, C., 2004. *Creative arts and Humanities in healthcare: swallows to other continents*. Research and Policy Studies in Health Services (London).
- Stickley, T., Hui, A., Morgan, J., Bertram, G., 2007. Experiences and constructions of art: a narrative-discourse analysis. *Journal of Psychiatric and Mental Health Nursing* 14, 783–790.
- Strauss, R., Marzo-Ortega, H., 2002. Michelangelo and medicine. *Journal of the Royal Society of Medicine* 95, 514–515.
- Thomas-Maclean, R., 2004. Understanding breast cancer stories via Frank's narrative types. *Social Science and Medicine* 58, 1647–1657.
- Thomas, B., Marshall, R., Gold-Smith, S., Forrest, A., 2004. Visual art and breast health promotion: artists' perspectives. *Canadian Oncology Nursing Journal* 14, 233–243.
- Timmons, A., Macdonald, E., 2008. 'Alchemy and Magic': the experience of using clay for people with chronic illness and disability. *British Journal of Occupational Therapy* 71, 86–94.
- Titchen, A., 2004. Helping relationships to practice development: critical companionship. In: McCormack, B., Manley, K.G.R. (Eds.), *Practice Development in Nursing*. Blackwell Publishing, Oxford.
- van Manen, M., 1997. *Researching Lived Experience: Human Science for an Action Sensitive Pedagogy*. Althouse Press, London, ON.
- White, C., 2000. Body image dimensions and cancer: a heuristic cognitive behavioural model. *Psycho-Oncology* 9 (3), 183–192.
- Zimmerman, A., 2008. Sexuality sells: a content analysis of lesbian and heterosexual women's bodies in magazine advertisements. *Journal of Lesbian Studies* 12, 381–392.