

AN ARTS-BASED ENQUIRY INTO MY

LIVED EXPERIENCE OF BREAST CANCER

KAY GRAVELL



BREASTLESS LANDSCAPE

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An arts-based enquiry into my lived experience of breast cancer.

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Declaration

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Name: Kay Gravell

Signed:

Date:

Write your self. Your body must be heard.

Helene Cixous, 1991, p.335.

Abstract

This enquiry is grounded in my own personal experience of breast cancer. I experienced the loss of my breast, not only as a change to the shape and feel of my physical body but also in the way I understood and expressed myself as a woman. Still largely based on the bio-medical paradigm, the medical system in Australia encourages women to have a breast reconstruction at the same time, or soon after, their mastectomy in order to finalise their treatment and ensure they get back to “normal” as soon as possible. This enquiry explores how I used creative arts to find meaning in my lived experience of breast cancer; in particular, how I made sense of my changed body, came to a decision to not have a breast reconstruction, and explored how to live as a one-breasted woman.

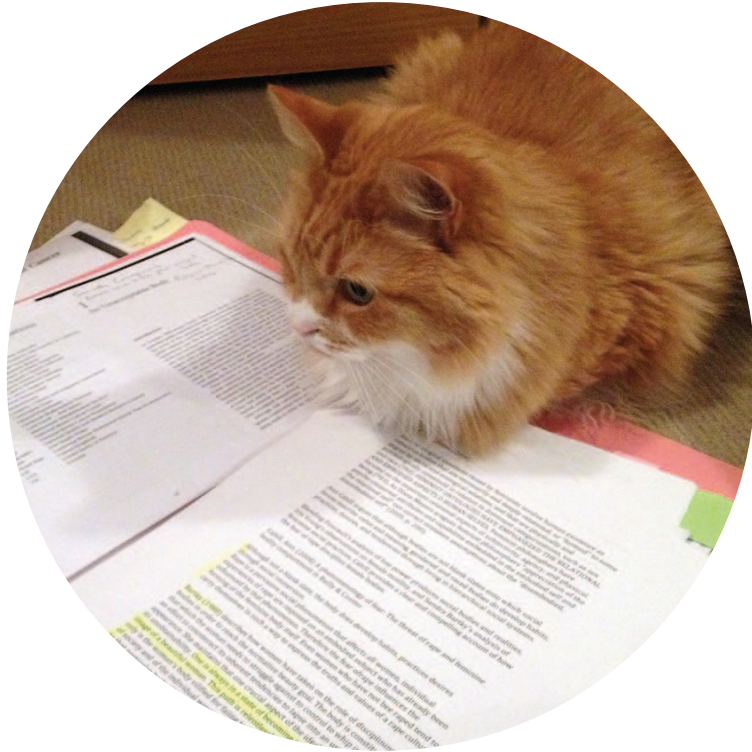
Using creative arts I attempted to speak from my body. Situated within a review of different discourses of the body, my enquiry centres on an understanding of the feminist phenomenological body as a continuously forming shape-shifting entity intermingled and coconstructed with the social and natural world. Working alone and alongside other women, I undertook numerous enquiry cycles using a range of different art modalities, with a particular focus on sensory knowing formed through relationship with the art materials. Touch provided the bridge between my experiencing, emotion,

and movement into art-making, allowing me to heighten my sensory awareness thus providing the space for new knowing to arise within my body.

Using a fusion of different modalities, my enquiry centred on two key images. One image created from my painted body allowed me to explore existential issues of mortality and the meaning of life, while the pink lady image provoked me to explore my feelings of anger, vulnerability, and shame. Through these images I discovered that a particular artwork is able to hold the complexity of lived experience.

My own arts based exploration of my breast cancer experience provides a method for other women to follow, it will inform my own arts based practice, provides a template for arts based groupwork, and contributes to the understanding of women’s lived experience of breast cancer that can influence the support provided by family, friends, and health services.

*For my sister Ann
who died too young of breast cancer.
You showed me how to enjoy the simple pleasures
of a sunny day and a blue sky.*



Acknowledgments

Undertaking this professional doctorate has been a challenging, frustrating, and fulfilling journey that would not have been possible without the support and assistance of many people who have contributed to this project in all sorts of ways: from reading drafts; encouraging me when I doubted my ability to complete the task; discussing ideas; going for walks, bike rides and swims. I am truly grateful to you all. In particular I would like to acknowledge the generosity of the three women who gave up their time and shared their own experiences of breast cancer with me and allowed me to draw on their stories as part of this thesis. I would also like to acknowledge all the women with breast cancer with whom I have shared stories, both in person and through cyberspace, and to the many inspirational authors I have read and engaged with over the years.

I would like to thank my dear friend and colleague Gillian Jones, who facilitated the group workshops, and provided me with constant support through the many challenges along the way. Special thanks to my MIECAT doctorate colleagues Nona Cameron, Edwina Entwistle, Jane Mortiss and Kerry Kaskamanidis who provided skillful companionship throughout my enquiry that led to many transformative insights. The key motivating factor in undertaking my professional doctorate at MIECAT was my wish to continue my studies and exploration into arts-based research with Jan Allen. Jan's breadth of knowledge, incisive intellect, and insightful artistic response

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I would like to thank my gorgeous children, Annie, Sam and Patrick, who inspire me to keep pushing my boundaries and giving me such a strong reason to live my life fully. My special thanks to my partner Claire Garnham, who not only provided personal support and encouragement, fed and looked after me, but also assisted me in the graphic design aspects of this thesis. Lastly my cat, Jasper, who kept me company during the many hours spent at my computer.

Creative Declaration

In order to value the creative aspect of this thesis I have made slight adjustments to the formal APA format in the way I have presented this thesis. I have used APA format for referencing and citing of works of others. However I have made the following variations:

I have used Australian spelling, other than in direct quotations.

I have united text and image in order to emphasise the equal importance of image and text in my enquiry.

I have presented my art-making enquiry chapters in a creative way that highlights the emergent meaning-making process.

I have used the normal fiction format style of punctuation and presentation for my fictionalised short story in chapter seven.

I have used the feminine pronoun when referring to breast cancer patients in recognition that the overwhelming majority of people affected by breast cancer are women.

I have used the first names of authors as a way of acknowledging them as people with whom I engaged in a conversation and as a form of feminist awareness in highlighting the gender of authors. Authors whom I have continually referred to such as Maurice Merleau-Ponty, I have used surnames following the initial citation.

I have enclosed a DVD of three short films I made throughout this enquiry. One film – The black hole of grief was submitted to the Victorian Cancer Council Arts Awards in 2013.

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Chapter one

Introduction



Human enquiry is as complex, generative, curious, conflicted, nuanced, dark, particular, transitory, changeable, enduring and hopeful as is a single human life . . . to live with curiosity, compassion, integrity and mindfulness is to inquire . . . to engage in a living enquiry is to learn to let go, to leave the spurious safety of research – that crumbling roof over education that often separated us from life and rarely protected us anyway – and to enter an open field, ears and wings bristling. (Neilsen, 2008a, p. xvi)

Enquiry topic

My enquiry is about my post-mastectomy body in its various relationships as “a changed body”. I had recently been diagnosed with breast cancer and was still undergoing treatment when I decided to enrol in the MIECAT doctorate program. As I was placed under pressure to regain a “normal” two-breasted body, through a breast reconstruction, I was keen to pause so that I could access my embodied knowing to provide me with a pathway through my intense emotional turmoil. This enquiry explores how I used creative arts to find meaning in my lived experience of breast cancer. In particular, I wanted to make sense of my changed body, use creative arts to help me to come to a decision about whether to have a breast reconstruction, and if not, to explore how to live as a one-breasted woman.

Motivation for my enquiry

My motivation for this enquiry was clearly personal, but not entirely so; I wanted to find a way out of the pain of grief I was feeling. I began this study with a desire to make sense of my distressing, traumatic, and potentially life-changing experience of breast cancer. My research began as an urgent existential quest for meaning, to make decisions and “get on with my life”. Through the MA in Experiential and Creative Arts Therapy undertaken at MIECAT I had previously discovered that using my body as a canvas on which to paint, allowed me to access and explore painful emotions (Gravell, 2009). When confronted with a sense of emotional upheaval through my breast cancer diagnosis, I again turned to using creative arts as a way of dealing with, and finding meaning from my pain. It is this commitment to embodied knowing through creative arts that led me to enrol in the doctorate program at MIECAT. I wanted to have the structure of a formal enquiry to provide me with the space, support, and permission to immerse myself in this enquiry process.

My approach

I responded to my breast cancer diagnosis by trying to make sense of my experience by:

1. making art and using MIECAT procedures to enquire into my creative output;
2. reading, writing, and conceptualising about notions of the body as they related to breast cancer; and
3. connecting with others—other women who have breast cancer, doctorate

colleagues, writers, and strangers.

My breast cancer diagnosis immediately brought to my attention the dominant breast cancer narrative based on traditional notions of femininity and symbolised by the colour pink. As a graduate of the feminist movement of the 1970s, I was astonished to find myself in my 50s being depicted in girlish pink. This led me to re-examine my feminist ideology and explore the literature around different discourses of the body, which I have discussed in chapter two.

I followed my drive to make art as a way of trying to make sense of my feelings and my experience. As described in chapter three my methodology and arts-based method developed as I continued to make and explore my artwork. Through this arts-based enquiry, three dominant colours—black, red, and blue—surfaced and provided a structure for my enquiry. Even though they did not emerge in a linear sequential way, I have described these colours in separate chapters—four, five, and six. I gradually came to new understanding as I undertook numerous cycles of enquiry which I formed into a poetic narrative. In each of the colour chapters I have also provided an outline of an enquiry cycle to illustrate the process I used.

During this enquiry I worked alongside other women with breast cancer. I have struggled with how to convey their experiences in a way that respected their individual uniqueness but also highlighted the commonality of our experiences. I attempted to capture their stories through a fictional short story, which I have included in chapter seven. As well as sharing their stories I also wanted to take my own story out into the

world to confront my own lingering sense of shame, and to highlight an alternative breast cancer narrative that challenges the dominant pink breast cancer discourse. In chapter eight I have discussed the public exhibition of my art work as a creative synthesis of my findings from the different stages of my arts-based enquiry.

Finally in chapter nine I have discussed the themes that emerged from my enquiry in dialogue with a range of literature. My enquiry is transformative. I made many significant discoveries about myself, and how I live my life. The other women I worked alongside also found that using creative arts enabled them to develop meaning from their breast cancer experiences and clarity about their decisions in relation to whether to have a breast reconstruction.

In speaking from, and about my own personal experience, I acknowledge the risk of providing to the world yet another personal breast cancer story, which may be of limited interest or relevance to others. Di Herndl (2006) and Mary DeShazer (2008) critique the increasing number of personal accounts of women's breast cancer experiences over the last decade, finding that many fall within the trope of the heroic journey, with little analysis of broader social issues. In writing my story I hope to follow in the tradition of key narratives from women, such as Evelyn Accard (2001), Sharon Batt (1994), S. Lochlann Jain (2007, 2010), Audre Lorde, (1980), and Jo Spence, (1986), who write evocatively of their personal experiences interwoven with feminist critiques of the causes and treatment of breast cancer. By using creative arts to explore my lived experience of breast cancer, particularly in relation to life after a mastectomy, and linking this with the broader breast cancer narratives, I hope to contribute to greater

understanding of the complexity of breast cancer experience, the supports required, and the usefulness of creative arts in assisting women with breast cancer. As Norman Denzin (1997) argues:

It is not enough to write moving tales of the self that emotionally move the reader. Self stories should answer at one level, to the criterion of cultural criticism . . . Such works should be a stimulus for social criticism and social action—a joining of the personal, the biographical, with the political, the social. That is, the tale being told should reflect back on, be entangled in, and critique this current historical moment and its discontents. (p. 200)

In accordance with my feminist phenomenological approach, I have privileged my own voice and written in a personal and emotionally evocative way so that I might contribute to a conversation and share my experience in a way that readers “feel the story in their guts, not just know the ‘facts’ in their heads” (Ellis & Bochner, 2006, p. 435). As breast cancer is overwhelmingly a female disease I have used the female pronoun throughout when referring to people with breast cancer.

I have also use the plural arts rather than the singular art when discussing arts therapy or arts-based enquiry to denote the multimodal creative arts approach I have taken. In order to emphasise the emergent nature of this work, I have used the term enquiry rather than research. Although contrary to the accepted academic protocol, I have used the full name of authors when referring to them in the text. I have done so in the spirit of my intention to contribute to a conversation with other writers, researchers,

and women experiencing breast cancer, to confront the often-patriarchal nature of academic research, and to highlight the contribution of female as well as male writers and researchers.



Chapter two

The Body



The throbbing vein will take you further than
any thinking

(Rumi translated by C. Barks 2004, p. 152).

My body demands my attention

This enquiry is grounded in my experience of my changed body following a mastectomy. Even before my breast cancer diagnosis my body was demanding my attention. I was in the midst of menopause, which had brought to the fore the experience of my ageing body—extreme changes in my body temperature, the end of my years of menstruation, and hormone-driven surges of emotion. My body, which had previously reflected my athletic lifestyle, was no longer taut and fit. The years I had spent in the sun were now written on my skin as it began to sag and wrinkle. I would sometimes catch sight of my hands and feel shocked to realise that these “old lady’s hands” with their wrinkles and age spots, were in fact mine. How had this happened? I still felt young inside but seemed to have quite suddenly found myself encased in the body of an older woman. I experienced menopause in a similar way to my adolescence—my hormone-driven changes seemed to trigger a time of existential questioning. Who am I? Where do I belong in the world? What is the meaning of my life? My children, who were now reaching adulthood, no longer needed me to centre my life on their needs. My mother, who had dementia and for whom I had been the primary carer, had recently died. I now had space to pursue my own interests more fully. What did I want to do with my life?

My breast cancer also came at a time of other momentous changes in my life. I had recently left my husband of 28 years. I had resigned my full time position as an executive manager in community health to establish my own consultancy business, and relocated from growing flowers on a beautiful lakeside farm on an island in the

Gippsland Lakes in Victoria, to a small one-bedroom flat in Melbourne. As a fifty-year old woman, this was my first experience of living alone. I drove away from my home with my clothes and a few precious possessions to establish a new life for myself in Melbourne, leaving behind my 17-year old twin sons, my friends, my dog, my cat, my garden, my lifestyle and my sense of belonging to a close supportive country community.

My sense of confusion and disorientation was heightened by the fact that I had begun questioning my sexual orientation. Leaving the security of a long-term relationship and “coming out” as a lesbian woman in my 50s, I experienced wild emotional swings—from feelings of excitement about new possibilities, to fear and insecurity about a future faced alone. I felt invigorated as I threw myself into a new lifestyle, but also experienced moments of deep despair and fear.

*Coming Out
Emerging from the chrysalis
to experience the potential
of a bright new world
I want to retreat
to the safe confines
of my cocoon.
But I can't.*

*The strength of desire draws me
out. Knowing that to live
in the full power of my beauty
leads to annihilation.*

The upheaval of wrenching myself from my former life of quiet rural domesticity to that of a newly-single woman living alone in the city was expressed through my body. In the first 12 months I lived in Melbourne, I spent more than six months on crutches, recovering firstly from a ruptured left achilles, and then a reconstruction of my left knee. I was still on crutches when I had my first bout of surgery on my left breast—the removal of a small non-malignant lump in my milk ducts. My body compelled me to stop and challenge my pattern of rushing through life without taking time out to process or reflect on my experience. Literally unable to walk, I was faced with the opportunity to deal with some of the dramatic changes in my life. I began to have a new-held respect for listening to my body, tapping into its wisdom to show me how to

pause and reflect on how to move forward in my life.

Further breast surgery and then a full mastectomy focussed my attention onto my body again. As I confronted the pressure to have a breast reconstruction, I found myself thrown into a state of emotional turmoil and confusion. How much of my sense of identity as a woman is connected to my physical appearance? What does it mean for me to live as a woman with one breast? Would I ever be able to find love again? Not only was I getting older but now I also had a scar replacing one of my breasts. Yet again I could feel myself rushing forward in the desire to get over my breast cancer experience and get on with my life. This life pattern brought a sense of urgency to my need to gain clarity about my decision as to whether to have a breast reconstruction and triggered emotions connected to other stories of my life.

Exploration of different understandings of the body

As I pondered whether to have a breast reconstruction, I was confronted by a tangle of emotions, values, and political beliefs, both my own and others', in relation to the female body, that were enmeshed in this decision. I needed to come to a clearer understanding of how I felt about my own body. Through different life experiences I have developed different understandings of my body some of which are in conflict; its functioning, how others perceive it/me, and how my body is interactive with the world. To be able to resist the pressure to make a quick decision and discover whether

I want to have a breast reconstruction I felt a need to examine my ideas of my body. By delving into the literature around discourses of the body, I hoped to begin the process of clarifying my own understanding of the body in general, and thereby refine my philosophical and practical understanding of my own female body. Perhaps then, I would have a clearer idea of whether to have a breast reconstruction.

The loss of my breast has not had any major physical impact on me in terms of how I function in the world. It is not like I have lost a foot or a hand that seriously limits what I can do. But I still mourn its absence. My body, with one breast and a scar, feels strange to me. I experience the loss of my breast, not only as a change to the shape and feel of my physical body but also in the way I understand and express myself as a woman. I was surprised to notice a feeling of shame, a sense of needing to hide my difference. Like the women in Samantha Cromptvoets' (2006b) study, I was not able to find any support to help me come to terms with my changed body in a physical, psychological, or emotional way. The medical system in Australia seems intent on rushing women through to have a breast reconstruction at the same time, or soon after, their mastectomy; to finalise the treatment and ensure that women with breast cancer get back to normal as soon as possible.

The body as “a broken machine”

My experience of breast cancer and medical treatment left me feeling as if my body had been taken over by both the invasive cancerous cells, and the experts fighting to annihilate them. It had become a site for other people's work. My breasts had been

squashed flat in mammograms, holes had been punched in them for biopsies, and they had been smeared with cold lotion and scanned. My breasts had been felt, prodded and squeezed, been imaged by MRI, and been talked about by a range of medical experts. Finally one breast was gradually cut away in three operations, starting with my nipple and ending with a full mastectomy. After each operation, as my breast was slowly excised, I was left with a new body shape. I was left with new bruises, swelling and scars, and more baffling discussion about pathology results and the lack of clear margins.

I felt like a broken machine needing to be fixed, rather than a whole complex, sensing being with emotional, spiritual, and psychological needs. The modern medical system, which is still largely predicated on the Cartesian understanding of the separation of the mind and body, tends to treat disease as if it is caused by a malfunctioning body part, that can be repaired, removed or replaced, rather than treating the patient in a holistic manner (Carel, 2007; 2013; Wolff, 1997). Writing in the 17th Century, the French philosopher, Descartes was influential in the promotion of the mind/body dualism. According to the Cartesian perspective, not only is the non-material mind separate from the material body, it is also superior to it (Blackman, 2008; Foster, 1991; Robertson, McQuat, & Vinci, 2008). Our sense of self is expressed through the mind, with the mind viewed as the source of knowing, while the body, body sensations, and experience are seen as inferior sources of knowledge.

Viewing the body as a machine to be repaired encourages health experts to treat the body in an atomistic and mechanical fashion and to use the intelligence of the rational

mind to assert authority over the patient's body. The hierarchical valuing of the mind over the body is mirrored in the relationship between the privileged positions of the medical experts in relation to the patient's body. I felt like I had limited agency and was dependent on the skills and expertise of the doctors, and ceded to them the authority to use all available technology to make the required repairs.

It is not unexpected then, that in western societies, medical practitioners occupy privileged positions in society with high status and remuneration. The power imbalance between patients and medical experts is further amplified when considered through a gendered lens, as in Australia males still outnumber females in these high status positions. It is important to acknowledge the complexity of this power dynamic, and not define all patients as lacking any sense of self-determination or agency, however, the more serious the medical diagnosis the more difficult it is to challenge the medical power relations (Lorentzen, 2008). When it is a matter of life and death, relying on a mix of intuitive knowledge and incomplete factual information, it is indeed a feat of resistance, especially as a female patient, to challenge the team of generally male medical experts armed with their indecipherable "scientific truth" and wide array of technology. Even when the medical experts are female, as was the case with my surgeon, they tend to be co-opted into the medical/scientific culture that perpetuates the power differential between patients and medical specialists. Occupying the disempowered position of the patient, it is not surprising that I, like most other patients, felt unable to assertively challenge the decisions of the medical experts once on the conveyor belt of cancer treatment.

Viewed as a machine, I felt defined in terms of a "failed production model" with the expectation that I should submit to vigilant detection to control and eliminate my flaws. This emphasis on surveillance and monitoring has become the primary response to breast cancer (Thorne & Murray, 2000; Krupar, 2012). Couched in the terms of prevention, screening (using mammograms and ultrasound), has become the focus of dealing with increasing rates of breast cancer in western countries such as Australia and the United States. The fact that mammography does not prevent cancer, but merely provides another diagnostic tool, is largely concealed in the scientific medical rhetoric (Fosket, 2000). Conceptualising the body as a machine perpetuates the idea that the individual patient is responsible for the disease and deflects attention from prevention. Breast cancer is understood to be largely behavioural, with responsibility resting with the individual, rather than the result of societal issues such as exposure to disease-causing agents in the environment (Brown, Morello-Frosch & Zavestoski, 2011; Fosket, 2000; King, 2006; Steingraber, 1997, 2000; Thorne & Murray, 2000).

The focus on molecular biology in medical research has spawned a modern equivalent of the body as machine to "a view of the body as a hierarchically organized bureaucratic system of control" (Clorfene-Casten, 1993, p. 74) in which disease is seen as a breakdown in central control. Kathryn Morgan (1991) points out that although the particular type of machine selected as paradigmatic of the human body has shifted from clocks, to hydraulics, then to thermodynamics, and now to information-processing models, the view of the Cartesian machine modeling of the body continues to dominate. This view of the body as a combination of parts has held back a coordinated approach to holistic care, in which the patient is seen as central (Carel, 2008, 2011, 2013).

The body as a “battleground”

The dominant Cartesian medical discourse provides fertile soil for the development of the prevailing narrative of cancer as a battle, with the body as the battleground (Batt, 1994; Lind & Brzuzy, 2008). According to this narrative, cancer is seen as an invasion of the body by foreign cells which need to be destroyed by whatever means necessary—whether this is cutting them out, poisoning them through chemotherapy, or killing them through radiation. Treatment is constructed as a battle of good versus evil with all the power of the artillery available to the modern medical system waged against the enemy. A surgeon interviewed in the documentary entitled *Cancer as a Battleground* on Radio National Australia claimed that “the war metaphor is apt as we use the same instruments of war, chemicals and radiation as are used in traditional warfare. Real biological weapons are used against the bodies of cancer patients” (Brennan, 2012). The pervasiveness of this narrative is highlighted by Marietta Elliott-Kleerkoper in her response to this radio program:

When I contracted breast cancer. The surgeons called it “aggressive” (as if a cancer had feelings!) and prescribed surgery (X2), chemo and radiation . . . The Iraq war was going full bore and I experienced my body as Iraq being bombarded by weapons of mass destruction (2010, July 3).

The idea of our bodies being killed from within by this unseen invasion of an army of killer cells also reinforces the Cartesian dualism of the importance of the mind in controlling the anarchic body. Cancer is seen as a lack of discipline of the body,

which creates cancerous cells, which multiply exponentially until causing death. The battleground narrative not only views cancer as evidence of a chaotic body but also through “vigilant detection of breast cancer induces the patient to militarize her body” (Krupar, 2012, p. 60). Perhaps the most profound impact of the cancer as a battle narrative is that, in encouraging us to see our own bodies as harbouring the enemy, our sense of trust in our bodies is undermined (Frank, 1995). Catherine Lord (2004) in her narrative of breast cancer disputes the notion of a silent infiltration of an imaginary enemy “You cannot find one single moment, however, when soft innocent tissue went wrong and turned into a monster that will grow unchecked until it bleeds its host to death” (p. 5).

The battle narrative is extended to not only the body as a battleground but to the idea of eradication of the disease through the use of the war metaphor. This can be identified as far back as 1971 with the appropriation of \$100 million in the United States to launch a war against cancer in the belief that cancer, a major burden of disease, could be defeated in much the same way as other major diseases such as smallpox or polio. It only needed enough money to find the magic cure. So the war on cancer, like the war on drugs and the war on terrorism became an easy slogan to garner our attention and justify large amounts of public and philanthropic funds to create a voracious scientific medical research machine. The beauty products company, Avon’s *Crusade against cancer* campaign is a good illustration of the prevalence of this war metaphor for breast cancer. On the Avon website (<http://www.avonfoundation.org/causes/breast-cancer-crusade/>) in the page titled *Army Hall* there is a call for women to volunteer to join the army against breast cancer to help eradicate the disease.

Breast cancer activists are increasingly questioning current treatment and research approaches (Lind & Brzuzy, 2008; Thorne & Murray, 2000). The cancer treatments available today of surgery, radiation, and chemotherapy or slash, burn and poison are essentially those that have been available for the last 80 years and perpetuate the notion of the body as a battleground. Like Harvi Carel (2007; 2008, 2011) I yearn for a greater acknowledgment of the varied ways that breast cancer impacts on all aspects of lived experience, so that a more holistic health response may be possible; one that includes prevention, treatment and also the ongoing psychological, emotional, and physical adaptation to the disease and its treatment repercussions.

The primal body stained by original sin

Based on the belief of the separation of the body and mind, the scientific medical approach to the body can be traced to the classical Greek philosophical writings of Hippocrates (460- 377 B.C.), Socrates (369 – 399 B.C.), Plato (428-348 B.C.) and Aristotle (384-322 B.C.) (Peters, 2004; Turner, 2008). In the premodern era, the world was seen as God-given, everyone and everything occupied a preordained place in the grand scheme of things, and it was believed that the truth of things would be revealed by God. The body was viewed as the site of primal desires, as inherently sinful, requiring subjugation by the authority of the rational mind. Early Christian theology saw the body primarily as an adversary to be defeated. Flesh, particularly female flesh, was seen as a threat to spiritual perfection. As Marilyn Yalom (1997) writes “From Saint Jerome’s battle cry of ‘Conquer the flesh’ in the fourth century to Saint Theresa’s efforts to ‘gain dominion over the body’ in the sixteenth, Christianity taught its adherents to

minimize (if not mortify) corporality” (p. 31).

My mother’s Catholic religion led me to being raised as a Catholic, attending Sunday Mass and being educated in Catholic schools from the age of 5-15 years of age, where I was mainly taught by Irish nuns of the Brigidine order. I was indoctrinated with the belief that I was born into the world already blackened by original sin, and the nuns inculcated a notion of my body as shameful, impure, and dangerous. As young innocent children we were taught to fear our nakedness and even advised to not look at our bodies when bathing. We were instilled with the notion of the primal female body as the site of the competing desires of pure innocence and primitive sexuality.

The understanding of the primal body was intertwined with the growth of the narrative of the female martyr. Historically women, who were seen to be different or who challenged the dominant social norms, were often classified as witches and tortured or put to death. On the other hand, women were expected to preserve an idealised version of pure innocence rather than accede to the depraved sexual desires of men, even if this resulted in death. Marilyn Yalom (1997) identifies Saint Agatha and Saint Maria-Goretti as epitomising this construction of female martyrdom. The virgin Saint Agatha, who lived in Sicily in the third century, and ironically became the patron saint of nursing mothers and more recently of breast cancer, had her breasts cut off by the pagan governor because she refused to accede to his sexual demands. The canonization of Maria Goretti, who died in 1902 aged just eleven, from multiple stab wounds inflicted by her attempted rapist after she refused to submit to him, illustrates the resilience of the mythology of martyrdom (Yalom, M., 1997, p. 32). I was

so enthralled by her heroic story, told to us by the nuns, that, aged 11 years, I took Maria as my confirmation name in tribute to Maria Goretti.

In accordance with this view of the primal body, ancient medical treatment of breast cancer was focused on ridding the body of this incarnation of evil. Disease was seen as related to the possession of the body by malicious forces and a lack of control of the mind. “The cause of breast cancer was thought to be women’s inner pollution, her ‘dark drains’ and the treatment was to excise the offending parts” (Thorne & Murray, 2000, p. 146). This notion of the primal body can still be seen in the modern understanding of breast cancer as an invasion of alien cancerous cells that need to be expunged from the body through surgery, or killed by chemicals, or radiation. In Western countries, the legacy of female martyrdom is also evident, in the belief that women should confront the disease of breast cancer with a stoic martyrdom, which is heavily promulgated as part of the dominant breast cancer narrative (Ehrenreich, 2001, 2009; Lorde, 1980; Nielson, 2010; Vitry, 2010).

The biological body driven by natural instincts

Closely related to the idea of the primal body, the notion of the physical body as a cluster of biological systems driven by natural instincts also impacted on my experience of breast cancer. According to this understanding the body is seen as the seat of irrationality and emotion that needs to be under the control of the rational mind: it is the rational mind that elevates humans above other animals (Lakoff & Johnson, 1999; Turner, 2008). Because human reason is disembodied, humans are

considered to be free to decide their actions; our will can override the bodily influence of desires, feelings, and emotions. The superiority of the mind over the body can be seen in the “positive thinking movement” which locates the causes of cancer, a disease of the body, as the responsibility of the individual’s negative thinking. The call to think positively as a way of dealing with breast cancer, left me feeling guilty and alone as I was not able to subscribe to the belief that my lack of positive thinking was firstly the cause of my cancer, and secondly hindering my cure.

The Cartesian mind/body split also has a gendered subtext. The pursuit of scientific knowledge is figured rhetorically as the domination of the female body of nature, illuminated by the light of masculine science (Jacobus, Fox Keller & Shuttleworth, 1990). The superior rationalist mind is linked to the disembodied male who through his superior intelligence, reason, and logic, holds a position of authority over the female who is defined in an embodied way connected to the irrational, intuitive, and biological functions of the body. Scientific discourse has been especially crucial in constructing reality as something women can embody but not know. Because the body is discounted as a source of knowledge, women are discounted as “knowers” (Davis, 1995; Jacobus et al., 1990).

Being defined by our greater immersion in our bodies, women are considered to be too weak, too emotional, and too irrational to take on a range of positions in the social world. According to this essentialist notion of the body, physiological, mental, and emotional spheres are considered interdependent and yet in conflict. A dichotomy is perceived between women’s reproductive organs and their capacity for intellectual

pursuits, thus limiting them to the biological function of reproduction. According to this viewpoint, women's "natural" or given psychological characteristics, such as nurturance or empathy, and their connection to certain social practices, such as caring, universally applies to all women at all times in all social contexts. As Elizabeth Grosz (1990) states, "essentialism refers to the existence of fixed characteristics, given attributes, and ahistorical functions which limit the possibilities of change and thus social re-organisation" (p.334).

Hierarchies involving both power and gender are intimately associated with the ideology and practice of science. Feminists such as Sharon Batt (1994) and Judith Hooper (1994) argue that the restriction of women's social roles because of the perception of their innate physiological connection ensured that until recently, they have been often constrained to the role of the helpless patient. Men, on the other hand, have generally taken on the role and corresponding power of the medical expert. Commencing in the Victorian era, the classification of much of women's behaviour as "women's diseases" created a new specialisation for the male medical profession (Shuttleworth, 1990; Yalom, M., 1997).

With the development of the new specialty in women's diseases, the male medical profession arrogated to itself the exclusive right to diagnose the pathology of both the female mind and body, offering thus a forceful lesson in the power of male science to read and control the mysteries of nature. (Shuttleworth, 1990, p. 52)

Although in Western countries, the domination of men in positions of authority over women's bodies is gradually changing as increasing numbers of women enter the traditional male bastions of medical specialisations such as surgery, this history is still influential. The main treatment for breast cancer has been radical mastectomy, which leaves the woman with a concaved chest and restricted movement on one side of her body. The fact that this procedure, which inflicts the maximum possible deformity, disfiguration, and disability, continued to be the major treatment for breast cancer from the time of ancient Greece to the 1990s, may be read as a reflection of this gender role distribution (Batt, 1994). Perhaps it is not chance that less invasive treatment options such as lumpectomy, that are available today, have surfaced as women break into traditional male medical roles of research and surgery.

Divorcing the biological body from all other contexts can also result in the normal response of sadness and grief to the experience of breast cancer being diagnosed as a medical illness requiring pharmacological intervention. The biomedical literature exploring the link between depression and cancer reinforces the notion that depression is fundamentally biological (Clarke & Gawley, 2009; Spiegel & Giese-Davis, 2003). The biomedical discourse which views the body as a biological entity promotes the use of drugs as a means of "fixing" the biological imbalance that leads to depression. There is little tolerance within the medical system for addressing the normal emotional response to traumatic life events other than with drugs or surgery. My experience reflects this bias in the medical system. I was offered surgery to rid my body of cancerous cells but was not offered any form of support such as counselling to help me with the emotional and psychological impact of having my breast removed.

The contested female body

I was still reeling from the shock of knowing that I needed to get my breast cut off, when my surgeon asked me whether I wanted to have a breast reconstruction, as this would determine the type of mastectomy she performed. It was explained to me that the breast reconstruction was normally performed at the same time as the mastectomy. The question totally threw me. I felt under enormous pressure to make a decision quickly as I was having my operation the next week. Feeling overwhelmed by fear, grief, anxiety, and confusion about what to do, I went home and surfed the net looking for information on breast reconstruction. Instead I was bombarded by websites promoting breast enlargements. It transpired that I was able to postpone my decision; my mastectomy operation occurred a week before Christmas, and there were no plastic surgeons available to do a breast reconstruction at the time. My surgeon performed a “skin-saving” mastectomy that would allow me to have a breast reconstruction at a later date, thus leaving me time to make up my mind. I felt torn by indecision.

I consulted a plastic surgeon, who informed me that it would be quite easy to create another breast for me, although it would take about six months to complete a breast reconstruction, through the use of implants. As soon as the surgeon started talking about operations I burst into tears. The trauma of having had a total of four previous operations on my breast hit me. I felt a sense of urgency, if I was going to do it I wanted to get it over with as soon as possible. But I felt incapable of making a decision. Having survived four operations to treat my cancer, what if I died in the pursuit of vanity?

Surely as a good feminist I didn't need to have my breast reconstructed in order to feel complete.

My feminist beliefs were formed as a young woman attending university in the 1970s, while participating in radical student politics opposed to the Vietnam War. Reading Germaine Greer's (1970) *The Female Eunuch* and Kate Millet's (1970) *Sexual Politics* as part of my course in women's politics, had opened my eyes to another way of understanding the world and my place in it. It was during this period that feminists developed their signature catch cry the “personal is political”. So perhaps not surprisingly, my first instinct was to decry the superficial focus on body image, and resist the pressure to conform to culturally imposed stereotype images of what it means to be a woman by rejecting the idea of having a breast reconstruction. Why would I do this to my body? Do I need to resist the reality of my body by having a reconstruction?

On the other hand why shouldn't I have two breasts if that is possible? I could even have two new, firm, uplifted breasts of any size created. A breast reconstruction is presented as a routine part of treatment following a mastectomy. Why wouldn't I take the opportunity to have two breasts again, even if, one of these is constructed by a surgeon? Was I barricading myself into an equally oppressive hard-lined feminist view? Why shouldn't I be able to look good? After all I try to keep myself healthy and looking physically attractive by eating well, exercising and taking care in the way I dress. Isn't this conforming to society's expectations of beauty? What are my understandings of my female body? What sort of feminist am I? As I tussled with

these questions I realised that I had to confront my own understandings of the female body before I could come to accept my post-mastectomy body and gain any clarity about whether to have a breast reconstruction. This led me to a further exploration of the literature around understandings of the female body.

Female breasts are inherently political (DeShazer, 2008, 2013; Ehlers & Krupar, 2012; Potts, 2000; Wilkinson & Kitzinger, 1994; Yalom, M., 1997; Young, 1990a) and inextricably connected to social understandings of femininity, motherhood, and sexuality. As the female signifiers of sexuality they highlight the conflicted thinking about the female body and social role often summarised in the dualism of the Madonna and the whore (Thorne & Murray, 2000; Yalom, M., 1997). In her history of the breast, Marilyn Yalom (1997) claims that the breast has been coded with both “good” and “bad” connotations since the beginning of recorded time. The good breast is seen as the nourisher of babies, and even allegorically, of entire religious communities (symbolised by the nursing Madonna) or political communities (as seen in the bare-breasted images of Liberty and Equality of the new French Republic). The bad breast is viewed as an agent of enticement and aggression, often issuing from a combination of sex and violence as found in much contemporary cinema, television, advertising, and pornography.

Feminist approaches to the body are complex and highly contested involving a debate about the biological and political constitution of sex and gender and ideas of the body/self. Elizabeth Grosz (1995) delineates two approaches to theorising the body: the Foucauldian notion of the “inscribed body” upon which social law, morality and values are inscribed and the “lived body”, which holds the lived experience of the

body. She claims that postmodern theorists tend to focus on the socially inscribed body and shy away from the complexity of the corporeal body. By denying the body as lived experience, the social constructionists also fail to account for the experience of embodiment and the sensory body as a source of knowing.

There is a diversity of views incorporated within a feminist perspective including those who argue that the postmodern socially constructed female body is textual, devoid of the materiality of flesh and organs (Bordo, 1992, 2003), to those who argue for a return to the fleshed female body (Grosz, 1991, 1994, 1995; Somerville, 2004; Young, 1990a, 1990b, 2005). However, the conflicting arguments between the feminine body as a figure in discourse and as a material presence or biological entity is more complex than just a simple continuum with the essentialists at one end, and the social constructionists at the other (Conboy, Medina & Stanbury, 1997; Jacobus et al. 1990; Lennon, 2010). The complex interaction between the socially constructed and the corporeal body discourses have varying influence on how women understand and live their lives, with neither being sufficient in itself to provide the foundation for an embodied understanding of women’s lived experience of breast cancer.

The socially constructed body

Simone de Beauvoir’s (1953/2011) seminal text *The Second Sex* is often credited with laying the groundwork for our understanding of the social construction of women with her statement that “one is not born, but rather becomes, woman” (2011, p. 293). She translates the philosophy of self and other to understandings of gender,

an understanding that fashions man as “self/subject” and woman as “other/object”. According to Simone de Beauvoir, man is associated with the self which is imagined as transcendent and associated with the mind, an entity that floats free of the body and is superior to bodily functions, while woman is associated with the other, trapped in immanence and defined and evaluated by bodily shape, size, and functions.

During the radical second wave feminist movement of the 1960s and 1970s, in which I came of age as a nascent feminist, the traditional notion of women being prescribed by their biology was challenged. Pioneer feminists such as Germaine Greer (1970) and Kate Millett (1970) argued that the concept of the essential body provided a powerful philosophical rationale and political justification for reproducing patriarchal values and entrapping women into social roles and positions that were seen to be unalterable. That rationale assumed that females, saturated by their biological drives and needs, were defined as other to the masculine norm of the rational and scientific, and entrenched in a position of oppression through their relationship with their material bodies.

In order to achieve social, economic, political, and sexual equality with men, the second wave feminists argued for reconceptualisation of what it means to be female and liberation of women from the confines of their biology (Kolman & Bartkowski, 2013; Lennon, 2010). According to this viewpoint sex is seen as biologically prescribed, while gender is seen as a social construction, “we are made male or female through the social, political and cultural practices of our particular place and time in the world” (Davis & Walker, 2010, p. 460). Thus while biology was seen as immutable,

the second wave feminist effort focused on changing the construction of gender as a means of liberating women. In challenging the oppression brought on by biological determinism, many feminists (Bartky, 1988, 1990, 1997; Bordo, 1992, 2003; Haraway, 1991, 2004, 2008; Wolff, 1997) have adopted the postmodern conception of the socially constructed body as described by Marc LaFrance (2007) as:

The body produced through the inscriptions of language and discourse, the investments of power and knowledge, and the penetrations of science and technology . . . the body has shifting borders, fluid boundaries, prosthetic parts and plastic processes. The body, then, is not an origin but is an effect: an effect of how we think and how we speak, of how we move and how we dress, of how we love and how we hate. (p. 8)

Postmodern social constructionism is founded on the philosophical idea that things are socially produced and social reality can be viewed most effectively as a narrative or text (Turner, 2008). This postmodern conception of the socially constructed body attempts to overcome the mind/body dualism through the notion of the symbolically constituted self. The self is constructed through interaction with the political, social, and cultural world as mediated through language. According to the postmodern perspective, culture is comprised of narratives that are available resources through which the individual makes sense of the world, and the body is a product of entangled material, social, and historical forces.

Drawing on the work of Michael Foucault (1979), many feminists (Bartky, 1988; 1990, 1997; Bordo, 1992; 2003; Butler, 1993, 1997, 2004) have moved away from the feminist body discourse of the 1960s and 1970s, with its political categories of oppressors and oppressed, villains and victims, to develop a more sophisticated analysis of the oppression of women. They argue that the body is, not only a text of culture—a surface on which social and cultural norms are inscribed, but also a locus of social control—“a docile body” (Foucault, 1979). This docile body is produced through cultural norms that form a set of practical rules and regulations, through which the living body is trained, shaped, and programmed to obey and respond in a way that is socially adaptable; it becomes a “useful body” (Foucault, 1979). Rather than external oppressive forces, this perspective views the oppression of women as occurring through “the network of practices institutions and technologies that sustain positions of dominance and subordination within a particular domain” (Bordo, 1992, p. 15).

According to this position, laws that prescribe the behaviour, dress, or appearance of women are no longer required as we have now internalised this policing function into a very effective form of self-surveillance. Michel Foucault’s analysis enables us to understand how we as women become, at times, enmeshed into colluding with forces that sustain our own oppression. In modern western countries the evidence that we are complicit and collude in our own oppression is present all around us. The typical western woman focuses much of her energy, intelligence, and time on attempting to maintain a normative concept of female beauty and attractiveness through a focus on diets, beauty regimes, dress, exercise, behaviour, and increasingly, through cosmetic surgery. I acknowledge my own complicity in this through my focus on diet and exercise.

It is this feminist understanding of the socially prescribed body that has contributed to my own confusion about whether to have a breast reconstruction. If I decide to have a breast reconstruction would I be further colluding in my own oppression and falling into Foucault’s definition of a docile body? Would my decision be driven by my memorising on my body the feel and conviction of lack, insufficiency, of never being good enough as contended by Susan Bordo (1992)? It is not surprising that I felt pressured to adhere to a concept of the normative body, as Susan Bordo (1992) writes:

Viewed historically, the discipline and normalisation of the female body—perhaps the only gender oppression that exercises itself, although to different degrees and in different forms, across age, race, class, and sexual orientation—has to be acknowledged as an amazingly durable and flexible strategy of social control. (p. 14)

Is a breast reconstruction evidence of this form of social control? Some feminists (Bartky, 1988, 1990; Bordo, 1992, 2003) argue that this preoccupation with appearance and behaviour and the outright rejection by many modern women of any form of feminist consciousness is part of the backlash to reassert traditional power relations. This is reinforced by the dominant discourse regarding how females of today should be: able to catch and keep a man happy; be a good home maker; chef; sexual siren; as well as have a successful professional career; and financial independence. Like other older feminists, I look on in dismay as I see young women re-embrace traditional notions of femininity such as taking their husband’s name on marriage and spending a fortune on traditional weddings “complete with virginal white dress, squeezed into

after months of virtual starvation” (Pike, 2012). Many younger women contest this view labelling themselves as post-feminists and arguing that their choices in changing the appearance of their body, through exercise, cosmetics or surgery, are the actions of a liberated woman of the 21st century (Lazar, 2011; Press, 2011). Are they right? Is having a breast reconstruction the act of a liberated woman or an oppressed woman?

The pressure placed upon women in the West to aspire to an almost unobtainable body image has been extensively critiqued (Bordo, 1992, 2003; Featherstone, 2007). We are bombarded with a social construction of the feminine body as an emaciated model with cosmetically enhanced breasts and collagen plumped pout. Gendered separation of mind and body circulates endlessly across social practices that position women in relation to their bodies rather than their intelligence. This notion is all pervasive; it is deployed and is socially embodied in all aspects of society—medicine, law, literary and artistic representations, the popular construction of self, interpersonal relationships, popular culture and advertising (Featherstone, 2007). It is therefore necessary, argue social constructionist feminists, to maintain a continual vigilance to counter this disempowering patriarchy through an understanding of the socially constructed body summed up by Susan Bordo (1992) when she says, “I view our bodies as a site of struggle, where we must *work* to keep our daily practices in the service of resistance to gender domination, not in the service of ‘docility’ and gender normalisation” (p. 28 *italics in original*).

Whilst the feminist discourse of the socially constructed body highlights the structural and institutional nature of patriarchy embedded in every aspect of our lives, it has done

so at a cost. In their attempt to challenge the notion of women being defined by their biology, social constructionist feminists risk losing sight of the embodied woman. In the wake of the understanding of the body as cultural text, the concept of the material body has been left behind. The focus on the cultural production of the body has been criticised by both feminists (Blackman, 2008; Grosz, 1995; Howson, 2005) and male sociologists (Featherstone, 2010; Shilling, 2003; Turner, 2008) as perpetuating, albeit in a more sophisticated way, the mind/body dualism. They critique the concept of the socially constructed body as being passive, a blank slate, awaiting its social inscription devoid of creative energy and possibility for resistance. The body becomes hidden or eclipsed by the focus on language and what we end up with “is a view of culture from the neck up . . . and the body again disappears from analysis” (Blackman, 2008, p. 24). In examining the focus on the body as cultural text, Rosi Braidotti (1997) argues that this “left all issues related to bodies, pleasures, eroticism and the specific ways of knowing the human flesh hanging nowhere” (p. 30).

The fleshed body

The bias of some feminists towards the socially constructed body at the expense of the biological body is understandable, given the history of women being disempowered through their identification with their biological bodies. However I am interested in exploring my experience of breast cancer and my post-mastectomy body through my fleshed body “inscribed with residue traces of culture” (Spry, 2011, p. 711). I am not arguing for a going back to biology, but rather a conceptualisation of the body as flesh formed through interaction with the social and cultural world. Elizabeth Grosz

(1994) argues that felt intentions derived from bodily sensations contribute to social constructions such as body image.

Rather than being constrained by our physical boundaries we are formed within a complex social space that requires us to 'hang together' different logics and rhythms that are felt through the lived body which is understood as a relational non-dualistic process rather than just a material substance. (Grosz, 1994, p. 105)

Elizabeth Grosz further argues that "by focusing on the body, sexual differences become visible and the subject can no longer readily succumb to neutralization and neutering which has occurred as a consequence of women's submission under male definition (Grosz, 1994, p. vii).

The current body discourse is still highly contested and complicated by a range of agendas from different feminist approaches as well as from a diversity of male scholars. Some male sociologists (Crossley, 2006, 2011; Featherstone, 2007, 2010; Shilling, 2003; Turner, 2008) have also called for a rehabilitation of the material body. They maintain that as the female has historically been saturated with corporeality, existing only in and through her body, so the male has been defined by the social and intellectual. Whilst it is recognised that women have been disadvantaged by their bodily identification, Nick Crossley (2006) argues that this has also disadvantaged men. He maintains that the male body has been so heavily invested in the social and cultural world that it has been divested of its corporeality, which has precluded any acknowledgement of

embodied knowing.

While it is important for the corporeal body to be re-instated into the body discourse generally, Anne Witz (2000) points out, that it is also important for feminists to be wary. Unless the divestment of notions of the male as primarily social is done in a way that challenges the male/female binary, which prescribes the masculine as the norm, the female will yet again be placed in a subordinate position to the male, with female embodiment seen through a normative male lens. It is argued that the feminist cause would be better served through an articulation of difference; rather than fighting for equality, the concept of the corporeal body must acknowledge the difference between male and female bodies (Grosz, 1990; Witz, 2000; Young, 2005).

Like Elizabeth Grosz (2005), I understand the body as the pliable, variable condition of both women's identities and their differences—from men, from other women, and from the narrow patriarchal characterisation spawned by our received histories of thought. Rather than being objectified and spoken about by medical experts, the integration of the corporal body into the conceptualisation of the self, allows for a subjective voice to be heard. Reintroducing the messiness of the corporal body (the blood, tissues, and the organs) into an understanding of the dynamic self provides the space for a more encompassing breast cancer narrative to be told. The corporeal body as described by Elizabeth Grosz (1994) creates the foundation for an understanding of embodied knowing. In focussing on her corporeal body, Nancy Mairs (1997) describes the power of the physical fleshed body and its capacity to challenge imposed limitations as fundamental to embodied knowing.

I've 'found' my voice, then, just where it ought to have been, in the body-warmed breath escaping my lungs and throat. Forced by the exigencies of physical disease to embrace myself in the flesh, I couldn't write bodiless prose. The voice is the creature of the body that produces it. I speak as a crippled woman. At the same time, in the utterance I redeem both 'cripple' and 'woman' from the shameful silences by which I have often felt surrounded, contained, set apart; I give myself permission to live openly among others, to reach out for them, stroke them with fingers and sighs. No body, no voice: no voice, no body. That's what I know in my bones.

(Mairs, 1997, p. 305)

Conclusion

In this chapter I have delved into the literature to inform my own understanding of the female body. The mind/body dualism still influences modern day conceptions of the body, particularly the scientific medical discourse that dominates contemporary medical practice encouraging the view of women with breast cancer to be seen as a faulty machine, rather than a sensing person with an illness. The contested field of feminist understandings of the body shows the resilience of the mind/body dualism as feminist social constructionists risk "losing" the material body in their attempt to challenge the patriarchal oppression of women based on their biological construction. Elizabeth Grosz (1994, 2005) has been at the forefront of a call to re-integrate the fleshed female body into the feminist body discourse.

Through this exploration of competing discourses of the body, I have become aware of the legacy of the different body discourses on the understanding and treatment of breast cancer and come to understand that my early views of the female body were influenced by my immersion in the early social constructionist feminist movement of the 1970s. I now have a greater appreciation of the importance of the corporeal body and the complex interaction between our fleshed and socially inscribed bodies. Journeying through this rich tapestry of conceptions of the body I have arrived at an understanding of the body as a relational non-dualistic dynamic entity that incorporates its fleshy substance and is intermingled with the flesh of the world. This body concept accommodates the complexity of the lived experience of the body within the social and natural world and captures the process of embodiment. As described by Karen Barbour (2011), "my woman's lived body is unstable and open to change, potentially resisting both socio-cultural and biological definitions" (p. 68). My embodied knowing that arises from the intersection of my experience of my lived body with the cultural, social and natural world (Braidotti, 1994, 2011) forms the conceptual thread of my enquiry and, as discussed in the next chapter, informs my methodology and methods.



Chapter three

Methodology



My enquiry emerged organically.

Rather than building an engineered structure: it felt more like knitting a jumper, without a pattern, using lots of different coloured yarn, dropping stitches along the way, and never being quite clear about how the finished product would look.

The trick for art-based research will be to enjoy the slippery, web-like associative, divergent and irreverent properties of the arts as methodology (Learmonth & Huckvale, 2012, p. 107)

Starting to make art

I could present this methodology chapter in a concise orderly manner as if everything fitted together like a series of organised boxes that started with a clearly defined research question or questions that I then slotted neatly into a particular methodology from which a structured method developed. But that was not my experience. I want to be truthful to the messy, circuitous, at times frightening, journey I experienced, rather than give in to the temptation to present my enquiry as if it conformed to a neat logical ordered structured process. My method was like diving into a basket of coloured wool and just starting to knit the different colours together without any prescribed pattern. I just wanted to absorb myself into the joy of making as if I were feeling the texture of the wool as it moved through my fingers, the clickety-clack sound of the knitting needles and seeing the colours and patterns emerge. My enquiry was akin to Sandy Sela-Smith's (2002) description of phenomenological enquiry "Each phase is an uncharted territory because the ground is not formed until the enquirer creates both the territory and the path by surrendering to the unknown and then walks the territory to discover what is there" (p. 64).

I want to locate my enquiry within a methodology that will enable me to capture the complexity of my embodied experience, one that allows me to speak from or through

my body rather than about my body. My review of different discourses of the body, as discussed in the previous chapter, informed my own understanding of the corporeal body as a shape-shifting entity forming in relationship with the cultural, social, and natural world. In writing this thesis I want to capture my lived experience of breast cancer as it formed through the process of enquiring into it. Like Kay Inkle (2010), who enquired into body-modification, I was searching for a methodology that could "handle the messy realities of corporeal experience . . . [and] reflect the multifaceted, contradictory, ambiguous nature of lived experience" (p. 27).

I felt driven to make art as a way of making sense of my experience and dealing with my pain, and it was through the process of making art, that my methodology and method emerged. Like the inside of a hand knitted garment, I want to show the messy side of my enquiry process and reveal the tied knots where I have joined the different threads. It is in this spirit that I have tried to be transparent in terms of the choices I made and show that like other postmodern (Hess-Biber & Leavy, 2006; Hess-Biber 2008; Somerville, 2007) and arts-based (Levine, 2013; McNiff, 2011b; Prior, 2013) researchers, my enquiry developed as I continued to use arts to explore my breast cancer experience.

While I didn't have a clear methodology there were some aspects of this research that were non-negotiable for me. A social worker by training, I was motivated to undertake this enquiry for both personal reasons—to understand my own experience, and assist my own decision-making—and also out of a desire to assist other women who have had a mastectomy. This mix of personal and political, the desire to bring about

personal transformation and also have an impact on the experience of other women in combination with a gender analysis of the social construction of breast cancer, places my enquiry within a feminist tradition. In this chapter I outline my search for a methodology that can hold my commitment to using arts as a way of coming to embodied knowing, and guide my enquiry into my lived experience of breast cancer with a sensitivity to the gendered nature of experience. Both the topic and my use of creative arts as my enquiry method pose particular ethical issues, which I discuss at the end of this chapter.

Overview of key moments that formed my enquiry

My enquiry was undertaken over several years in which I immersed myself, through my art-making and journaling, in an exploration of my breast cancer experience. The shock of being diagnosed and treated for breast cancer was recent and raw as I began my doctorate. I was left feeling disoriented with my whole life world disturbed. The removal of my breast, at a time when I was coming to terms with my ageing body and exploring my sexual identity, left me questioning how I engaged with, and presented myself to, the world. I resonated with Harvi Carel (2013) who describing her own experience of chronic illness writes “because of the inseparability of embodiment, perception, action and subjectivity, changes to one’s body can lead to far reaching changes to one’s sense of self” (p. 4). Through a painful fog of grief and fear I felt driven to make sense of my experience, and working in collage, clay, paint, photography,

printmaking, film, and movement I explored my one-breasted body.

I had no clear direction of where my enquiry into my breast cancer experience was heading. I allowed the enquiry process to be emergent and proceeded wherever the data invited me. At times I became stuck in some dark and painful places, but a way forward surfaced through my commitment to use creative arts to explore my feelings and experience. Key moments along the way determined the direction of my enquiry as I tried to be open and allow myself to follow the path as it formed ahead of me.

My enquiry was bookended by two exhibitions of my artwork—one in the first year and one at the end of the third year. At the exhibitions I provided the space for people to offer artistic responses, which I then incorporated into my data. At my first exhibition, several women, who had also had mastectomies, approached me about working together to explore their experience through creative arts. I was keen to support other women to explore their experience of breast cancer and mastectomy, particularly their post-mastectomy bodies. In talking to them the idea of a series of arts-based workshops for a small group of women arose.

I organised a series of four half-day experiential workshops, which focused on our post-mastectomy bodies and the decision as to whether to have a breast reconstruction. In line with the focus of the group, it was limited to women who had had a mastectomy but not had a breast reconstruction. Initially there were six participants, but for a range of reasons three dropped out which left a group of three, including myself. The two other group participants were also in their mid 50s, and had been diagnosed with

Ductal Carcinoma In Situ (DCIS); one had had a single mastectomy, and the other a double mastectomy; one of the women identified as a lesbian.

At the time I thought that this series of group workshops would allow me to enquire into the experience of other women who had had a mastectomy, and would form the central component of my doctorate enquiry. However, the timing of this group occurred when I did not have sufficient clarity of, or distance from, my own experience. I was in the midst of my own strong response to breast cancer, and was unsure as to whether I would be able to hold the group safely while they explored emotional and painful experiences that I also shared, and to which, I still had a strong emotional response. My need to make sense of my own experience was paramount at this time; I therefore made the decision to not facilitate the group myself but to use an experienced group facilitator.

This decision significantly changed the focus of the group. Rather than me supporting other women to explore their post-mastectomy bodies through creative arts, as I had initially planned, the group became an opportunity for me to immerse myself in my own enquiry alongside two other women. The use of a group approach provided the opportunity for the development of a fertile intersubjective space, which allowed us to connect with the emotional experience of each other and deepen our enquiry through the exchange of creative responses. Being present to each other's experience through the use of a range of experiential arts activities allowed us to view aspects of our own lived experience, which may otherwise have remained hidden. I created a blog for the group members to use as a reflective space between the workshops. We

all posted responses to each other in the form of photos and creative writing. Below is an example of the responses on the blog following the second workshop.

Haiku on Mastectomy posted by Sue



Kay's response to Sue



Image 3.1 Example of creative response from group blog

Another key moment occurred when, following the workshops, one of the group participants approached me to do some individual sessions with her; she was eager to enquire into her experience in more depth as she said the workshops had just allowed her to “scratch the surface”. An acquaintance of mine, who had also undergone a mastectomy shortly after my own operation, had expressed interest in using creative arts to explore her experience of breast cancer, however, as she had had a breast reconstruction, she did not meet the group criteria, so she also raised the possibility of individual sessions. I felt able to respond to these requests, as I was now further along in my own process and not feeling so raw. I also felt confident in being able to provide a safe space for just one other rather than the more complex task of facilitating a group.

In discussion with the two women we agreed to use creative arts to explore our breast cancer experience over six individual sessions of two hours duration. There were no specific goals for each session, apart from using arts-based procedures in an emergent and improvisational way to explore each woman's experience of her body following breast cancer treatment. I photographed images and took notes to record key moments during these sessions. We used a range of modalities such as clay, collage, visual art, improvised drama, and sand tray, and I provided an artistic response following each session. Despite the participation of other women in aspects of my enquiry, and my initial strong motivation to use my findings to inform breast cancer services, my doctorate developed into a more personal enquiry, undertaken alongside others.

I have struggled with how to honour the generous contribution of the three other women to my own journey in a way that assists them in their own enquiry, and respects the authenticity of their own experience. All three women were clear that, while they had freely participated in a particular aspect of my doctorate, they did not want any further involvement in forming or contributing to a written or creative response following the completion of the workshops or individual sessions. I eventually decided to develop a narrative based on the stories that arose through my involvement in the group and individual sessions and gave this to the participants to alter or add to as they wished. None of the women requested any changes or expressed any reservations about the material being included in my doctorate thesis.

As well as the two exhibitions, I presented my material to a broader audience through three conference presentations. This gave me the opportunity to pause and reflect, and helped consolidate some of the experiential arts-based knowing that had occurred in the time preceding the conferences into a creative synthesis using my images and words to form three short movies, which are attached on the accompanying CD. Throughout my art-based enquiry I had the opportunity to work alongside others at the MIECAT studio, either in facilitated structured workshops, or in open sessions organised by my doctorate colleagues and myself. As found by Pat Allen (2008, 2013) and Shaun McNiff (2004) working alongside others in a group enhanced my personal enquiry process, and many of my most powerful moments of new knowing or understanding appeared from these shared arts-based sessions.

Developing a clearer focus

As I continued to intuitively make art within a broad phenomenological approach a multi-layered methodology began to form. I have used the metaphor of the camera lens as a way of representing the different layers of my methodology. Phenomenology, with its epistemology of knowing grounded in embodied experience of the everyday as we interact in a relational world, forms the base lens that underpins my enquiry. To this base lens I add a feminist lens, a form of propositional or cognitive knowing that brings into focus the gendered nature of my lived experience as it is formed through the intersection of my female gendered body with the social and cultural world. I then add the lens of an extended epistemology of four ways of knowing as articulated by John Heron and Peter Reason (1997) that allows me to zoom in on

presentational knowing as a way of knowing through expressive arts. This camera metaphor illustrates that what I see is informed by bringing all these different lenses together into my visible field while at the same time it is possible to bring a particular aspect into focus with the rest remaining in the background.



The phenomenological lens: Experience as a way of knowing

The passion to come to understand my lived experience of breast cancer—something so embodied and so present in every lived moment—drew me to an investigation of phenomenological philosophy. Phenomenology, with its focus on the lived world as experienced in an embodied and relational way, forms the foundational lens of my methodology.



Figure 3.2 Phenominological lens

1. Experience: My life as lived as a way of knowing

My data for this enquiry comes from maintaining a reflexive and open attitude, while holding a highly attuned presence to my lived experience. I was eager to understand the shifts and changes in my experiencing and wanted to access my wisdom as it arose from my body in relationship with the world. Rejecting the positivist scientific method as a means of explaining the world, I took on the phenomenologist's view that knowledge of the world can be obtained through "practicing a certain attentive awareness to the things of the world as we live them rather than as we conceptualise or theorise them" (van Manen, 2006, p. 720). Unlike a traditional phenomenological approach as developed by Edmund Husserl (1970), with its emphasis on the things being experienced, I was more interested in my own subjective lived experience of breast cancer. Therefore a new (Crotty, 1996) or empathetic (Willis, 2004) phenomenological approach with a focus on "the meanings and significances given to an experience by those experiencing it" (Willis, 2004, p. 3) seemed a better fit.

By describing the world as I lived it, I hoped that the depth and complexity of my experience, which was normally hidden under my habitual unreflective attitude, would be revealed. As Eva-Maria Simms & Beata Stawarska, (2013) write, “as a method of enquiry phenomenology slows down the stream of consciousness in order to create a descriptive attitude which focuses attention on the fullness of things” (p. 9). Believing that we are present, in our totality, in each moment of our life, I felt that an enquiry into “a present moment of experience” (Stern, 2004), using multi-modal arts, could generate new meanings. A phenomenological approach focused on the exploration of everyday present moments can reveal deep insights into our lived patterns. Harvi Carel (2013) argues that illness provides an opportunity to tune into the ordinary aspects of living as these are often brought into the foreground through illness or disability. She claims “by pushing embodied experience to its limit, illness sheds light on normal experience, revealing its ordinary and thus overlooked structure” (p.345).

2. Intersubjectivity: experience formed in relation to the world

My breast cancer experience impacted on, and was influenced by, my personal and social world. Some friends were able to be supportive and open while others were uncomfortable in confronting the reality of my diagnosis of breast cancer and withdrew. As discussed in chapter two, as a living body I am not a separate physical entity in a world external to me, but am sensitive and in deep communion with all aspects of my environment. My body is relational, actively and continually in touch with the world, and inextricably entangled in existence. Merleau-Ponty’s (1945/1962) understanding of perception as a reciprocal act, a mutual interaction, between the lived body and its surroundings allows us to comprehend the interdependence and intermingling of

humans with the environment. Living in a relational world, in which all experience is coconstructed within an intersubjective context, is central to the phenomenological philosophy and was a key aspect of my breast cancer experience and underpins every aspect of my enquiry.

As well as being influenced by my personal and social world I was also influenced by the material world, particularly in my relationship with art-making materials. The reciprocity of my intersubjective relationship with art-making materials highlighted the sensation of touch as particularly significant in my enquiry method. Merleau-Ponty (1962) argues that we can experience things—touch, hear, and taste things—because our sentient bodies are continuous with the world of which we are a part; we have our own textures, sounds, and tastes. He uses the example of touching a tree to illustrate this entanglement with the world, noting that when we touch the coarse bark of a tree, we also experience our own tactility, we feel ourselves touched by the tree.

3. Embodiment

Through my review of different conceptualisations of the body in chapter two, I came to an understanding of the importance of the corporeal body, as formed in relation to the world, as a source of knowing. Like David Abram (2011) I too have faith that our “animal body, for all its susceptibility and vertigo, remains the primary instrument of all our knowing” (p. 8). It is the multisensory, relational living body that offers the very possibility of reflection, of thought, and of knowledge; every understanding that we can have of the world is only possible through our bodies. As I explored my art-making I was increasingly drawn to my physical senses as a portal to developing meaning from

my experience of breast cancer. I relate to Eugene Gendlin's (1996) description of embodied knowing as a bodily felt, implicitly rich "sense of some situation, problem, or aspect of one's life" (p. 20), a fleeting moment of knowing that is caught, reflected and acted upon. It is this understanding that we can experience the world and make contact with, not just others, but ourselves, only through our physical bodily sense, that attracted me to phenomenology.

Whilst I can know something in my body, through this bodily felt sense, an inherent challenge of embodied knowing is bringing it into the world in a form that I might further explore and share with others. The action of making manifest in some expressive form my sensory embodied knowing is complex. There is a subtle difference between whether this process of bringing forth embodied knowing into expressive form is merely one of translation—trying to capture the essence of what I feel and translate this as accurately as possible into some expressive form—or whether the act of expression provides an opportunity to generate new knowing.

Phenomenologists (Gendlin, 1981, 1996, 1997, 2003; Todres, 2007; and Todres and Galvin, 2008) as well as feminists (Grosz, 1995, 2005; Richardson, 1994, 2000, 2002; Somerville, 2004, 2007), focus on the expressive act as a process of bringing the knowing from our inner world into the external world as a way of putting into words the rich complexity of the bodily felt sense of an experience. Les Todres (2007), for example, compares the attempt to share our felt sense with another, to a dance between two people trying to communicate in different languages. He proposes a form of "interembodied listening" as a means of getting a felt sense of the experience

of the other (2007) and "embodied interpretation" (Todres & Galvin, 2008) as a more evocative and aesthetic form of phenomenology that aims to capture our felt sense of lived experience. Eugene Gendlin (1996) talks about this process of externalising our bodily felt sense through expressive form as one of finding a handle, just as "a handle of a suitcase brings the whole weight of the suitcase, the whole weight of the felt sense is brought forward by the word, phrase or image" (p. 24).

Unlike phenomenologists such as Les Todres and Eugene Gendlin, I believe that the very act of trying to call forth my embodied knowing into the world through some form of physical expression necessarily transforms it into something else. I do not see the expressive forming of my embodied knowing as one of merely translation or an externalising of my internal feeling. I have found that the process of being highly attuned to the process of making manifest what I feel I know in my body, provides a further opportunity for something else, something additional to emerge. Rather than an externalising of my internal feelings this process is a relational interaction, an intersubjective interaction involving my sensing body, art materials, the environment or space, and perhaps other co-enquirers. Through a mindful attention to the relationship with the art materials and my sensing body new meaning that extends the knowing of my bodily felt sense can arise quite spontaneously. The process of coming to new knowing through bringing my bodily held knowing into an expressive form, is more akin to presentational knowing as articulated by John Heron and Peter Reason (1997) in their extended epistemology. Presentational knowing forms the final lens of my methodology.

The importance of “bracketing in” the context of experience

Edmund Husserl (1970) developed the concept of *époché*, the practice of attempting to “bracket out” our prior knowledge, assumptions, and beliefs that prevent us from making primitive contact with the concreteness of lived reality. In other words we need to be suspicious of our own cultural prejudices and accept that we can never see phenomena in their transcendental purity. Later exponents of phenomenology, (Heidegger, 1962; Merleau-Ponty, 1945/1962), however, saw perception of the everyday world as inseparable from social, cultural, and historical influences.

As discussed in the previous chapter I believe that it is important to acknowledge that we are formed in relation to our interaction with the world. This understanding of the social construction of the body requires an acceptance of the importance of bracketing in the social and cultural world. I am a white middle-aged, middle-class, and educated woman living in a wealthy Western country. It seemed evident to me that if I were a black, poor, uneducated woman with few resources living in a developing nation, or in a remote community in Australia, my breast cancer experience would be fundamentally different. The importance of bracketing in the social, cultural, economic, and political context was reinforced when I gave a presentation at an international conference on the topic of normative bodies, in which I examined the pressure faced by western women to have a breast reconstruction following a mastectomy.

At the end of my presentation, there was a lively discussion to which women from other cultures contributed. A Nigerian woman highlighted the importance of cultural

context around any discussions of women’s bodies. She stated, that unlike western societies, in which the breasts symbolise female sexuality and attractiveness, in her culture it is the “booty” or bottom, which plays this role, therefore, she claimed that the removal of breasts would not be experienced in the same way. Another woman from Malaysia commented that in her country having a breast reconstruction is not even an option as the scarce health budget is focused on medical intervention to save lives rather than on quality of life, thus highlighting the economic context. She also emphasised the impact of cultural attitudes towards ageing. She spoke of her experience as a nurse assisting a surgeon doing a mastectomy on a woman aged in her 50s:

When the male surgeon was preparing to “butcher” off the woman’s breast with no regard for her appearance, I begged him to operate in a way that minimized her scarring. His response was that as she was an old woman of 50, she didn’t need to feel sexy anymore so why would she be concerned about what her breasts and body looked like. (Conference participant, July 7, 2011)

As discussed in the previous chapter, the breasts in western countries are saturated with symbolism—sexual, political, and cultural. In accepting the importance of bracketing in the context of lived experience one of the most important social, political, and cultural contexts in relation to my enquiry topic is that of gender. It seemed imperative to me to place the issue of gender at the forefront of my enquiry, which led me to an exploration of feminist methodology.

The feminist lens: intersection of the personal with a gendered and social world

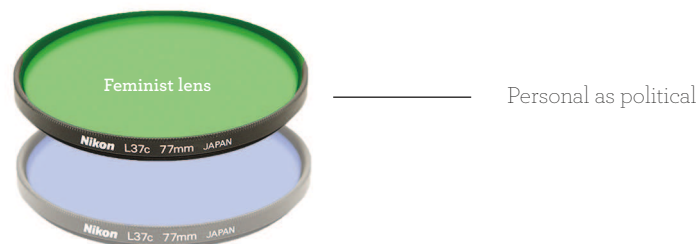


Figure 3.3 Feminist lens overlaying the phenomenological lens

In my discussion of the body, I examined different feminist conceptualisations and arrived at an understanding that the fleshed body is formed in relationship with the social and cultural world. Feminists have utilised the experience of the gendered body through the slogan the personal is political to highlight how the practices, representations, and knowledge of the female body are not simply innate, natural occurrences, but rather are political, that is contrived, monitored, controlled, and moralised by a patriarchal social system (Pillow, 2000). In this enquiry I am committed to the feminist task of connecting the personal to the political, highlighting the power differential between vulnerable female patients and a mostly patriarchal medical system, and being aware of the social construction of the normative female body.

A feminist approach provided a framework to hold my values in relation to how I wanted to be in, and with, my enquiry, how I wanted to involve others, my motivation for doing this work, what changes I wanted to achieve and how I wanted to re-present my findings. Whilst feminism is now a very broad container, which holds many divergent values and approaches, all forms of feminist research practice share a common commitment to “understanding that human experience is embodied, intersubjective, and contingent, and woven into personal and cultural webs of significance” (Simms & Stawarska, 2013, p. 12).

Identifying and addressing common experiences of women’s oppression, without denying the varying individual lived experience of women across, race, class, nationhood, and sexual orientation, continues to be an ongoing project for feminist advocates. The evidence of gender oppression is impossible to deny, however, the challenge remains as to how best to overcome this in a way that doesn’t further oppress marginalised women or negate the differences in the individual lived experiences of women. Feminists have drawn on a number of different philosophical traditions in grappling with the development of an understanding of the body that provides the means to challenge institutional oppression, without losing sight of women’s lived experience of their fleshed body.

Carol Bigwood (1991) notes the challenge is to “historically contextualize broad categories like ‘female experience’ and ‘woman’ and to use these concepts so that they are neither exclusionary nor fleshless abstractions” (p. 55). In accepting the idea of the body as “not merely matter but a continual and incessant materializing of

possibilities", (Butler, 1997, p. 404) and allowing for "its inevitable indeterminacy and open possibilities for historical and cultural variation" (Bigwood, 1991, p. 61), I, like many other feminists, argue that it is possible to arrive at a feminist philosophy of the fleshed and gendered body. This feminist understanding provided a good fit with my enquiry into, and from, my fleshed and gendered body.

While committed to a phenomenological approach as a basis for the epistemology of my enquiry I felt the gendered context of my experience was inadequately addressed. I agree with Simon de Beauvoir (1953/2011) who although concurring with key phenomenologists, particularly Merleau-Ponty, and, of course Sartre, that "to be present in the world implies strictly that there exists a body which is at once a material thing in the world and a point of view towards the world" (1953, p. 39), maintained that importantly such bodily existence and point of view is lived differently for men and women. The early proponents of phenomenology were largely characterised by their masculine, western, white, privileged status and I could not locate in their writing a sensitivity to the gendered nature of lived experience.

Feminists, such as Iris Young (2005) and Elizabeth Grosz (1995, 2005), have criticised the failure of many traditional male phenomenologists to acknowledge female experience, arguing that their ungendered view of the world, assumes a masculine norm, which is presented under the guise of neutrality and objectivity. By ignoring the gendered nature of the body, phenomenology can be seen to perpetuate the notion of the masculine norm, with the female proscribed to the subordinate position of other (de Beauvoir, 1953/2011). Iris Young (2005) points out that the early male

phenomenologists failed to articulate the particularities of women's experience such as the embodiment of pregnancy thus betraying their underlying assumption that the male account sets the standard and encompasses all possibilities, and in this manner phenomenology functions to diminish and marginalise the experience and perspectives of women.

Phenomenology seems to lack an effective power analysis (Bigwood, 1991) and as pointed out by Judith Butler (1993, 1997, 2004) a consequent inability to accommodate the particular issues of gender, race, sexual orientation, and disability. Phenomenology is critiqued by feminists as being apolitical, concerned with only generic lived experience and ignoring the role of cultural and social constructs, remaining inherently individualistic in its preoccupation with individual perception rather than the material forces of power, domination and false consciousness (Butler, 1989, 1997; Moran, 2000; Stoller, 2000, 2013).

In searching for a way to incorporate a feminist power analysis to my methodology I came across other feminists, particularly Judith Butler (1989, 1993, 1997), Elizabeth Grosz (1991, 1993, 1994, 1995), and Iris Young (1990a, 1990b, 2005) who had been developing the ideas of embodied lived experience, particularly as articulated by Merleau-Ponty, within a feminist context. Judith Butler (1997) argues that both feminism and phenomenology share a commitment to grounding theory in lived experience and in illuminating the way the world is revealed through the constituting acts of subjectivity.

The feminist claim that the personal is political captures the tension held within feminism of the emphasis on the uniqueness of women's experience, while at the same time endeavouring to articulate a common women's experience that can explain the oppression of women in society and culture, and form a springboard for social action. Taking a feminist lens to the phenomenological notion of lived experience provides a means to capture the dialogical interplay between the social construction of gender and women's individual lived experience (Alcoff, 2006; Braidotti, 2011; Young, 2005). Toril Moi (1999) identifies a way forward by suggesting that the categories of sex and gender be replaced with the category of the phenomenological lived body, which can capture the way material features of our bodies play a role in our subjective sense of self. She aligns herself with Merleau-Ponty in claiming that a body as lived, is always a body in a situation; a body is always subjected to culture, therefore always gendered.

Whilst Merleau-Ponty (1962) focused on our connection with the sensing material world, he also acknowledged the influence of the cultural world as he writes, "our body is our medium for having a cultural world, indeed for having any world at all" (p. 146). It is this acknowledgement of the cultural context of our lived body that provides a bridge between phenomenology and feminism. Overlaying a feminist lens to my phenomenological approach allowed me to bracket in the gendered context of my experience, to grasp the rich complexity of my lived experience of my one-breasted female body as I negotiated a gendered world. Like Linda Fisher (2010) I found there were advantages in bringing both approaches together:

Phenomenology can provide the style for an analysis which retrieves and retains the immediate, vibrant, tangible, and compelling lived experience, and enables our understanding of the phenomena and meanings of this lived experience and situation; while feminist thought and analysis can expand and deepen phenomenological investigation by recalling and insisting on the importance of the lived context, and the multiple aspects, particularities, and dynamics of the social and cultural world, of social and political being in that world, and the necessity of a phenomenological analysis and framing of these phenomena. (p. 94)

This understanding of feminist phenomenology provides a good fit with my desire to ground my enquiry in the flesh, the stuff, tissue, blood, and muscle of my body as well as my sensing self and its relation to the world in which I exist, while acknowledging the role of the social construction of gender which is integral to my enquiry. By incorporating a feminist lens to my phenomenological approach I hope to contribute to an acceptance of the changes—physical, psychological, emotional, and social—brought about by illness, while illuminating the social construction of breast cancer and its impact on the lived experience of women with breast cancer.

Presentational knowing: Using arts to generate new understanding

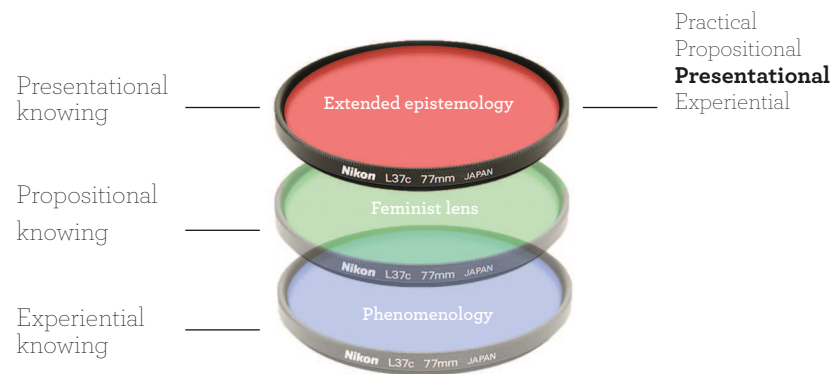


Figure 3.4 Extended epistemology lens overlaying feminist and phenomenological lenses

To the two lenses of phenomenological and feminist approaches, which are grounded in an experiential and conceptual or propositional epistemology, I have added a further lens of extended epistemology. This brings into focus presentational knowing that provides the rationale for my arts-based methods. The notion of presentational knowing was developed by John Heron (1999) as part of an extended epistemology of four interwoven forms of knowing—experiential, presentational, propositional and practical:

Experiential knowing—imaging and feeling the presence of some energy, entity, person, place, process or thing—is the ground of presentational knowing. Presentational knowing—an intuitive grasp of the significance of patterns as expressed in graphic, plastic, moving, musical and verbal art-forms—is the ground of propositional knowing. And propositional knowing—expressed in statements that something is the case—is the ground of practical knowing—knowing how to exercise a skill (Heron, 1999, p. 122).

Experiential knowing is embedded in the phenomenological approach, while feminism with its intellectual understanding of the role of gender and calls to action, incorporates propositional and practical knowing. Presentational knowing, which is formed through creative representation, is the focus of this last lens of my methodology. John Heron in collaboration with Peter Reason, conceptualised these four ways of knowing both as cyclic, in which each successive way of knowing builds on previous iterations of all the different ways of knowing, and hierarchical, in that each form of knowing is grounded in the previous one (1997). Through my enquiry I came to an understanding of these four forms of knowing as comprising different epistemologies that can be called forth at different times, depending on the situation and the motivation or intention of the knower. They are not commensurate, nor is one more important than the other; they are different in their very nature. Although experiential knowing is the ground of all other forms of knowing, it is not possible to merely translate experiential knowing into propositional knowing via presentational knowing.

As John Heron and Peter Reason (1997) state “Propositions themselves are carried by presentational forms—the sounds or visual shapes of the spoken or written word—and are ultimately grounded in our experiential articulation of a world” (p. 281). They further locate their extended epistemology within the intersubjective context of our world as articulated by Merleau-Ponty, by acknowledging that experiential knowing “is also the creative shaping of a world through the transaction of imaging it, perceptually and in other ways” (p. 281). Experiential knowing is similar to the notions of the “felt sense” (Gendlin, 1996) and “tacit knowing” (Polanyi 1966, 1968; Polanyi & Prosch, 1975) as they all involve “a body knowing that is more than we can tell “ (Polanyi, 1966, p. 4).

Through creative representation, presentational knowing “clothes our experiential knowing of the world in metaphors of aesthetic creation, in expressive spatiotemporal forms of imagery” (Heron & Reason, 1997, p. 281) that “reveals the underlying patterns of things” (Heron, 1992, p. 168). The understanding of presentational knowing as valuable in itself, and more than a bridge between experiential and propositional knowing, differentiates John Heron and Peter Reason from other writers of embodied knowing (Gendlin, 1996); Todres, 2007; Polanyi, 1966, 1968). By remaining closely attuned to my multisensory body as I explored my emotions and feelings through arts I tried to remain in a space of complexity and the not quite known and resist the temptation to rush into intellectual or propositional knowing. As Christine Seeley and Peter Reason (2008) argue, remaining in this muddled space of presentational knowing allows “non-intellectual space for fundamental, wise, right, essential knowing to distil from complexity and, at the same time for fundamental, wise, right, pluralised knowing to multiply from complexity” (p. 36).

In my enquiry I was attuned to my sensuous interaction with the world, as a means of allowing new knowing to emerge. I then used creative arts to generate new knowing in the form of presentational knowing as I gave expressive form to this experiential knowing. Presentational knowing was central to my enquiry, as using the metaphor of the camera, I zoomed in and brought into sharp focus the knowing that emerged through giving expressive form to my experiential knowing. Using creative arts was therefore central to my enquiry. As I continued to use creative arts to access my embodied knowing, my arts-based enquiry method emerged.

Arts-based enquiry method

Arts-based enquiry is uniquely positioned as a methodology for radical, ethical, and revolutionary research that is futuristic, socially responsible, and useful in addressing social inequities. By its integration of multiple methodologies used in the arts with the postmodern ethics of participative, action-oriented, and politically situated perspectives for human social enquiry, arts-based enquiry has the potential to facilitate critical race, indigenous, queer, feminist, and border theories and research methodologies. (Finley, 2008, p.71)

This enquiry is an emergent journey into the “not quite known”, into that liminal in-between space in which new meaning can arise (Somerville, 2007). I start this enquiry with an intention of curiosity and openness, to trust in emergence, to listen deeply to my embodied self and to be attuned to my different voices as they reveal themselves (Gilligan, Spencer, Weinberg & Bertsch, 2006). My data does not come from structured

experiments or interviews, but rather from the process of being attuned to my life as I live it and to making manifest in creative forms this lived experience. By being mindfully present and practicing reflection and reflexivity, new meaning emerges from my data. I try to follow the suggestion of Lorrie Neilsen (2008a) as she writes of her own research, “All this enquiry asks is that we attend, that we listen, attune ourselves so that we may come to our senses” (p. xvi). This commitment to embodied knowing, this desire to speak from my body has led me to a belief in the power of the creative arts as an enquiry method that fits well with my feminist phenomenological philosophical foundation. I concur with Mitchell Kossak’s (2013) views as he writes:

In art-based research, the phenomenological experience is represented through the creative act itself. The artwork, no matter what the medium (sound, rhythm, movement, enactment, poetry, paintings), opens up a space in which both the world and our being in the world is brought to light as a single, but inexhaustibly rich totality. (p. 20)

Arts-based methods, which are likely to generate or reflect emotion, were largely excluded from research within the positivist paradigm, out of a concern that this would be seen to contaminate research (Barone & Eisner, 2012; Eisner, 2008). However, the use of arts-based enquiry methods, although by no means accepted as part of mainstream research, is increasingly becoming more commonplace within qualitative forms of enquiry, as we acknowledge the importance of engaging with emotion in the struggle to develop cross-disciplinary understandings of the complex issues facing us today. There is a diversity of epistemologies, approaches, and procedures under

the umbrella of arts-based enquiry. Creative arts can be used as a means to open up and invite enquiry, to express the non-verbal, or the not quite known, as a means to articulate or represent emotion and the felt sense within the body, and to integrate and/or to present findings. (Barone & Eisner, 2012; Knowles & Cole, 2008; McNiff, 2004, 2008, 2013; Springgay, Irwin & Kind, 2008). A common thread across arts-based enquiry is the commitment to “increase human meaning, purpose, and capacity for positive transformation” (Chilton, 2013, p. 460).

Diverse forms of creative arts have emerged from different disciplines including, dance (Cancienne & Bagley, 2008), drama (Mienczakowski, 2001), film (Trinh, 1991a, 1991b), movement (Rasberry, 2002), poetry (Leggo, 2008a, 2008b; Neilsen, 2008b), photography (Knowles and Thomas, 2002), performance (Spry, 2001, 2011), and visual art (Allen, P. 1995, 2013; McNiff, 2008). Like other researchers (Barbour, 2011; Deacon, 2006; Trinh, 1991a, 1991b; Somerville, 2007; Spry, 2001, 2011), I used a range of emergent arts-based methods incorporating different modalities that traverse different disciplinary traditions as a means of generating knowing.

The foundation of my arts-based method is a cycle of exploration and discovery drawn from the MIECAT intersubjective multi-modal form of enquiry (Lett, 2001, 2011), which has developed within a phenomenological tradition. Each enquiry cycle is not complete in itself, but rather the enquiry cycles represent a journey, in which I continually revisit and build on previous knowing. My arts-based method developed in an emergent way as I engaged in making art in response to the emotional upheaval I experienced following my breast cancer diagnosis.

In the past responded to strong emotion by grounding myself in my body through physical activity. When I felt anger I would go for a long bike ride or a swim and tune into my physical body—focusing on the blood pumping through my arteries and veins, my muscles extending and contracting, my heart pumping, and my breath going in and out. This process of physical exertion, while attending closely to my bodily sensations, allowed me to regain a sense of calm and reduced the feeling of pain, but it did not allow me to explore the emotion and come to new understanding. Introducing the use of artistic expression to this attunement to my physical senses, has allowed me to stay with strong emotion, to enquire into its meaning without becoming overwhelmed, and form new presentational knowing.

Initially I started with a structured enquiry process following a set of clear steps and procedures as developed by MIECAT that fits comfortably within a post-positivist paradigm. Whilst I tried to capture the embodied process of art-making in my journal, my primary focus was on using the completed art representation to come to new meaning through a phenomenological description and reduction to key words and themes. In the service of transparency, I have shown the application of this process in Appendix 2.

As I immersed myself in my arts-based enquiry I came to understand that the embodied art-making process formed a major element in my coming to new understanding of my breast cancer experiences. Close attunement to the physical sensation of making art led me to an appreciation of the importance of touch in my enquiry process, which led me to a more intuitive contemplative way of being with

the art representation in response to my bodily felt sense. Touch, which allows for a physical contact with the world in a much more direct way than the other senses, became a key element in my enquiry process and firmly located my arts-based method within the phenomenological tradition as espoused by Merleau-Ponty.

Historically much arts-based research or arts therapy has focused on the product of the art-making process—the completed art representation. My focus on embodied knowing, particularly through the sensation of touch, has sensitised me to the importance of the art-making phase. Close attunement to the body, while attending to the intersubjective relationship with the art-making materials, allowed me to tap into my embodied knowing. The active nature of this process is reinforced by Jan Jagodzinsky and Jason Wallin (2013) who propose replacing the term art-making with “art-doing” in order to emphasise the importance of the doing of the art rather than the art product.

Throughout my enquiry process I focused my attention on my embodied knowing through practicing the principles of Insight Dialogue (Kramer, 2007) of pausing, being open, receptive, trusting emergence, listening deeply, and speaking my truth for that moment in time. I concentrated on what was happening in each moment, tuning into my bodily sensations and my feeling state. I responded to what was happening now, with each step building on the one before. I did not go back to the start; I just kept moving on, trusting emergence as my understanding accumulated with each step. I moved onto the next step when it seemed right—something changed, a change in emotion or some knowing started to surface. I captured my feelings and my experience

through writing in my journal or speaking into a recorder. As I continually refined my attempts to notice and articulate what I was doing, I began to develop an arts-based method that reflected what I actually did, rather than attempting to fit what I did into a set enquiry method.

The arts-based method, which emerged through this process, comprises a seven-step cycle of enquiry:

1. Noticing the emotion;
2. Identifying a bodily felt sense;
3. Using movement to deepen my bodily felt sense;
4. Making an art representation;
5. Being with the art representation;
6. Creating a dialogue in response to the art as other; and
7. Coalescing the threads of knowing into a clearer understanding

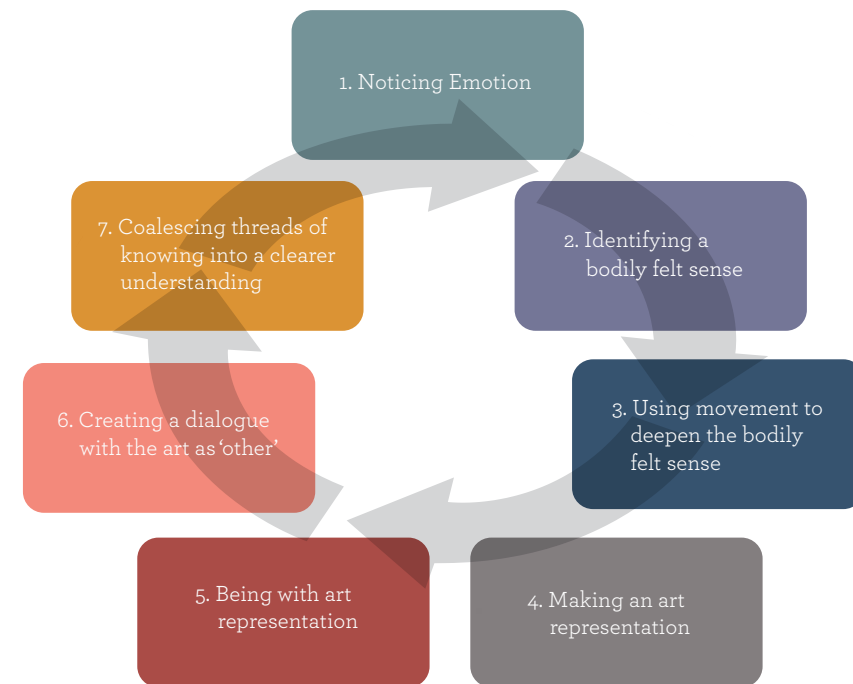


Figure 3.5 Cycle of Enquiry

This cycle of enquiry, illustrated above, relates to the extended epistemology as articulated by John Heron and Peter Reason (1997). The first four steps emphasise sensory knowing through a close attending to my multi-sensory body and my relationship with the art materials during the process of art-making. This sensory knowing is analogous to the experiential and presentational form of knowing (Heron and Reason, 1997), knowing that is not possible to put into words. Being

with, and creating a dialogue with, or from, the art representation (steps five and six) emphasises reflective knowing, however, as I used expressive forms of responding to the art representation, these steps could also involve experiential and presentational knowing. I attempted to come to some form of propositional knowing through the final step of coalescing the threads of knowing into a clearer understanding, however, at times it was not possible to articulate what I had come to know into propositional knowing; my understanding remained in the form of presentational knowing such as a poem. At times there was a significant time lapse between the making and contemplation of the art representation. This pause could be several hours or several weeks. I repeated this cycle of enquiry using different modalities as I strove to develop greater understanding of my breast cancer experiences, and clarity about whether to have a breast reconstruction. I have described in detail the seven steps of my enquiry cycle below.

Step 1 Noticing emotion

A feeling of discomfort or pain brings an emotion to my conscious awareness. Noticing, expressing, and then, exploring emotion provides a pathway to self-understanding and is at the heart of much therapeutic practice, particularly in the field of Emotion Focused Therapy (Greenberg, 2004; Greenberg & Watson, 2006; Kennedy-Moore & Watson, 1999). The study of emotions is extensive and beyond the scope of this thesis, other than to recognize the important role of emotions in our survival and personal transformation (Damasio, 2000, 2003). Emotions are complex, relational, and multi-layered, e.g. I might initially feel sad at being alone, but upon exploring this further

I might uncover a feeling of anger at being rejected by others. Rather than thinking about the emotion, I try and experience it, to really immerse myself in the feeling. Has this emotion arisen from a significant moment of experiencing? What is this experience? I put myself back into this experience: sit quietly and re-experience this moment and contemplate the emotion. Can I name the emotion? What is its quality? How big/small is it? Are there other feelings connected to it?

Step 2 Identifying a bodily felt sense

I next turn my attention to my physical body. Can I locate the emotion in my body? What does it feel like? Does it have a texture, shape, colour, or sound? What else am I feeling in my body? Do I feel heavy, light, tight, or tense? The process of attempting to locate the feeling in my body allows me to stay with the emotion without feeling overwhelmed by it. In my later reading, I realised that, in focusing my attention on what I was feeling in my body, I had been utilising the concept of the bodily felt sense in a similar way articulated by Eugene Gendlin (1996). He describes the felt sense as a physical, somatic sensation, that is more than an emotional feeling such as feeling scared, and different from a feeling, memory, desire, a body sensation, or thought; it comes in response to mindful attention and a friendly, welcoming attitude to what is present. The bodily felt sense is described by Eugene Gendlin (1996) as a holistic, implicit bodily sense of a complex situation, “a very distinct feeling that has not yet opened to reveal what it contains” (p. 19). Closely attuning to the feeling in my body, being prepared to stay in this murky place of unknowing, allows new meanings to emerge.

Step 3 Using movement to deepen my bodily felt sense

In this phase I move into presentational knowing as I intuitively immerse myself in improvisational movement as a way of focusing my attention into the bodily felt sense. I try to experience it as fully as possible, to deepen and consolidate it. Whilst being attuned to my body I am also curious and reflective. What is happening? How is my body moving? Is there a particular action that holds this felt sense? This bodily felt sense is further deepened through the interaction with my moving sensing body. As I move do I notice a gesture or sound that is being repeated? What am I feeling now? Has the bodily felt sense changed? If so, in what way? I follow the impulse to explore this movement further through some form of artistic expression—painting, sound, sculpture, collage, or movement. I try to hold the bodily felt sense to carry it forward with me as I continue to attune myself to my physical sensations as I make art.

Step 4 Making an art representation

I try to stay with my bodily felt sense and allow my body to intuitively move into making art. I don't think about what I am creating. If I am painting, I just start moving my arm towards the paper, picking a colour intuitively. The potter, painter and poet, Mary Caroline Richards captures this sense of immediacy and intuition when she describes her process in the film of her work *The Fire Within*:

I take the brush and suddenly I'm scrubbing the paper. Why? Why am I doing that? I'm not doing it because of any visual effect. I'm doing it because there's something about the motion that is calling me. (Kane & Lewis-Kane, 2003)

I immerse myself in art-making while being attuned to my bodily felt sense. Whilst making the art representation I focus on the relationship with the art materials—being with the art materials as I influence them and they influence me. The process of art-making is an intersubjective one in which I dialogue with the materials and through this intersubjective relationship new possibilities emerge. The art-making or art-doing becomes a coconstructed process in which the material is an active partner in the creation of the art representation.

I can access greater understanding by attending, with all my senses, to the relationship with the art materials—the texture and smell of the paint, the touch of my feet on the floor, the feel of my muscles as I move through space, the sound of the scissors as I cut the paper, and the sight of the paints as they merge to form new hues. Focusing on the physical sensations in my body brings my attention to the present moment, to the intercorporeal space in which meaning is constituted. This process of mindful presence to my physical sensations allows new understanding or meaning to arise without the need for interpretation: I just try to notice what is happening. At times, even the process of trying to speak what I know in this moment seems to take me out of this mindful physical attunement.

In an attempt to tap into all my senses and give voice to this “imaginal, pre-analytical mode of knowing and being” (Willis, 2004, p.8), I utilise a number of different modalities: body painting, photography, body prints, sculpture, drawing, movement, and creative writing. It is this fusion of different modalities of creative arts (Minge, 2007) that enriches my quest for meaning, giving me access to my deeply held bodily

feelings and knowing (Lett, 2011). Like peeling away the layers of an onion, each mode of representation reveals new layers of meaning. The choice of modality is determined by what seems the right intuitive fit—it might be a movement, a sound, dramatic enactment, or visual representation. Sometimes a particular modality quickly emerges as the right one to use, at other times I am less sure, so I might just start with what is at hand and see where that leads me, or go back to improvised movement and see what emerges, or use movement as my art representation. No matter what modality is used to create the representation it can be argued that all art-making starts with embodied movement, whether walking around locating material with which to construct a sculpture, the movement of the arm in creating marks on the paper, or the movement of the breath that enlarges to a whole of body movement or vocalized sound. The hand, arm, shoulder, and torso move while drawing, painting, and sculpting.

Whilst immersed in the physical act of art-making, a part of me retains a sense of curiosity, noticing what I am doing. I maintain a mindful awareness of being present to my experience of coming to new knowing, while in the midst of my embodied art-making. I am open and receptive to what surfaces in the process of doing art. I allow whatever is there to arise naturally; it might be a feeling, a memory, an image, or a physical sensation. “There is a part of the self that listens to the felt experience, asks questions, and receives answers—while simultaneously experiencing the felt sense” (Rappaport, 2009, p.267). I endeavour to be open, to improvise in accordance with my felt bodily sense, to stay in the emergent non-intellectual imaginal space, to stay “poised at the edge of the realm of experiential knowing where our senses and imagination meet” (Seeley & Reason, 2008, p. 35).

I describe my embodied experience of art-making through writing or recording a detailed description of what I did, how I felt, and any new understanding that emerged. Writing a description of my art-making process occurs after I have been in a place of visceral knowing. The very act of writing engages me in a different space—a more reflective space. The act of tapping into my language storehouse to locate the right words to portray the texture of this bodily felt sense seems to awaken memories and reflections that project me from the present moment back to past memories or towards future hopes. My sensory experience of my material body retreats to the background. I am not aware of the feel of the pen in my hand or of my muscles in my arms and hands, as I manoeuvre the pen to form words on the page as I struggle to put into words what I have felt and known in my body.

Step 5 Being with the art representation

I try to reconnect with the bodily felt sense while moving onto the next phase of exploring the art representation. The focus of my attention is now on the relationship with the art representation, including the relationship between its different elements. I try to engage with this art representation in a phenomenological way, i.e. I view it as if I am encountering it for the first time. I undertake prolonged contemplation and stay open to what may come into view. I often intuitively choose a particular art representation or an aspect of an art representation that provokes an emotional response. The response may be one of resonance, dissonance, or merely curiosity. Using a finely attuned multi-sensory approach to contemplate and interact with the art representation opens up opportunities for discovery. The use of multimodal arts

provides a bridge between my lived experience or pre-reflective embodied knowing and my cognitive or reflective knowing. As Warren Lett (2001) argues, the multimodal nature of an art representation allows me entry to a multiplicity of meaning, which may not otherwise be accessed.

Being present with the art representation is an embodied experience that involves attending to the felt sense. I contemplate the art representation maintaining an open, receptive, curious, and mindful stance. What do I notice? Do I have a physical response, an emotional response? What am I curious about? What draws me in? Is there a particular aspect/element that draws my attention? How do I feel? I focus on what I am most curious about; what draws my attention. I use focused attention as a way of coming to know; a process described by Anne Sullivan (2000) as staring with a curious eye, an eye that doesn't yet know how to understand. As Goia Chilton (2013) writes:

the artwork, as an object, opens up, and in turn opens up the viewer, who is no longer a viewer but a co-traveler, a participant in the performance of the artwork, an artistic co-researcher in the quest for understanding (p. 462).

In being with my art representation I enter into a space of stillness and possibility. Jean Rumbold describes this experience of contemplation as:

like pushing the pause button on the video player, this allows a moment of 'being with' the image. Such a moment can invite further 'staying with' even

'a casting around' from this place. And sometimes imagination enters this silence, expands the space, and transforms the noisy prison of circumstance. (Allen & Rumbold, 2004, p. 133)

The process of meditative contemplation allows the energies, vitality, and creative spirits held within the representation to open up new meaning (McNiff, 2004). Describing his process of meditative contemplation or indwelling Moustakas (1995) writes, I "direct myself toward the meanings beyond the *appearance* of things. It is an active process of being open to receive intuitive visions, feelings and sensings ... [that can] involve hunches, guesses, visions, risks, and spontaneous impulses" (p. 84, italics in original). This intense process of being with and open to the representation allows new knowing to arise.

Step 6. Creating a dialogue in response to the art as other

Developing a dialogue with the art representation as other as described by Mala Betensky (1987) and Shaun McNiff (2004, 2008) opens up new avenues of enquiry and opportunities for making meaning. I am able to capture the intricacies of my lived experience and thus bring "more of the unsaid" (Heidegger, 1962) into the world to enable me and others to know it, and converse with it; it allows me more direct and less censored access to material that cannot be put into words, access to the not quite known (Hogan & Pink, 2010; Leavy, 2009; Pink, Hogan & Bird, 2011). The dialogue may be between different elements within the representation, between the art representation and me, or between the art representation and another co-enquirer.

Shaun McNiff (2004) argues that dialoguing with images we have created “takes us into a deeper, more intimate and creative exchange . . . and we open ourselves to the surprises and discoveries that occur through interplay” (p. 91).

Maintaining my commitment to improvise in accordance with my felt sense, I converse with my art representations in various ways. I might respond through another modality as described by Shaun McNiff (2008) or empathically enter into an element or figure of the art representation and speak from this in a form of “ventriloquising performance” as described by Cameron Tonkinwise, (2008) in which “the art-maker extends one’s self into things, projects one’s being empathetically into the inanimate” (p.8) with new knowing emerging through this sort of projected “back-talking”. At other times I create a dialogue between different elements of the artwork by allowing the character to “well up from the body” (Gendlin, 1996, p. 195).

The dialogue may also involve a creative response by amplifying a particular element of the art representation that draws my curiosity to open up new meaning e.g. in a movement representation, a small hand gesture may be repeated or enlarged, an element of a visual image may be enlarged or recreated using another modality. Using different modalities, I continue to gather further data through dialoguing with, from, and about, the art representation, while I stay as open as possible to what is being communicated. The dialogue may be in words, writing, movement, or some other form of artistic expression.

This step may also involve the presence of a companion to facilitate the process

of dialoguing with the representation. The open, curious, focused attention of the companion allows me to be receptive to new meaning. With the well-timed query of a companion, insights may come forward that may not otherwise come to light. In order to create an open trusting intersubjective space in which new meaning is coconstructed, a companion is present in a way that engages their entire being (Moustakas, 1995) while taking on a stance of “listening love” (Rogers, 1995) with the curiosity and openness of what Zen Buddhists’ term the deep listening of the “beginner’s mind” (Suzuki, 1970).

Having a companion to facilitate an exploration of the representation adds to the richness and emergent nature of this process. The companion’s response through another multi-modal representation can be a powerful way to focus the data, introduce another avenue of enquiry, or allow new meaning to come to light. Using whatever modality seems right, my companion’s intersubjective/creative response is a representation of an empathic intuitive understanding “that holds the respondent’s resonance to the material of the dialogue offered with an intention of enhancing the activity of making sense of things” (Rumbold, Allen, Alexander, & van Laar, 2008, p. 298). Clark Moustakas (1995) uses the term *being-with* to describe this highly attuned presence to the other as a “joint enterprise – two people fully involved, struggling, searching, exploring, sharing” (p. 84). This is an active role in which responses are provided to assist the progress towards new meaning; these responses may be affirming statements, queries, or challenges and may be expressed in different modalities.

Step 7 Coalescing threads of knowing into a clearer understanding

While staying attuned and open, I aim to reduce the created data to a more distilled form, to capture this new understanding through some form of artistic expression. As I contemplate this artistic expression I try to take this new knowing into my body. How do I feel now? Is it complete or is there something more? Through an intense inner searching, I attempt to grasp the quintessential sense of meaning.

I use different forms of writing including poetry and creative fiction in an attempt “to grasp the naked now and rescue it from the just now” (van Manen, 2006, p. 717). I embrace the phenomenological imperative of turning to the things themselves, trying to grasp the lived experience in its raw richness before it has been conceptualised, sanitised and located within existing knowledge frameworks. I am inspired by Hélène Cixous (1997) as she writes “What is most true is poetic. What is most true is naked life. I apply myself to ‘seeing’ the world nude” (p. 3) and in order to see the world nude requires that I move to the space “at the edge of existence” (van Manen, 2006, 718).

The knowing that emerges through my arts-based enquiry is visceral and difficult to distill into words. My arts-based methods call for a focused attention of present awareness and an intuitive sense of possibilities through an attuned presence to my bodily felt sense and a preparedness to improvise in response to this felt sense. The enquiry is deepened through continual cycling through the different steps in a sequential manner.

Presentation of my findings

As I continued to depth my understanding through numerous enquiry cycles, I confronted the challenge of how to present my findings in a coherent form. I wanted to respect the creative arts-based process I had engaged in, and attempt to convey the complexity of what I had come to know. I felt that using different forms of creative writing in conjunction with images would best allow me to communicate my circuitous journey.

A rich field of narrative based enquiry such as ethnographic poetics (Marcus & Fisher, 1986), poetry (Richardson, 2002), lyric enquiry (Neilson, 2008a, 2008b), reflexive fiction (Ashmore, 1989), messy texts (Clough, 2002), and autoethnography, (Ellis, 1995; Reed-Danahay, 1997) has gradually become legitimised over the last twenty years. Carolyn Ellis (1993, 1995; 2000; 2004; 2007;) along with her partner and collaborator Arthur Bochner (Ellis & Bochner, 2000; Bochner, 2000, 2012) has been a key proponent of autoethnography, which has become the most widely accepted form of narrative based enquiry in recent years. They describe autoethnography as “an approach to research and writing that seeks to describe and systematically analyse personal experience in order to understand cultural experience” (Ellis, Adams & Bochner, 2011, p.1). In this tradition I too hoped to effectively connect the personal with the political and through the power of story highlight the experiences of the many, by providing a textured telling of a personal narrative that is able to shine a light on the cultural context in which it is embedded. I sought to tell a “true cancer story” as defined by Linda Park-Fuller (2009), one that was credible, authentic, accountable, and accessible.

As I struggled with how to convey my embodied knowing in words I drew on the insights of other postmodern qualitative researchers who, guided by a belief in the multiplicity of voices and constructed nature of reality and knowledge, have experimented with different forms of creative writing and performance to present their findings (Bagley & Cancienne, 2001; Barone, 2000; Ellis, 2004; Gray, 2003, 2004; Gray & Sinding, 2002; Jago, 2011; Lahman, 2011; Leggo, 2008a, 2008b; Neilsen, 2008a, 2008b; Rath, 2012; Richardson, 2011; Spry, 2001, 2011). While lost in grief, it was difficult to articulate the chaotic emotions I was feeling, although I found comfort in Lorri Neilsen Glenn's (2011) poetic reflection on grief and loss. I was also inspired by Alice Terry's (2012) story of her daughter's death, and Gresilda Tilley-Lubbs' (2011) depiction of her experience of a college massacre. Following the leadership provided by Laurel Richardson (1998, 2001, 2011) and Carolyn Ellis (1993, 1995) they use a personalised multi-voiced narrative as a way of making sense of experiences of grief and trauma.

The difficulty of articulating in words the richness and complexity of my lived experiences of breast cancer is an endemic challenge of the phenomenological approach (van Manen, 2007). I find it an effort to not engage in a cognitive process of ordering and reshaping my raw lived experience in the very act of trying to convey it in writing. In an attempt to not lose the essence of my enquiry through the process of pinning it down in words I follow the approach as outlined by Peter Willis (2004) who writes:

This approach seeks to use the artistic tools of fiction, metaphor and poetry, the visual tools of pictorial and graphic art and sculpture and other artistic

forms to create a portrayal which carries the immediacy and impact of an experience rather than any explanation of it. (p. 8)

Using creative forms of writing and imagery, not only enables me to speak more directly from my lived experience, but also allows a more evocative telling that potentially engages the audience on an emotional level (Knowles & Cole, 2008; Neilsen, 2008b). By using a creative narrative, that incorporates poetry and images, I hope to capture the complexity of my multi-modal arts based enquiry in a way that evokes an emotional response. As Caroline Ellis and Arthur Bochner (2000) write:

Evocative stories activate subjectivity and compel emotional response. They long to be used rather than analyzed; to be told and retold rather than theorized and settled; to offer lessons for further conversation rather than undebatable conclusions; and to substitute the companionship of intimate detail for the loneliness of abstracted facts. (p.744)

Connecting to others on an emotional level is more likely to open up new ways of viewing the world and thus has greater potential to bring about personal and social change. There is an increasing acknowledgement that in order to be useful or influential, research requires an audience and to gain an audience requires the research to be presented in an engaging and interesting way (Ellis & Bochner, 2000; Richardson & St. Pierre, 2005). The importance of disseminating research outside the cloistered corridors of the academy in order to reach out to new diverse audiences is increasingly being acknowledged, particularly in relation to research with a social

change agenda (Barone & Eisner, 2012; Denzin & Lincoln, 2008; Nash, 2004; Richardson & St. Pierre, 2005). It is argued that the traditional objective academic discourse, which prioritises the use of sanitised, anonymous voices, can struggle to engage and connect with others (Richardson & St. Pierre, 2005). Roxanne Doty (2004) contends the very act of adopting an objective, neutral style of writing is normative and political as the divergent, challenging voices slip into “an abyss of academic jargon that ensures the sterility of the stories we tell and erases the blood that might otherwise drip from our narratives” (p. 380-381).

The conference presentations I have done during the course of this enquiry have reinforced for me the power of the personal story. In contrast to sitting in a room of academic presenters talking in dry objective language about their research about other people’s lives, the potency of telling my own story in my own voice about my own life from my own body has been compelling. To show a movie containing pictures of my naked body, of my scarred chest, to allow myself to be seen by a room full of strangers in all my nakedness and vulnerabilities, elicits a strong connection and a way to allow people to experience for themselves their own emotional reaction to the lived experience of breast cancer. An experience of breast cancer that, although holding my own uniqueness, is also shared by millions of women across the world. Like Peter McIlveen, (2008), I have seen the possibility of personal narrative to improve service delivery when I have presented my personal story in forums focused on improving breast cancer services. As well as providing a powerful means of connection and stimulus to discussion (Doty, 2010), it allows the often-silent voice of women with breast cancer to be heard; this is particularly important when talking to an audience

involving health service professionals.

Using a narrative to form an evocative telling has been criticised as risking the creation of a narcissistic, self-indulgent, personal story devoid of any broader cultural analysis (Roth, 2009) or of assuming an essential unified subject without questioning the many complexities of differing lived experience. Additionally queer writers, such as Judith Butler (2004), argue that subjective reflexivity of the personal narrative can be a trap that too easily reproduces normative conceptions of self, agency, gender, desire, and sexuality. In presenting my findings in a narrative form I have not attempted to generalise the experiences of a small number of white middle-aged, middle-class, professional women living in a major city of Australia, a rich western country to universal experiences. Rather I have attempted to meet the criteria of an effective narrative as identified by a number of writers (Bochner, 2000; Denizen, 1997; Ellis, 1995; Richardson, 2000; Spry, 2001, 2011) in ensuring that: it has aesthetic appeal, the writing is well crafted and “capable of being respected by critics of literature as well as social scientists” (Denizen, 1997, p. 200); it is emotionally engaging and evocative, in other words it is a good story with strong characters and a good plot (Ellis and Bochner, 2000); it is critically self-reflexive, contributes to our understanding of social life, generates new questions, and inspires some form of action (Richardson, 2000); and finally, it connects the personal to the cultural (Ellis, et al, 2011).

Ethical issues

Throughout my enquiry I was sensitive to the varied ethical issues I confronted. Using creative arts with other women to explore their breast cancer experiences held the potential to further traumatised women who had already undergone traumatic experiences. At all times I attempted to respect the rights of the women I worked alongside to be fully informed, to have control over their own material, and to withdraw from the project at any time. As an academic research project, my enquiry was bound by the ethics approval process of my teaching institution (MIECAT). The letter of approval from the MIECAT Human Resources and Ethics Committee is included in Appendix 1. The formal ethics process helped me to focus on the procedural ethics (Guillemin and Gilliam, 2004), including the purpose, potential harm and benefit of my enquiry, and develop useful processes and instruments around consent, confidentiality, privacy, and ownership of material. As a social worker and creative arts therapist, I have a strong grounding in professional ethics and abide by the Australian Association of Social Workers (AASW) code of ethics as well as the Australian and New Zealand Arts Therapy Association (ANZATA) and MIECAT code of ethics.

The feminist methodological approach has been at the forefront of advocating for a greater attention to all elements of research in terms of minimising potential harm, including how research findings are presented. Feminist and queer researchers have highlighted the importance of the power differential in all stages of the research process; attending to not only how and why one engages research participants but also how one talks and writes about what comes out of the enquiry. I therefore ensured

that the women involved in my enquiry were active participants in the planning of activities and had the right to withdraw their consent to the use of any of their material—either words or images.

There is a tension in providing an authentic, engaging account, with the potential of compromising the reputation, privacy, and trust of others.

I needed to look to my own values in addressing the additional ethical issues inherent in my arts-based personal enquiry, which involved personal stories—my own and a select few others. Values such as, treating people with respect, being honest and transparent, being open to different perspectives and views, being aware of the power relationships which can affect someone's capacity to say no, being sensitive to the power of images and words—whether spoken or written—and being alert to the potential for harm when dealing with personal, intimate material, formed the foundation of my ethical approach. These values are now being acknowledged as part of the ethical terrain under the term relational ethics (Ellis, 2007). This is particularly important in qualitative enquiry as often we are working with people with whom we have an existing relationship, which may change during and after the enquiry process. This applied to my enquiry as my formal ethics application was approved on the basis that I used word of mouth to recruit women to my arts-based group, which resulted in me having some form of personal connection with the three other women involved; with one woman this relationship has developed into a friendship during the course of the enquiry.

As well as attending to how to tell the stories of other women involved in my enquiry, I have also given much thought as to how to tell my own story. How do I want to present my story as “a wounded storyteller” (Frank, 1995)? I decided to be as honest and transparent as possible. I am aware, however, of the tension between exposing myself through my open honest telling of my story, while at same time, feeling the vulnerability of sharing aspects of myself that I am not particularly comfortable revealing; I have tried to find the balance between my continual desire to push myself to be open and honest while being aware of the need to take care of myself. I am conscious that ultimately I have no control over how you, the reader, will receive my story. I cannot assume that you will receive it in the way I intend; that is the risk I am prepared to take.

Although there is perhaps a greater safety in presenting my experience in modalities other than words, I am still aware of the confronting nature of my material and the possibility that it might trigger a powerful response in an audience member. The preparedness to show my vulnerability, the rawness, and confusion of my breast cancer experience through artistic media such as film, art, photography, and poetry brings with it another ethical challenge, in relation to the potential for harm to the audience. Ethics in relation to the audience is seldom explicitly discussed as part of academic research. It needs to be acknowledged however, that there is a tension in trying to evoke a strong emotional response and create a sense of connection, with the potential to do harm through the process of witnessing and perhaps tapping into past trauma. This is particularly important when working in the area of breast cancer, as it is likely, that in any audience most people will have had some personal connection

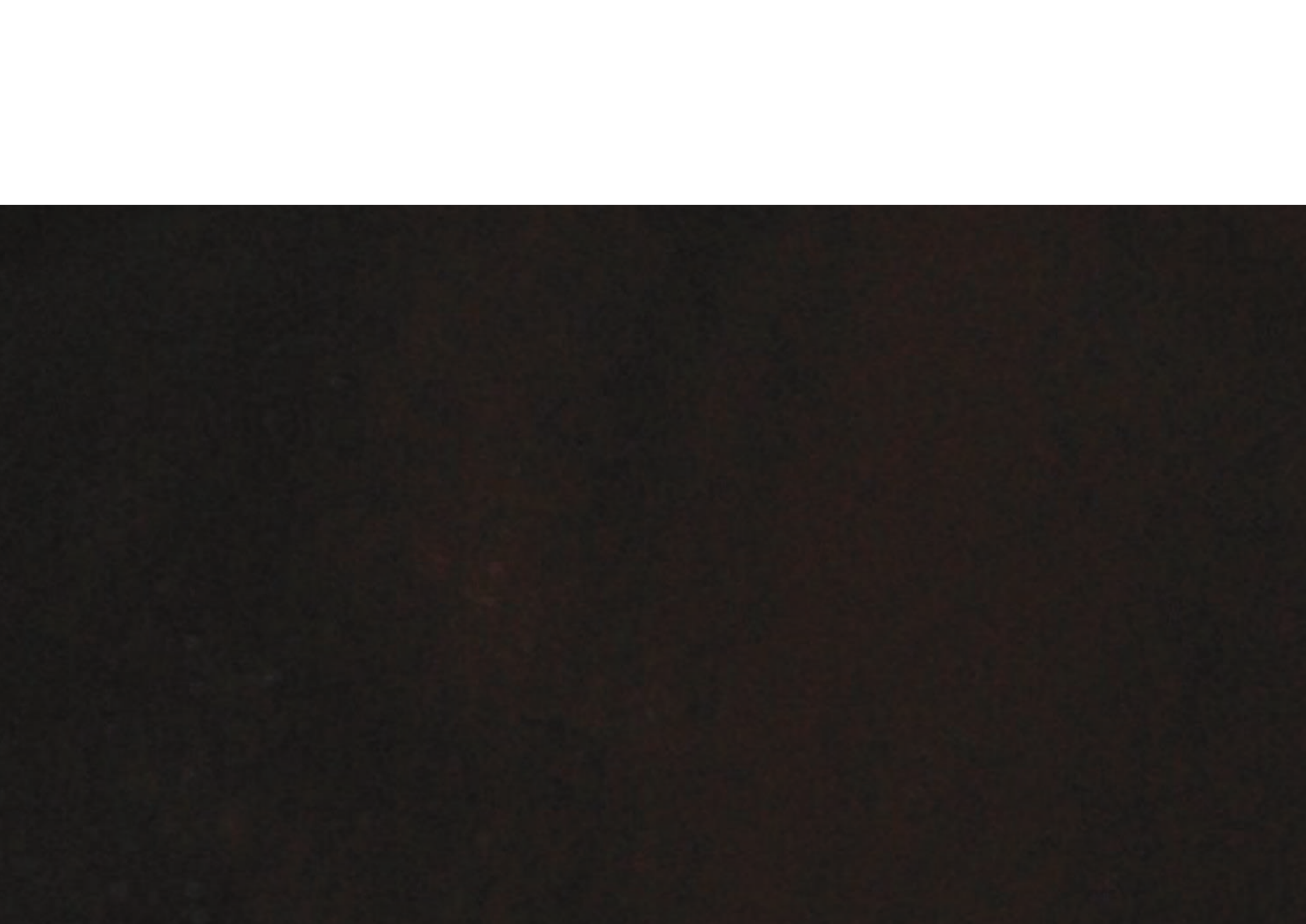
with this disease, either personally or through their relationship with other women with breast cancer.

It is important to balance the need to create the space to allow audience members to craft their own response with the need to protect them from any possible harm. In discussing the audience response to their plays about women with breast cancer, Chris Sinding, Ross Gray and Jeff Nisker (2008) argue that “at times it is important for audience members to experience a level of distress in order for the message ‘to hit home’. It is from this sense of connection that they may be inspired to take some form of positive action” (p. 465). They maintain that creating a consent-heavy, risk-adverse environment up front is at odds with the purpose of presenting an evocative personal narrative and risks foreclosing its possibilities.

I have tried to address the potential for harm to my audience by providing a brief description at the outset of the personal content and use of images they might find confronting. I acknowledge the potential for a strong emotional response and provide information on support options. I have also had to consider the particular ethics involved in image-based research (Clark, Prosser & Wiles, 2010). I obtained consent to use artistic material created by the other participants as part of this enquiry, giving them the right of refusal. Of course you, the reader, may also have a strong emotional response to the words and images I have used to convey my personal story. I cannot assume that you will receive my story in the way I intend, or protect you from possible painful emotional response, I can only acknowledge your autonomy in coconstructing your own experience from my story.

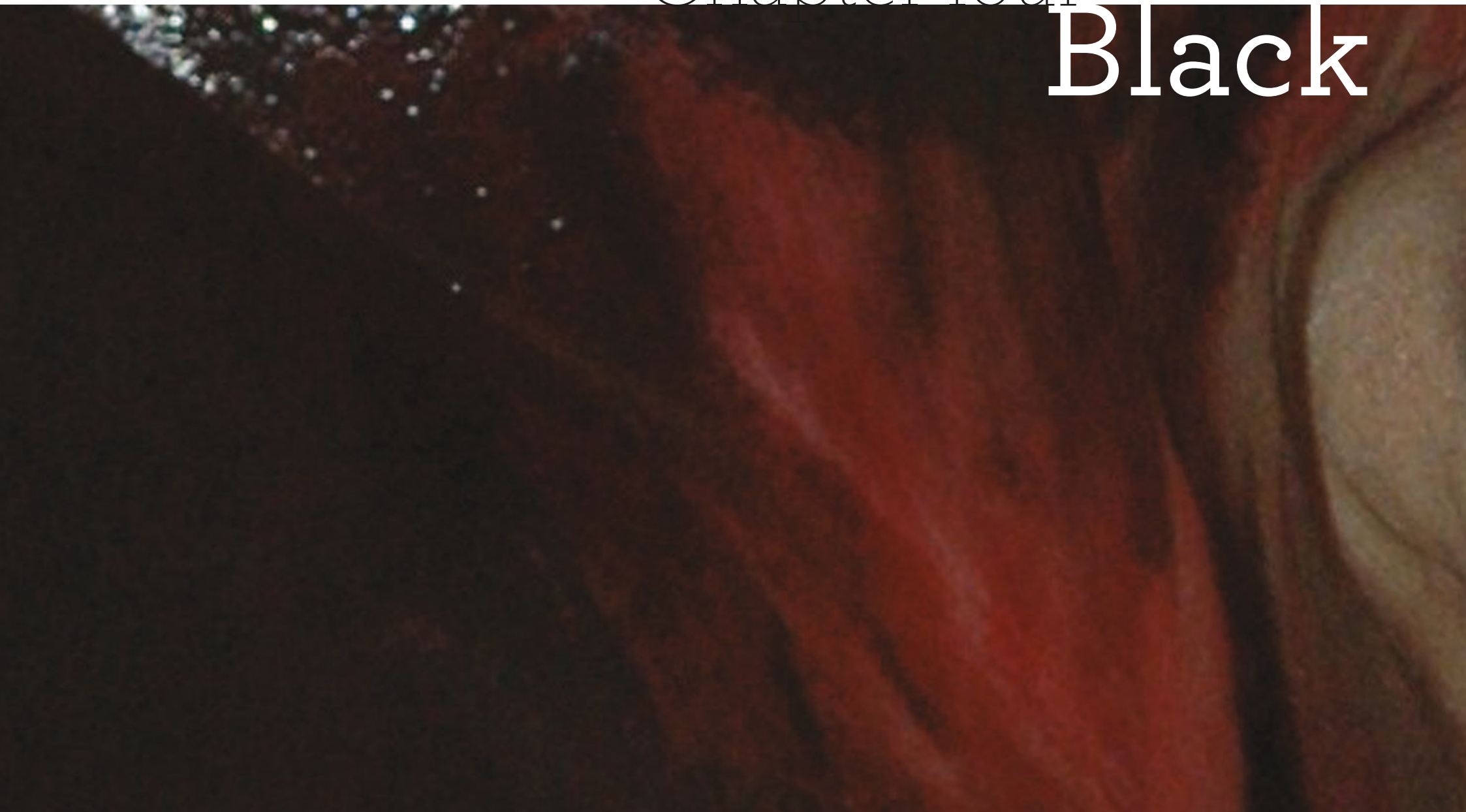
Conclusion

I have located my enquiry within a philosophical and methodological tradition of feminist phenomenology incorporating an extended epistemology of four ways of knowing. The feminist phenomenological methodology and arts-based method that I have described in this chapter emerged from my drive to make art as a means of tapping into my pre-reflective embodied knowing in order to make sense of my breast cancer experiences and find a way out of my confusion about whether to have a breast reconstruction. Adopting an open, curious, and reflexive attitude as I continued to make art, and engaged with the relevant literature, enabled me to gradually develop an understanding of what I was doing and be able to articulate it into a seven-step enquiry process. My arts-based method foregrounds knowing that arises from a mindful attunement to my multi-sensory body as I engaged with a range of art materials. In the next chapters I discuss the new understandings of who I am in relationship to the world that emerged as I apply my arts-based method to my enquiry into my lived experiences of breast cancer.



Chapter four

Black



Stuck up to my chin in black oozing mud
just enough clearance to breathe.

The rancid stench of decay fills my nostrils.
The taste of death in my mouth.

Introduction

This chapter begins my exploration and discussion of the findings from my arts-based enquiry. In traditional positivist research the different phases of data collection, analysis, and findings are generally conceptualised and implemented as discrete stages. Many postmodern qualitative researchers, however, argue that data collection and analysis cannot be separated (Finley, 2008; Heron & Reason, 1997; Richardson & St. Pierre, 2005). I too integrated the data collection, analysis, and findings stages as I undertook numerous enquiries following the seven-step process outlined in the previous chapter.

Over several years the colour black dominated my enquiry process. In this chapter I present my findings in the form of a layered telling (Rath, 2012) drawn from moments of significant meaning that emerged from these black-dominated enquiries. To demonstrate the application of my process I have included a detailed description of an enquiry, one that illustrates the significant role of a companion in assisting my exploration.

My desire to speak from my wounded body makes it difficult to capture, in words on the page, the disordered terrain of my embodied arts-based exploration. It is only now as I write and reflect back on my journey that I can shape my experience into a more coherent form. However, I want to try to convey my experience as I lived it, and resist the temptation to write a neat “quest narrative” as described by Arthur Frank (1995), in which I am the heroine of my illness journey finding atonement through my suffering. At the time I felt lost in a sea of pain and confusion as I grieved the loss of my breast and felt pressured to make decisions about whether to have a breast reconstruction. I felt driven

to use arts to explore what I was feeling in an attempt to alleviate my suffering and find meaning in my breast cancer experiences. As I continued to immerse myself in my arts-based enquiry I experienced moments of epiphany, in which threads of knowing coalesced so that I came to know in my body new understandings of myself and my lived patterns. However this embodied knowing did not follow a simple trajectory and is difficult to articulate as I moved from moments of black despair to moments of acceptance then back to despair.

My arts-based method, with its emphasis on the sensuous encounter, stimulates a reaching back into my past and brings threads of knowing I have held over time to coalesce into a more coherent form through my enquiry into the trauma of my breast cancer experiences. In each enquiry cycle these threads of self-understanding that emerge through my arts-based exploration coalesce into a stronger knowing expressed through poetic writing. Drawing on the poetic writing that forms the final step of my enquiry cycle I have formed a creative synthesis, in which I have attempted to give voice to my wounded body. This narrative uses poetic writing and images linked by the voice of a narrator who reaches back into memories and draws on the voices of other researchers, writers, and women diagnosed with breast cancer. My multivoiced narrative moves in and out of different temporal, physical, and emotional dimensions as I attempt to communicate the complexity of my lived experience of breast cancer. In the tradition of Laurel Richardson (1998, 2001, 2011) I aim to write myself into a new understanding, to shape my transforming self to incorporate an acceptance of my changed body shape. I write in the spirit of Carlo Leggo (2008a), “we need to write autobiographically in creative and courageous ways that acknowledge how each of us is composed in the intersections of multiple processes of identity shaping and re-shaping” (p. 17).

*I am going to have my nipple cut off!
You have malignant cells in your breast duct,
just behind your nipple,
my surgeon informs me,
I believe it is best to be sure we get it all.*

*I am going to have my nipple cut off!
It has nourished three beautiful children.
Memories of my newborn babies
their look of absolute contentment as my milk flows
in the incredible miracle of sustaining life.*

My nipple that has brought me so much sensual and sexual pleasure.

*Waves of delight course through my body
with my lover's touch.*

*My sister went into surgery.
"I'm just getting a lump removed," she said,
"It's no big deal."*

*She awoke
without her left breast.
Cancer had spread to her lymph nodes.*

*She died within a year.
She was only 35.*

I am going to have my nipple cut off!

*The perfect symmetry my nipple provides my breast
will be replaced with a scar.
A site of such strong sensation.
It changes shape, colour and texture
in response to emotion, sexual arousal, touch, and temperature.
It is a barometer of my inner and outer worlds.
A constant reminder of my womanhood.*

*As I walk forward
my nipples are the extremity of my physical boundary;
like a cat's whiskers
they are a radar
sensing the atmosphere ahead of me.*

*How do I celebrate my nipple?
Commemorate it?*

Connect with the emotion of its loss?

*I have a desire to somehow retain
its character.*

To allow it to make its mark.

To feel its physicality.

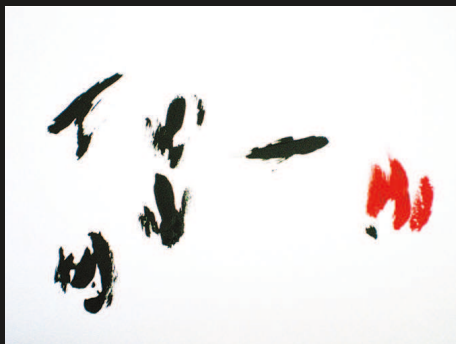
Like a paint brush

*I move my paint-smothered nipple
across the paper making a series
of abstract marks.*

*My nipple becomes tender and sensitive. The abrasive movement
across the paper becomes
more painful.*

*As I paint slashes of red through the black
the shooting pain
feels like
a knife cut.*

Alone in my flat, the night before my operation, I look in the mirror and struggle to imagine my breast without my nipple; such a small innocuous piece of human flesh that holds so much significance and symbolism for me. I smooth my hand over my left breast and feel the sensation as it moves across my nipple, which hardens as it reaches towards the touch of my hand. This brings tears to my eyes as I realise I will no longer experience this sensual feeling. I want to feel the physical sensation of my nipple one last time and allow it to leave its mark behind.





It seems a small thing to have my nipple removed in comparison with losing a breast. As my surgeon says, “you will still have your breast and it won’t be noticeable under your clothes.” But it feels big to me. I am surprised by my feelings of grief. I am repeatedly told that I am lucky that I do not need to have a mastectomy. But I don’t feel lucky. I feel incredibly sad, and also guilty that I feel so much grief, as I know there are women so much worse off than me. I imagine my nipple being carefully sliced off and placed on a silver platter, holding its shape as it proudly points upwards. It is strongly connected to my sense of myself as a woman—a nurturing, sensual, sexual woman.

Although there is an extensive literature, including personal stories, on the experience of having a breast removed through a mastectomy, I have not been able to find any writing on the emotional impact of having a nipple removed. It was not until meeting Hannah, one of the women with whom I worked in both group and individual sessions that I finally found someone who could relate to my feelings. Hannah, who had had a double mastectomy, said that she didn’t mind not having breasts but really wished she still had her nipples. She said that she had imagined that after her mastectomy she would be left with the chest of a boy. But, without nipples, she said she felt disfigured and ashamed of her appearance, and not comfortable in negotiating the range of responses if she were to remove her top in public. In one of our sessions together Hannah asked me to use clay to fashion a boy’s chest onto her body. She delighted in adorning her clay chest with nipples made of gum nuts and seed pods. She fashioned a ring out of a piece of wire and inserted this through her clay nipple. “I expected it to hurt”, she said.

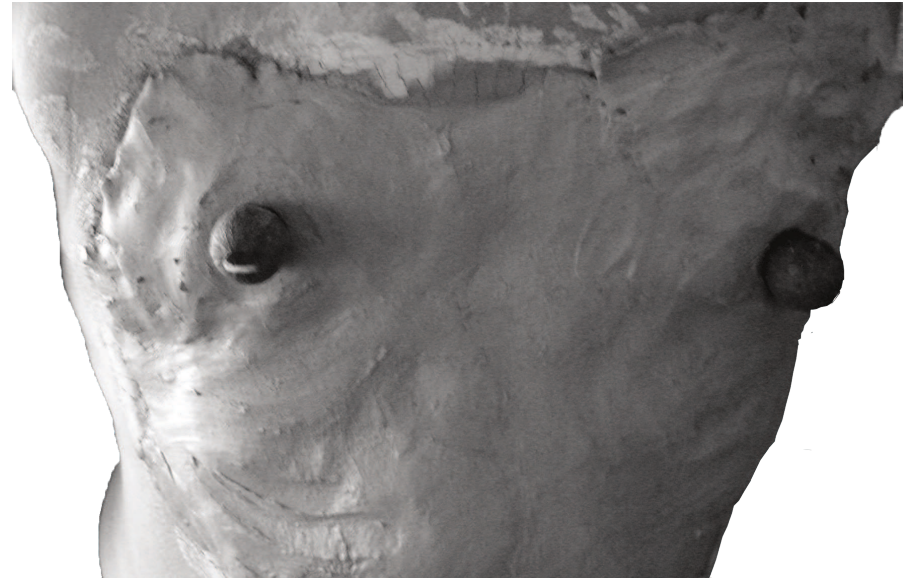


Image 4.2 Clay chest with seed pods

Sarah Lochlann Jain (2007) also talks about her desire to strip off and reveal her breastless chest following her mastectomy and the implicit dare in doing so as she writes, “can women not show their chests in public because they are women, or because they have breasts?” (p. 514). She takes her shirt off in a yoga class and compares this public act of revealing her scarred chest, as a way of challenging the many layers of social shame attached to this act, with the actions of gay men in public displays of affection that challenged homophobic stigma, “the taking-off-my-shirt moment offered perhaps a contravention to shame:-a tiny, hard resistance to the layering of social

shame on the experiences of cancer" (p. 515).

As I contemplate the images I created with my nipple, I feel myself drawn into the intense gaze of one image in particular, *Image 4.3 Two faces*. I see two faces each with a wide opened eye bound together staring into the unknown with focused intensity. What do they see? They seem to convey an expression of trepidation, fear, apprehension, knowing. The image has the quality of a painting by well-known Australian artist Mirka Mora and I am amazed when I find one of her paintings *Image 4.4 Couple with bird*, which has a strong resonance with my image.



Image 4.3 Two faces



Image 4.4 Couple with bird Mirka Mora 1958

As I contemplate *Image 4.3 Two faces* I am reminded of my sister Ann.

Suddenly she is powerfully in my presence. Ann and I were the middle of four children; she was only 18 months older than me, and we were always close. As we grew up we shared similar interests and friends, we played in the same netball team, and while at university we lived together in share houses. Ann died within a year of her breast cancer diagnosis when she was only 35 years of age. Will I die this quickly too? Fear washes over me. For the first time it strikes me that I might actually die from cancer.

*Fear, trepidation,
apprehension. Two sisters
linked through pain and loss.*

I have always experienced a strong sense of survivor guilt about Ann's death. Three years before her cancer diagnosis, she had been in a terrible car accident. A young man, drunk and driving a stolen car had crashed through a busy city intersection in Winnipeg, Canada and smashed her against a wall. She was very lucky to survive and spent a year in hospital and was left with a permanent disability with most of her left buttock gone and her pelvis shattered. After being rejected as too old to adopt, she and her partner had decided to try and have their own child. To assist her to conceive she borrowed my book on the Billings' method of ovulation (Billings, E., Billings J. & Catarinich, 1977), which I had been using to prevent getting pregnant. The week she borrowed my book she found out that she had breast cancer and I found out I was pregnant with twins. It seemed so unfair and unjust. I struggled to accept our differing destinies. Throughout her painful cancer

treatment she was still able to celebrate my pregnancy and the birth of my twin sons. She died before their first birthday. How can I draw on her strength through my own breast cancer experience and not feel overwhelmed by my fear of death?

In his book *Staring at the sun: Overcoming the terror of death* Irving Yalom (2009) draws on his experience of death in his personal and professional life as a psychiatrist to explore the fear of confronting our own mortality. He argues that although, particularly in western countries, we avoid confronting the reality of death, it is none-the-less our constant companion through life influencing the way we live.

Death, however, does itch. It itches all the time; it is always with us, scratching at some inner door, whirring softly, barely audibly, just under the membrane of consciousness. Hidden and disguised, leaking out in a variety of symptoms, it is the wellspring of many of our worries, stresses and conflicts. (Yalom, 2009, p.9)



and burning in hell in the afterlife, or my experience of gasping for air as a child in the midst of an asthma attack in a pre-Ventolin age, but I have always felt a close association with death; expecting to die at any moment. As a young child I would sometimes be convinced I was going to die on a particular night and would kneel on my bed for hours saying the rosary in an attempt to guarantee my safe passage to heaven. At my Catholic primary school, located next door to the church, a part of our normal school day was to go to any Requiem Mass (Catholic funeral service) that occurred during school hours.

My first childhood memory of death occurred when I was seven years of age. As we streamed out of school at the end of the day a little girl in her first year of school was killed in a car accident in front of us as she ran across the road to her home directly opposite the school. I can still see her small body lying still on the road and her undersized white coffin covered with roses as we all sobbed our way through her Requiem Mass. So when my sister died of breast cancer, I carried around the belief that I too would probably die of breast cancer one day. In holding my mortality close to me I have developed a pattern of rushing through life, trying to greedily grab as much experience of life as possible before I die.

I am aware of a sense of relief when I am finally diagnosed with breast cancer. Now I no longer need to feel guilty about my sister's death, now I can finally deal with something I have felt like a sword hanging over my head for years. Although I feel like I have been prepared to face this moment, the reality feels scary. By using arts I want to confront my fear of death and come to a

place of acceptance as outlined by Yalom (2009), "confronting death allows us, not to open some noisome Pandora's box, but to re-enter life in a richer, more compassionate manner" (p. 4).

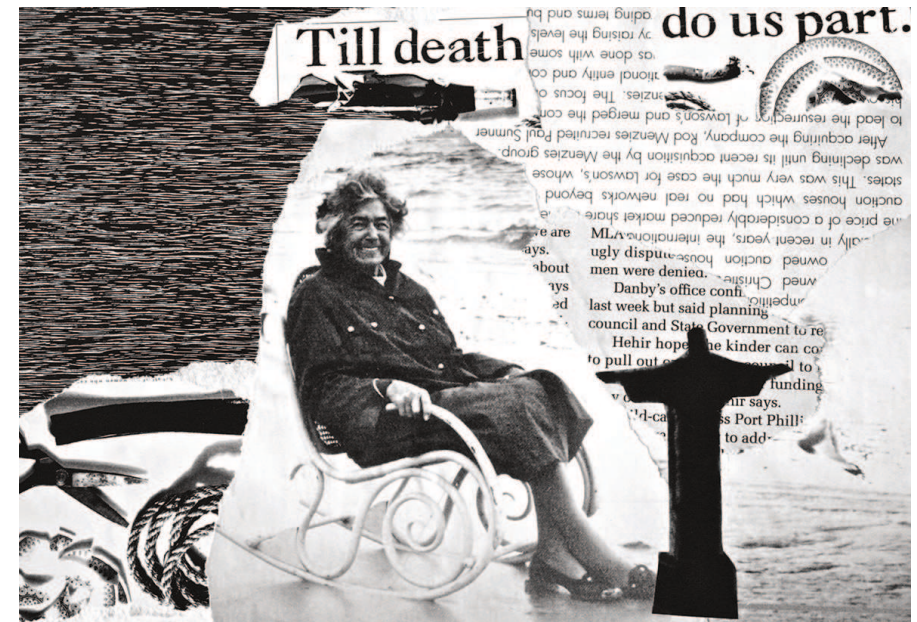


Image 4.6 Waiting for death

I survive my first operation but it does not capture all my malignant cells and I have two more operations in an attempt to obtain clear margins, the final one a full mastectomy and removal of my breast lymph nodes. With

each operation I become more convinced that this time I will surely die while under the anaesthetic. The night before my mastectomy I go for a walk along the beach. I have walked along this beach so many times. This will be my last walk with both my breasts. I focus my attention into my left breast. My breast is sore. I have already had two pieces cut away. I try to feel into my breast. Can I detect the cancerous cells? I can't. Maybe it does feel different. But I feel perfectly healthy. It seems so bizarre that I can feel so sick when I'm suffering from a common cold but when I have the life threatening disease of cancer I feel perfectly fine.

I am anxious about my surgery tomorrow. Including my hernia repair operation that I had on the day of my breast cancer diagnosis, this will be my fourth operation under general anaesthetic in two months. I hate having general anaesthetics. Having my life go past without any conscious experience of it unnerves me, and the thought of dying under anaesthetic frightens me. I want to be present at my death, to be able to welcome the moment of leaving this life. I am scared I will die tomorrow. As I walk along the beach I think of all the amazing support I have received from so many people over the last two months. My breast cancer is giving me such a precious gift. I have had so many people call and visit me and wish me well. I feel so loved. I feel content and at peace. In this moment I no longer feel driven to construct my life. I now know that my life is here. Perhaps for the first time I am truly satisfied with who I am, with my life as it is. A quote from a participant of one of Saki Santorelli's mindfulness workshops resonates with me:

The essence of it is to let yourself see how much clinging to how you want

your life to be is nothing more than a process of self-torture. Drop it, and allow yourself to fall openly and unguardedly in love with your life as it is and everything in it (Santorelli, 1999, p. 182).

I have an incredible feeling of peace wash over me. I realise I am ready to die. I would leave this life without any regrets. I have lived my life to the full and to the best of my ability. Although I would like to live longer to continue to experience the amazing miracle of human life, I am reconciled to the fact that I might die tomorrow.

Back in hospital again

I know the routine.

Remove my clothes and jewellery.

*All vestiges of my individuality replaced with the institutional
hospital gown, paper bloomers and cap.*

Sitting in my bed

feeling vulnerable

in my ill fitting gown gaping at the back. I entertain

a procession of experts.

*The anaesthetist's assistant, anaesthetist, surgical assistant, and finally
the surgeon who will cut into my flesh.*

Outside theatre

*I wait with five other patients corralled
into holding pens like animals
in an abbatoir
enclosed by fear and anxiety.
I scramble inelegantly onto the operating table
surrounded by instruments and bright lights
amid the bustle of everyone engrossed in their tasks
too busy to take any notice of me.*

*I feel the pain of the needle
in the back of my hand and the cold
liquid in my vein.*

*Then the discomfort of the
tube being removed from my throat
scraped and sore.*

*With gentle words
"Kay wake up
It's all over"
I have returned!
I have survived!
The incredulity of time past
without me. No memory of this lived experience!*

*The stench of anaesthetic fills my nostrils
and turns my stomach.*

*That night
alert and not able to sleep
an uncontrollable grief rips through my body.
I weep. As my body
mourns my breast that has been
cut away.*

Later I try to make sense of this series of operations. I decide to use clay to fashion this journey in which my breast was gradually cut away. I immerse myself in the sensation of working with the clay.

I fashion the gradual cutting away of my breast in clay. As I mould my breasts I focus on my relationship with the clay.

*Hard, grainy, rough
Immersed in water
You remain resistant to my touch*

*I rub my hands over you
And you give some of yourself to me
We are joined, connected – you provide a thin covering*

*I form you in my hands
Feel your softness
As you become supple with my touch
I make indentations with my fingers
It feels good.*

*Feeling the squelch of you
oozing through my wet fingers
sensuous oneness.*

*We join together
Each influencing the other
My wet hands squeeze your softness
Together we create a soft gooey mess
As we form the journey of the cutting away of my breast.*



Image 4.7 Cutting away of my breast

As I look at the sculptured shape I see that the last sculpted shape after the third bout of surgery looks like a crater — a pool of grief perhaps? But rather than being filled with deep dark liquid, this is a scooped out bowl shape, a hollow space, a container. I had imagined my chest to be flat but I now realize it is concave — a space for new things, a container for new stories. What stories do I want to place into this new space?

Reflecting now I wonder why I allowed myself to unquestioningly follow the advice of my surgeon and keep having pieces of my breast gradually cut away. It would have been so much less traumatic to have just had a mastectomy in the first place. But, as discussed in chapter two the scientific-medical paradigm of the medical system made it very difficult for me to be an equal participant in decisions around my treatment. Michael Foucault's analysis enables me to understand how the paternalistic scientific-medical paradigm enlists women into its ranks, so that although my surgeon is female I still felt disempowered and unable to negotiate with her on an equal

footing. As if I were a broken machine, I just handed my body over to the expertise of the surgeon for her to do what she thought best to fix me.

Before my first operation I create a plaster memorial of my left breast, and then a second after my mastectomy. As I place the wet bandages over my chest I feel the different texture, the softness of my right breast and the hardness of my now breastless chest wall. The feel of the white plaster as it hardens and encases my chest creates an armour of protection over my vulnerable scarred chest. When I place the first cast against my chest I feel the hollowed out space of my absent breast; the plaster cast accentuates the new concave shape of my left chest wall.



*Tracing the hollow.
Sensing space for new stories
behind the shadows.*

Image 4.8 plaster casts

Do I want to keep this hollow space for new stories or to reclaim my former body shape through a breast reconstruction? I can't decide. I run my fingers over the plaster casts feeling the hard slightly rough textured undulations casting shadows in different shades of white. I am reminded of a winter snow landscape. I have spent many seasons living in the snow, managing ski lodges and working on the ski patrol. As a ski patroller, one of our final tasks for the day was to sweep the slopes, which entailed skiing down each slope after the lifts had closed to ensure no one was injured or had been left behind. It was always my favourite time of the day, on the mountain as the sun was setting alone in the snow wilderness. One evening I found myself on top of the mountain in a complete white out. There was no one else around; the ski lifts had stopped so there was no sound. All my senses of hearing, sight, and touch were nullified. I had no idea which way was up or down, whether I was moving or still. I was completely enveloped in a thick white cloud – all was silent, still, white. I thought I was standing still until I crashed to the ground.

*Shadows of white shades
Swallow up sounds
and colours. All senses
nullified. In a fog
of unknowing.*

I don't know what to do. I feel broken and damaged. I am trying to come to terms with my changed body, with my scarred chest. I miss the way my body used to look and feel. I feel sad at the loss of my beautiful sensuous breast. My grief, like black liquid, seems to flood my entire body. I imagine the black liquid swirling through my body and pouring from my fingertips as I smother myself in black paint. Initially the sensation of the wet paint on my skin feels strange, it connects to my childhood of not being allowed to make a mess, to stay clean. Smearing paint all over my naked body, I feel rebellious, liberated. My body is the canvas of expression as, using my hands, I swirl the paint all over myself luxuriating in the feeling of immersion in the black paint. All my senses are alive and attuned to the act of painting my body, every crevice and bulge; my muscles contract as I shift positions. I became aware of time passing through my skin; it begins to feel prickly and tight, as the paint starts to dry and crack. Like the black paint, my grief sticks to me.

As I smear the black paint over and around my breast it feels sensuous, erotic. My chest wall, where my breast has been cut away is just a flat hard surface, without a breast it holds no sexual or sensuous energy for me. This takes me completely by surprise. I feel weighed down by grief. I miss my breast: my breast that was once perky and then gradually sagged a bit with age, that provided my body with a symmetrical beauty. I feel asymmetrical, unbalanced. I feel an overwhelming sense of sadness and loss. My breast is strongly connected to my sense of sensuousness and sexuality; without it I feel incomplete. I want to reclaim some feeling of sensuousness for my scarred chest.

Many other women, who have written of their breast cancer experience, have also identified their breasts as playing a critical part in their sense of their sexuality (DeShazer, 2008; Kohlman, 2005; Lorde, 1980; Ostriker, 1999; Tait, 1990). How do I regain a sense of completeness? How do I reclaim my sensuousness? Having a breast reconstruction is offered as a pathway to, not only reclaiming my former feminine sexual self, but to my complete recovery. Responding to the dominant discourses that frame my one-breasted body as incomplete, abnormal, and disabled (Cromptvoets, 2012; Ehlers, 2012; Garland-Thompson, 2002), I feel a sense of shame in my new body shape. Should I have a breast reconstruction? Will this make me feel more complete?

Women, most often cite this sense of incompleteness and loss of sexuality, as the reason they choose to have a breast reconstruction. Samantha Cromptvoets (2006a, 2006b) found that the women in her qualitative study were encouraged to have a breast reconstruction to restore their lost femininity, sexuality, and normalcy. They described their bodies as "different, abnormal, and personally and publically unacceptable, an interpretation confirmed by the surgeons they visited" (Cromptvoets, 2006a, p. 90). However, many women report that breast reconstruction does not restore their former sense of sexuality. They still have to come to terms with their "new" breasts, which sit differently on their body, feel different, may or may not have a reconstructed nipple, have little or no sensitivity and may have left scars in other parts of their body (Cromptvoets, 2006a; Ehlers, 2012; Kasper, 1995).

I don't know what to do. Feeling myself dominated by the "restitution narrative" (Frank, 1995) that pervades the medical construction of illness,

I experience a sense of urgency to get on with my life, to get back to how I was, back to work, back to swimming, back to socialising. As a newly single woman in my mid 50s I feel like I am running out of time; time to re-establish my life, time to find a new partner. I feel pressured, by medical personnel, acquaintances, breast support services, and my own tendency to rush forward into my life, to make a decision about whether to have a breast reconstruction. But within this vortex of urgency I feel stuck in indecision and confusion.

How can I move out of this place of stuckness? I feel overwhelmed, lost and exhausted, my grief like a leaden weight weighs me down. I lower my painted body onto a large piece of white paper. It feels good to rest for a moment allowing the paint to transfer from my body. As I peel myself off, the stickiness of my painted skin slowly separates from the paper, in places it has become quite stuck and takes some effort to break the painted bond. It reminds me of the feeling of peeling the bandage away from my chest wound. The printed images follow the landscape of my body, the mounds and hollows as well as the limitations of my skeletal structure.



Image 4.9 Hurling into my future

Image 4.10 Beseeching desperatness



*Black grief weighs me down
Help me.
I am frail, vulnerable, insubstantial.
I do not want to be smothered
by this blackness.
Help me.*

I ask a friend to take photos of my painted body, the paint providing a cloak for my insecurity. Having another person view my changed body, brings an additional element of vulnerability and exposure. I strike different poses, self conscious in the eye of the camera lens. In revealing my right breast I am aware of societal prohibitions around covering my breast from public gaze; it is private, intimate, sexual. Without a breast my left side holds no sexual or sensual energy, it is just a hard surface. Covered in paint, the scar is not visible, it looks like the chest of a young boy or young girl. I feel no need to protect it or be aware of any need for discretion. My body feels asymmetrical. It seems to express two different sexualities. My right side, with my breast intact, holds my womanly sensuality, while my left side with its flat chest wall feels genderless or perhaps prepubescent.

I feel confused as to how to present the ambiguity of my one-breasted body to the world. My right breast signifies me as female, feminine, sexual, while my flat left chest wall marked only by a scar, looks neither female nor male. As a young child I loved the freedom of running around topless in the summer and felt the social prohibition to cover up my developing body as another tiresome burden of my female gender. I have always resented the sense of constriction around my chest that wearing a bra brings, and have only worn one as part of my public professional persona, always stripping it off with relief as I enter my home or go about my personal life. The freedom to not wear a bra in public now comes with the complication of presenting my new asymmetrical ambiguity to the world. If I don't wear a prosthesis, will my noticeably absent breast be read as a political statement in the tradition of Audre Lorde (1980), who called for women with breast

cancer to proudly show the reality of their mastectomised bodies as a form of solidarity in challenging both the societal imposed stigma of shame in their non-normative bodies as well as the role of corporate culpability in their cancer. She writes, "I refuse to have my scars hidden or trivialised behind lambs wool or silicone gel. I refuse to be reduced in my own eyes or in the eyes of others from warrior to mere victim (Lorde 1980, p. 60).

But by choosing to be comfortable in not wearing a prosthesis, I no more want to be perceived as a warrior to a cause, as I want to be seen as "copping out" to stereotypical norms of femininity when I choose to wear one. Who would have thought that the decision to wear or not wear a prosthesis could bring such loaded political baggage? Sarah Lochlann Jain (2007) also talks of her confusion of how to present her one-breasted reality to the world:

I did not want to be coded as making some permanent radical political statement. But the prosthesis was uncomfortable: it was unwieldy and troublesome to keep track of throughout the day. So I did not want to have to wear a prosthesis just to seem as though I were not making a statement. One breast seemed to force me into permanent warrior status. (p. 512-513)

She eventually resolves the dilemma caused by her asymmetrical appearance by deciding to have her second breast removed. However, this does not seem a real option for me. I enjoy my remaining breast too much to think of sacrificing it in the pursuit of presenting to the world a symmetrical appearance or clarity around my political views.

As I look at the photos of my painted body I am drawn to a series that highlight the space of my absent breast painted in black encircled by a sweep of white. I crop one of the photos of my chest focusing on the painted black space previously adorned by my left breast. This image of the black space seems to distill my feelings of grief and loss, powerfully painted onto my body. Gazing into the inky blackness, I feel transfixed, as I try to see meaning in its murky depths. The more I gaze the less I see — nothing is reflected — it's a black hole absorbing all the light holding me in its icy grip.



Image 4.11 Red breast and black hole of grief

*I peer into the white rimmed
black space.
Where my left breast used to be
now looks empty
bottomless
black.*

*My rounded breast
punctuated by a nipple
dripping in red paint
proudly adorns my right chest
It has such beautiful symmetry, sensual shape
just the right size
to be gently cupped by a hand.*

*The concaved black emptiness
stares out at me
like an unblinking eye.
A large black pupil
holding hidden depths
of unknown meaning*

I go to an exhibition of Albert Tucker, a notable 20th century Australian painter. The paintings are very dark, depressing depictions of the senseless horror of war with many images of men with horrendous injuries. Staring blankly with tears streaming down my face I feel surrounded by death as I face my own fear of dying and the futility of life. At the gallery I had also seen an exhibition of concrete poetry in which the typographical arrangement of words is as important in conveying the intended effect as the conventional elements of the poem. I decide to use this form to further explore the black hole of grief image.

I hand write "black hole of grief" in continuous circles starting with small writing and moving out in ever increasing size. I repeat it creating several versions. I then type black hole of grief over and over in ever-increasing font sizes and stick the individually cut out letters to form concentric circles. Over several weeks I create a large one-metre square three-dimensional version of this concrete poem. Using foam board and wood I cut out the letters comprising black hole of grief in nine decreasing font sizes. I then hand paint each letter in black paint before sticking them down. It is painstaking fiddly work, particularly when I get to the very small letters, but it brings me a sense of control as I feel like I am doing something to move myself out of this black space. Rather than just feeling stuck in my emotional pain the physical act of cutting, painting and sticking on the letters provides me with a sense of moving forward.

The process of creating these concrete poems is meditative and hypnotic; repeating the phrase black hole of grief becomes a mantra for mindfully

being in this moment of creation. The letters get stuck to my fingers with the glue. This seems to be a constant theme having the black sticking to my skin.

As I contemplate this image I feel myself being drawn into the centre of this black hole into this all seeing black pupil of an unblinking eye. It reminds me of a full stop. I am frightened of being absorbed by the blackness, but as I feel myself being drawn inwards I also experience a sense of letting go. Perhaps I can rest in this black space for a while.

Full stop
Full. Stop! Stop full. Stop fully, Stop!
Filling while stopping
Stopping to full
Stop full
Full
Stop.

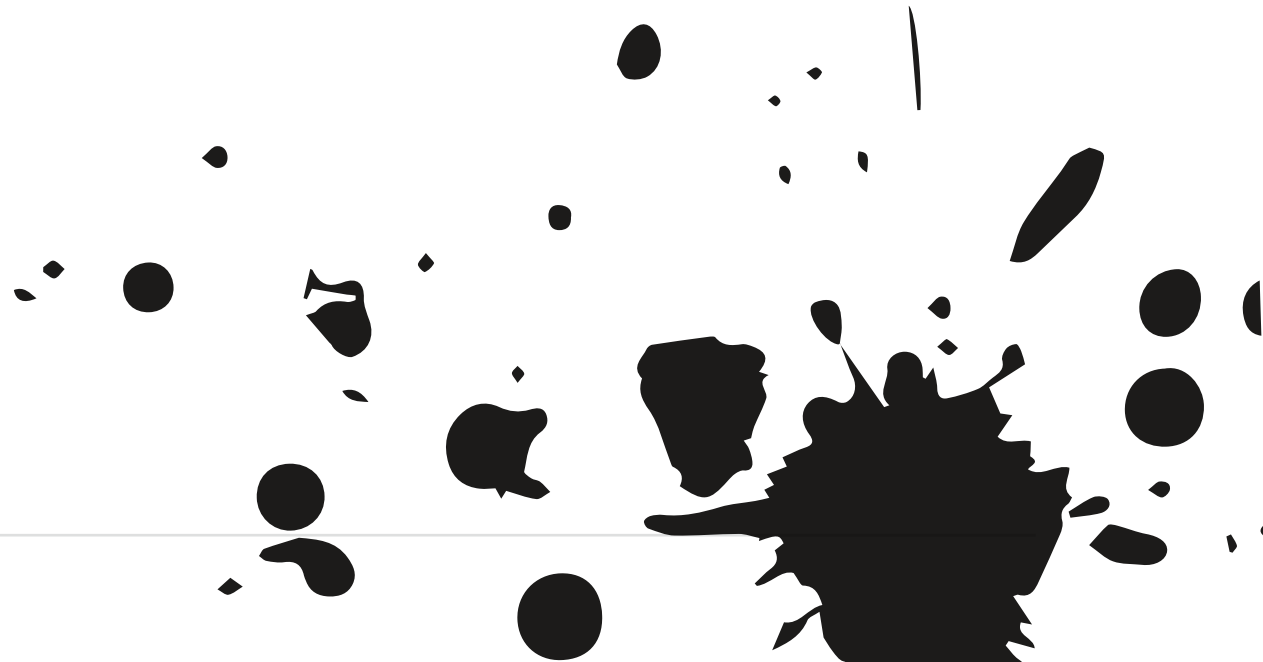




Image 4.12 Black hole of grief concrete poem

Stuck in black
stuck in grief
Grief at the loss of my nipple
the loss of my breast
the loss of my sister
the loss of my home, my dog, my cat, my garden.
the loss of my friends, my connection to community.
Grief at the loss of my envisioned future of growing old
in intimate companionship
with the father of
my children.

Stuck in black
Stuck in fear
fear of dying of cancer
fear of falling back into deep depression
fear of growing old alone, without an intimate partner or
financial security.

How do I drag myself free
of this blackness?

Detailed description of an enquiry

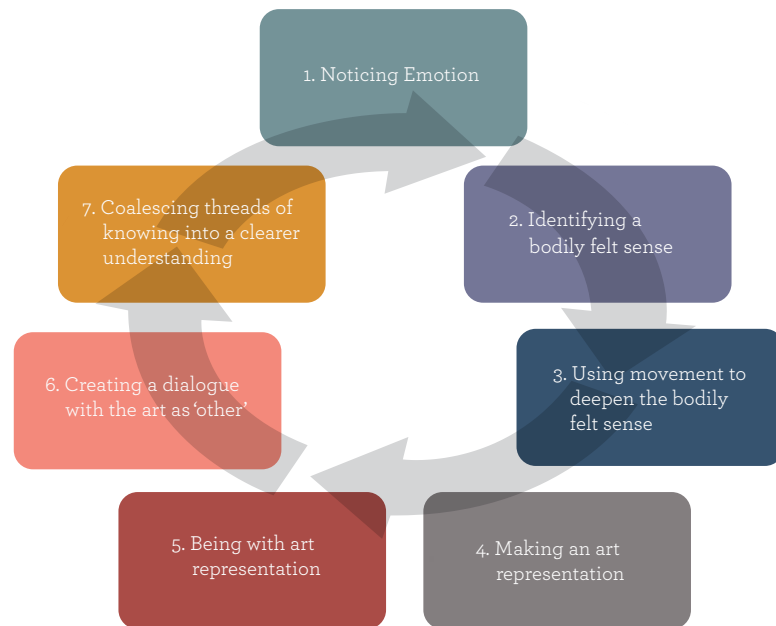


Figure 3.5 Cycle of Enquiry

I have included a detailed description of one of the many enquiries I undertook following the seven steps as described in chapter three and illustrated in Figure 4.1. As part of my doctoral program I had the opportunity to work, on a regular basis, with several other students in experiential workshops, in which we used arts-based enquiry processes, to explore our topics. The image of a close-up of my painted chest

highlighting my absent breast, is especially significant for me; it seems to hold so much power and calls me to continually explore it using a range of modalities. I decide to use the opportunity to work with a companion to further enquire into this image.

1. Noticing emotion

In the quiet attentive presence of my companion/co-enquirer I sit looking at this image, I feel myself drawn into the depths of the black space. I feel an overwhelming sense of sadness and loss and feel afraid of being overwhelmed by my grief.

2. Identifying a bodily felt sense

My companion asks me if I can describe the emotion, if it has a colour or texture, and if I can locate it in my body? I describe it as a great big black hole in the centre of my chest. I feel like I am hollowed out and filled with blackness. My insides are being swallowed up by this blackness. It feels like soon I will be just a shell filled with black liquid.

3. Using movement to deepen my bodily felt sense

With my eyes closed, I bow my head and cover my face with my overlapping hands. I feel my warm breath as I breathe through the spaces between my fingers. I bend over trying to protect my chest from the world. Bending over I sway slightly backwards and forwards from my toes to my heels. I visualise the black liquid slurping through my body as I transfer the weight in my feet from my toes to my heels, and feel my breath as it moves through my hands.

The weight of my body sways me backwards and forwards. I am unable to move in any other way.

4. Making art representation

I continue the rhythm of my improvised movement by tearing newspaper into small pieces, and start to form a paper maché sculptural landscape. As I tear the newspaper, my hands become covered with black newsprint, which then smudges over everything I touch, leaving behind a black stain. I dip the torn scraps of paper into the paste and place them on top of each other gradually forming a concave shape and two mounds. The newspaper scraps stick to my paste covered hands. It feels uncomfortable. I want to wash my hands clean. As I mould the wet paper pulp it gradually forms into a landscape with breast shaped hills and a sculpted hole. I use coloured tissue and cellophane paper to further define my landscape sculpture. I try to find some material that will represent a sense of depth in the concaved hollowed out shape. I layer dark blue and black cellophane and at the last moment grab some multicoloured sequins, which I sprinkle over the cellophane.

As I wash the glue and black newsprint from my hands, I reflect on how the black keeps physically sticking to me, whether it is black paint, newsprint, or charcoal. It takes so much effort to remove this black from my body. I feel like I have a film of black always clinging to me.

5. Being with the art representation



Image 4.13 Waterhole landscape



Image 4.14 Close up of waterhole

With prompting from my companion I describe my sculpture in detail. I am drawn to the deep blue concave shape. As I gaze into this I am reminded of deep still black waterholes in the Kimberley region in north-western Australia, where I have spent some time. These waterholes seem alive with the spirit of the land and of elders past, rich with dreamtime stories containing ancient wisdom still relevant to a contemporary world. The scattered sequins in the dark hole of my sculpture seem to represent the jewels of knowledge contained in these mysterious waterholes. I feel myself drawn into the dark hole of my sculpted landscape, to explore the mystery and to seek wisdom. Will I have the courage to dive into its murky depths, to seek the knowledge and wisdom held there for me?

6. Creating a dialogue with the art as other

My companion assists me in dialoguing from my waterhole sculpture. I immerse myself into the sculptural landscape. She asks me if I want to enter into the “water” and speak from there. I move closer. I lean over the edge. I can just make out my reflection; it distorts with the slight ripple on the water surface. I try to see below the surface, but all I can see is blackness; the water sucks the light into it and swallows it up. What am I trying to see? I touch the cool water. Am I brave enough to enter it? Will I drown? Will I sink to the bottom of this blackness? I am afraid. I am scared I will die if I enter the waterhole. I will be sucked down and engulfed by the black water.

As I imagine being swallowed up by the black water, I suddenly realize I know this place. It is not new to me. I have been here before. It reminds me of my place of depression. My companion’s compassionate presence encourages me to describe my experience of depression. I have struggled with depression since I was 19 years of age. The black blanket of despair envelops me from time to time. For most of my adult life I have lived with this dark visitor, struggling through as best I can. This waterhole sculpture powerfully brings my experience of depression back to me. When I am in the grips of depression I feel like I am stuck down the bottom of a very deep well, in deep sticky mud. I cannot move. It covers my mouth and reaches to my nostrils—just my nostrils and the top of my head are above this black sludge. I can just breathe. It is dark and cold and still; no noise reaches me. I feel like I am buried alive. When I look up I can just see a pinprick of light, the well opening, it so far away though. The task of climbing back up to this opening seems impossible. But the small pinprick of light sustains me. My feeling of grief about the loss of my breast feels like my experience of depression.

While my companion moves away to create an intersubjective response that will capture the essence of our exploration into my art representation, I re-experience this memory of being stuck in depression and write this poem.

The Black Well of Despair

*Stuck up to my chin in black oozing mud
just enough clearance
to breathe.*

The rancid stench of decay fills my nostrils.

The taste of death in my mouth.

*Raising my eyes, I can just see the pin prick of light
far above me.*

*I am down, deep down
stuck in this deep well of despair.*

*I hope,
one day I will
have the strength to climb out.
To make the tortuous journey
back up.*

Back up towards the light and rejoin the living.

But for now, I am stuck.

*Stuck here
in this deep black well of
despair.*

This feeling of being stuck in black oozing mud that I have associated with my former experiences of depression resonates with how I am feeling now as I struggle with my feelings of grief over the loss of my breast and my sense of stuckness about whether to have a breast reconstruction. I feel stuck and overwhelmed. I just want to curl into myself and shut out the world. Getting back in touch with my experience of depression is scary. I never want to go back to the bottom of that deep black hole.

My companion provides me with a painted response.



Image 4.15 Isle of curvaceous sensuousness

Looking at her image I am immediately drawn to the black circular shape. All I see is the black shape that reflects my image of the black hole painted on my body.

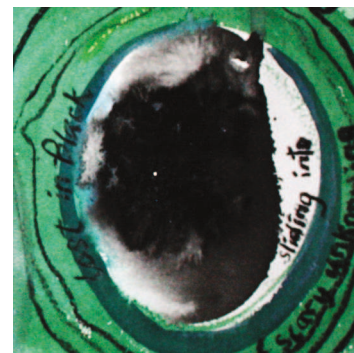


Image 4.16 Isle of curvaceousness detail



Image 4.17 Black hole of grief

Around the black circular shape she has written the following words "Place of strong emotion, looking in, depth of scary unknowing, lost in black, sliding into." Receiving her creative response I feel truly understood as she has captured so graphically my fear of sliding into the blackness. A companion's response through another multi-modal representation can be a powerful way to focus the data, introduce another avenue of enquiry, or allow new meaning to emerge. At the time it focused my data to the centrality of continuing to explore the black hole of grief.

Looking at her response now I can see that she was also trying to provide me with the opportunity to progress my enquiry to embrace a movement from the black to a place of transformation through arising to the light, as written on the other beautifully coloured circles. However at the time I was not ready to move from the place of blackness. It was not until two years later that I noticed the two beautiful light-filled green and aqua circular shapes in her image. This provides a good example of the

power of a multimodal creative intersubjective response. The ambiguity of the creative form provides an offer that allows the space for me to respond in the way that is right for me at the time. As this response was in a form that I could keep it also provided the opportunity to respond differently over time. Several years after receiving this response I was finally in a place where I could see the beautiful images of transformative light and this resonated so strongly, in terms of the colours, words and shapes with my experience at the time that I feel I must have been carrying this full image on the edge of my awareness. Still later when I am discussing this response with my companion who created it for me she tells me that she included the beautiful places of transformation as I had been speaking of these. I had not retained any memory of talking about these light filled spaces. This is another example of the importance of having a witness.

The next day, as another intersubjective response, my companion sends me a link to a video of a man free diving over 200 metres into a deep black hole and then resurfacing towards the pinprick of light above (www.youtube.com/watch?v=uQITWbAaDxo).

This video recording captures my memory of feeling sustained by the pinprick of light far above me when I have been stuck in the black hole of depression. The feeling of being understood by my companion, shown by her intersubjective responses, is reassuring and gives me the courage to keep exploring the black. After viewing the video recording I create a poetic response.

*Diving into the black unknown
Fear of submersion
into the mysterious depths.*

*Lungs screaming
I'm drawn back to the pull of the light
My body makes the ascent
sucking in the air*

7. Coalescing the threads of knowing to new understanding

This enquiry into the image of the black hole of grief has brought to the foreground my fear of falling into depression. My feeling of overwhelming grief at the loss of my breast encapsulated by this image resonates with my experience of being depressed in the past. The feeling of being stuck in the black feels very similar. However, my breast cancer gives me a reason for this feeling which makes it less scary than my experience of depression. I feel like I have more control and although I feel stuck, I feel like I can gradually find my way out of this blackness. In the past when I have been depressed, having no clear reason as to why I should feel so black, and not knowing how long it would last made it much more frightening. I had thought I was frightened of dying of cancer but I now realise that my fear of the living death of depression is far greater. My grief feels so big and I am scared of falling back into the blackness of depression. I feel stuck in indecision about whether to have a breast reconstruction; stuck in the black ooze of grief and fear. I create an image and a poetic response in an attempt to hold my current understanding.

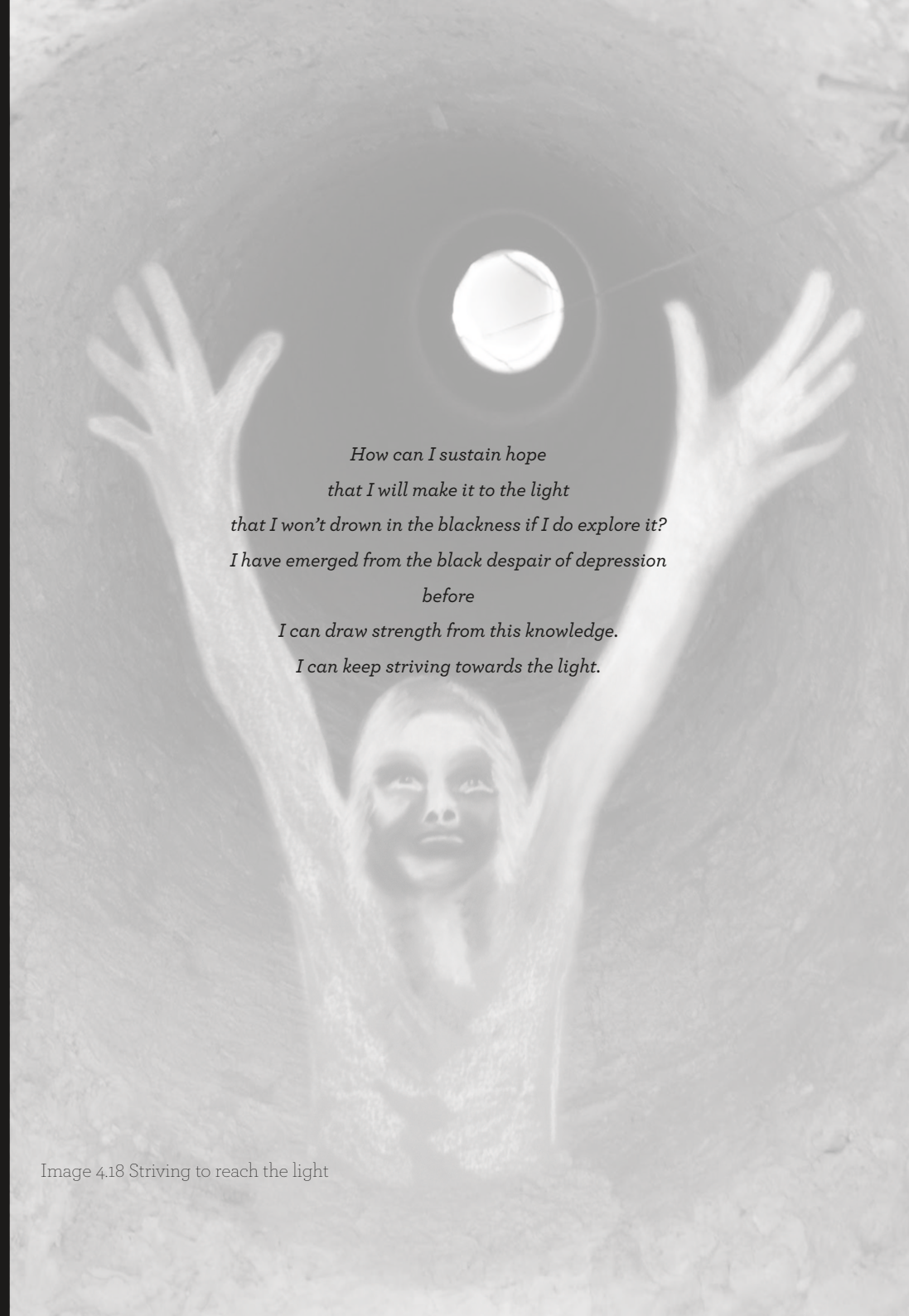
*I miss my breast.
My grief feels like a big black hole in my chest.
It feels so big.
I am afraid it will engulf me
I will dissolve into its blackness and disappear.
Can I muster the courage
to explore this blackness and
discover some rich wisdom?*

*This blackness reminds me
of my past experience of depression.
I am terrified of falling back
into the black despair of depression again.*

*If I have a reconstruction
get another breast made, perhaps
I will feel less sad, less stuck?
But I feel driven to explore this black
to discover new strength and wisdom.*

*How can I sustain hope
that I will make it to the light
that I won't drown in the blackness if I do explore it?
I have emerged from the black despair of depression
before
I can draw strength from this knowledge.
I can keep striving towards the light.*

Image 4.18 Striving to reach the light



Conclusion

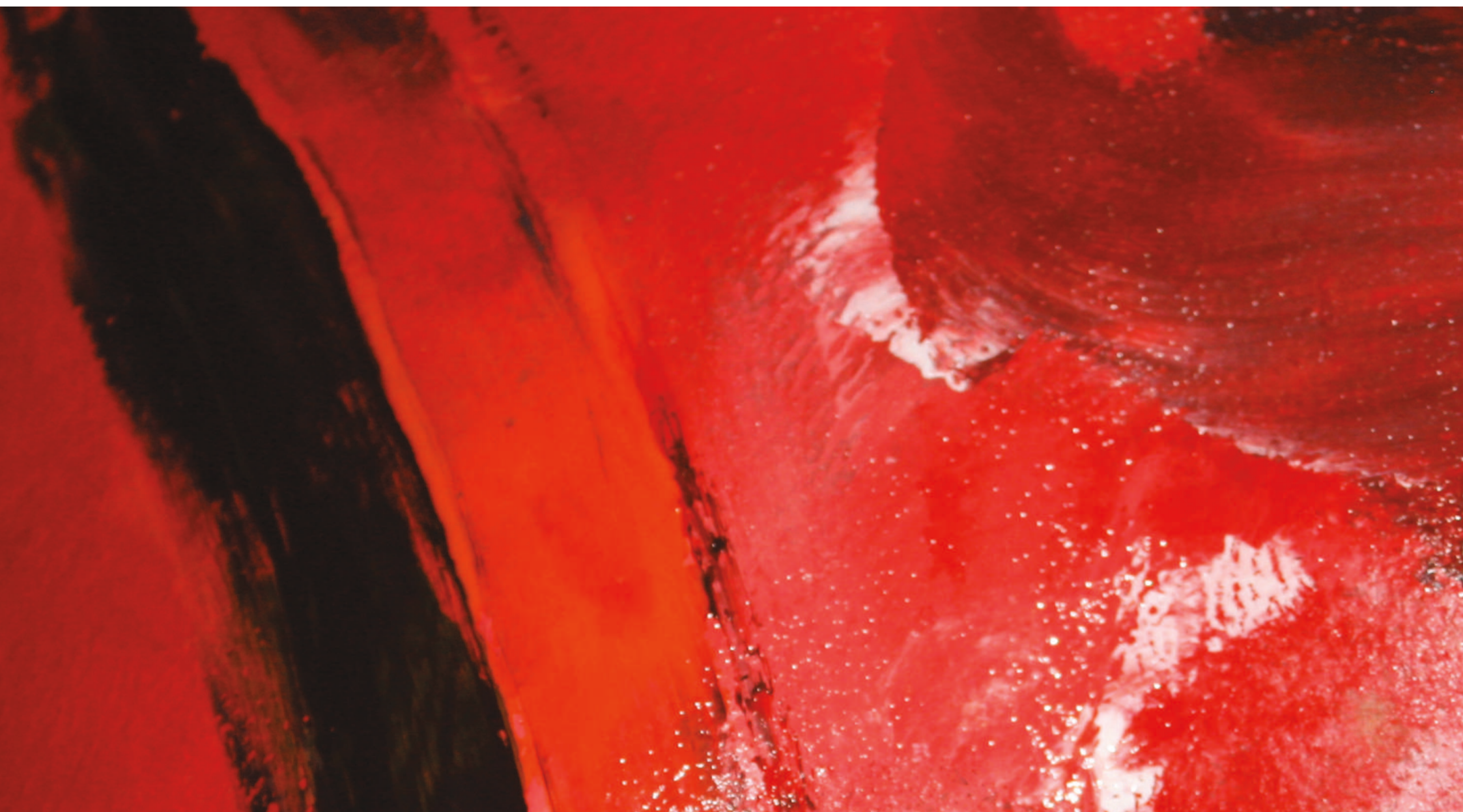
Based on the process I have described in detail above, I developed a narrative compiled from the numerous enquiries I undertook into my feelings of grief following my breast cancer diagnosis and treatment. I considered following medical advice and having a breast reconstruction, in the hope that this would make everything better, but I wasn't able to take this action. I felt stuck in indecision. Stuck in fear and grief. After having numerous operations the thought of another one was frightening, but being in the black space of grief and loss was also frightening. Using an arts-based enquiry process to explore whether I should have a breast reconstruction threw me into an exploration of bigger existential issues such as confronting: my grief and survivor guilt over my sister's death; my own fear of dying; and the fear of falling into severe depression again.

Unable to clearly articulate what I was feeling, but wanting to find a way out of the painful feeling of being stuck in the blackness, I felt driven to keep returning to my art-making as a way of shifting the black heavy weight and coming to some new understanding of my experience of breast cancer. Using different modalities enabled me to keep returning to the exploration of these feelings, approaching them in a slightly different way. Like Jeanine Minge (2007) who explored her experience of rape using different modalities, I also found the fusion of different modalities enhanced my embodied knowing. For example being highly attuned to the act of painting my body allowed a heightened sense of openness in engaging with the body prints I then created. Through a cycle of continuous exploration using different modalities, a

gradual awakening of new understanding about my lived breast cancer experiences emerged.

It was while immersed in my grief that I confronted the "tyranny of cheer" (Ehrenreich, 2001) of the dominant breast cancer narrative symbolised by the colour pink. I didn't feel cheerful, or thankful that I had breast cancer. I couldn't celebrate my survival by dressing in pink. I felt scared, sad and alone, the fact that I couldn't see my experience reflected in the world, made me feel even more alone. In the next chapter I explore the anger I felt at not having my breast cancer experience seen or acknowledged.





Chapter five

Red



I plunge my hands into the blood red paint
wet and viscous turning to a stickiness as it
touches my naked skin.

I bring my blood, my visceral femaleness to
the surface.

Introduction

My exploration in the previous chapter revolved around the colour black and was focused on my journey into the black hole of grief, fear, and depression. I felt like I was enveloped in this black space, alone and frightened. I was brought out of this immersion in the black into the public space of breast cancer discourses when I was confronted by the pink lady breast cancer symbol. This pink symbol had a major impact on my lived experiences of breast cancer. My anger at feeling as if I were being constructed as a *straight* stereotypical woman of the 50s, led me to submerge myself in making art dominated by the colour red that expressed the visceral nature of my experience and was a direct challenge to the pink I confronted everywhere. Driven by my feelings of outrage I undertook numerous enquiry cycles using photography, body painting, body prints, tissue paper image, painting and collage dominated by the colour red. As in the previous chapter I have included a creative synthesis from the findings of these enquiry cycles as well as a detailed description of one enquiry cycle.

*Red is the colour of my breast cancer,
Red blood pours from my wound,
Red is my anger.
the colour of menstrual blood,
of birth,
Red is my shame, strength and passion.*

My anger is triggered when I confront a giant inflatable of the pink lady breast cancer logo of the Breast Cancer Network Australia (BCNA), surrounded by lots of small pink lady cut outs planted in the garden in Melbourne city centre. It is part of a promotional campaign by the Berlie Lingerie Company for their newest lacy underwire bra guaranteeing “enhanced lift and cleavage”. Fittings are available, and women are being encouraged to purchase bras out of a sense of concern for their sisters with breast cancer; 10% of the takings are being donated to breast cancer research. As the giant inflatable pink lady towers over me, I feel small and vulnerable, and also angry, angry that breast cancer is being used to promote a product that is no longer suitable for me to wear now that I have only one breast. I am surprised at the raw energy of my anger. How dare they use breast cancer to sell sexy lacy bras!



image 5.1 inflatable pink lady

*Passive pink
insidious loading
of traditional femininity.*

*Pink lady,
symbol of breast cancer,
with upturned bob
pretty flared dress
and no breasts
towers over me.*

*I feel small and vulnerable
Angry sad, tears behind my eyes.
Pink lady logo
no hands
or feet,
immobilised
in her pretty girlish 'pinkness'.
At the supermarket
I photograph 'Pink stuff'
to make a collage
pink egg cartons,
pink capped bottled water,
pink toilet paper,*



image 5.2 pink stuff collage

*pink packaged milk, food products, make up, toiletries, hairdryers, curlers,
even pink buckets and mops.*

Everywhere pink breast cancer ribbons.

*Exploitation of people's concern makes me feel
demoralised and used.*

I feel even angrier when, leafing through the BCNA magazine, I come across a photograph of a beautiful full-breasted young woman wearing a bikini and pink sarong. The sarong is being advertised as a product to be purchased in support of breast cancer fundraising. I can't believe the insensitivity of this image in a magazine aimed at supporting women with breast cancer, women who no longer have perfectly shaped breasts. If the major breast cancer support network in Australia promotes this pink marketing with so little concern for the impact on the women they are supposedly helping, where could I go to feel supported? I leaf through the BCNA newsletters and angrily tear out images of the pink lady logo, which I use to create another collage card.



Image 5.3 Breast cancer promotion.



Image 5.4 Pink lady collage.

*I am overwhelmed by pink
 My world is being taken over
 by these multiplying pink ladies, who swallow
 all before them.
 I feel mocked
 by their one dimensional
 superficiality.*

Because the pink lady symbol is used to raise money for breast cancer research, I feel churlish criticising this image. I want to fight against this pink and all that it symbolises. I feel alone in my anger at this pink wave of passive femininity devoid of the beautiful passion, intuition, and wisdom of women. I need to find a new way of being in the world, but I don't fit in this pink "Cancerland". In her essay 'Welcome to Cancerland', Barbara Ehrenreich (2001) vents her anger at the cancer culture of apolitical cheer in which "cheerfulness is more or less mandatory, dissent a kind of treason" (p. 50), in fact, she contends, this cheerfulness "goes beyond mere absence of anger to what looks, all too often, like a positive embrace of the disease" (p. 48). This pink breast cancer culture offers enticing performative acts including fun runs full of pink, wearing pink hats and pink wigs, to special sporting events designated as breast cancer events, and engaging in retail therapy by purchasing endless pink branded paraphernalia, while all the time "cheering on cancer and feeling good about it" (Bode, 2010, p. 95).

My anger, linked to my sadness and sense of disempowerment about feeling exploited, feels enormous and a bit scary; it fills my whole body. I create a final collage card that seems to epitomise my feelings dressed up in shades of pinks, reds, and purples.



Image 5.5 Fighting the pink

As I look at this collage I am struck by the fact that none of the figures have eyes. To me it has become an image filled with blind anger and violence; rage without any clear intention. My anger seems out of control, big and scary; it makes me feel small. I wonder why it seems so big. I then realise it is about not being seen. My experience feels so different from the one promulgated by the breast cancer industry represented by the pink lady symbol. I do not fit the stoic polite pink mould. My surgery has left me feeling assaulted, with my breast cut off. I see none of my experience reflected in this pink world. Invisible, unacknowledged, small, and alone, no one sees me. How dare they not see me! It is from this sense of invisibility that my anger arises. My anger

is big but it doesn't help me to be seen so I still feel small and vulnerable. The public face of the pink marketing public relations campaign is largely a coalition of well-meaning fundraisers, often breast cancer survivors or people affected by the deaths of loved ones. In the U.S.A. the Susan Komen Foundation is the most powerful representation of this movement, while in Australia it can be seen in the BCNA's pink lady campaign. Although I acknowledge some of the benefits of raising funds and awareness in relation to breast cancer, I chafe at the way it is done. I wonder at the cost of promoting strong messages of how women should journey through breast cancer.

Surfing the web I come across a blog, (<http://accidentalamazon.com>) written by an American woman, Kathi Kolb, who has had a mastectomy. Reading her outraged polemic on the pink branding of breast cancer in the U.S.A. I feel connected, at last, to another woman who shares my experiences. I no longer feel quite so alone in my outrage at the pink. Writing in her blog she highlights a new low in the exploitation of women's experience of breast cancer in selling breast enlargements in the name of breast cancer awareness.

Riding across New York in a vehicle dubbed the Boob Bus by Pornhub. com, adult film star Bree Olsen and a team of medical professionals offered free breast exams to women. The medical professional was a plastic surgeon who specializes in cosmetic breast surgery (Kolb, 2012, 4 May).



5.6 Image of boob bus

I become even more incensed when I discover that, despite its cheerful call to raise money for breast cancer research, by having fun and spending money on pink “stuff”, this campaign is orchestrated by powerful behind the scenes players of, pharmaceutical, and chemical corporations as well as biomedical research organisations (King, 2006; Potts, 2000). The Breast Cancer Awareness month of October, which started in Britain in 1985 and has now spread across the western world, was the idea of Imperial Chemical Industries (ICI) and is now largely managed and controlled by its subsidiary, Zeneca, a multinational chemical/pharmaceuticals corporation (Potts, 2000). Zeneca is the fourth largest producer of pesticides in the U.S.A. and also manufactures tamoxifen, the most widely prescribed breast cancer treatment drug; the corporation also owns a management company that runs a chain of cancer care centres in the U.S.A. (Klawiter, 2008).

This highly effective public relations campaign has focused attention on detection and treatment thus expanding the market for treatment drugs and cancer care centres from which the company profits, while also concealing that the company and its allies also profit from producing pesticides which have been identified as a possible cause of cancer (Klawiter, 2000). But if you asked any of the millions of women fighting as pink crusaders against the battle of cancer by participating in the thousands of activities, under the banner of October Breast Cancer Awareness Month, most would be unaware of the more sinister origins of this promotion campaign.

How do I vent my anger at this pink exploitation without being seen as a

conspiracy theorist or as ungrateful for all the money raised for breast cancer research? I want to strip the sanitised white from the pink to reveal the beautiful rich blood red. My anger is red. It swells through my entire body, suffusing every cell. I plunge my hands into the red paint; it drips from my fingertips as I cover my pinkish skin in blood-red paint.

*Open, vulnerable, raw,
red rawness of meaty flesh,
not the soft pink of a baby's bottom,
but the red of blood, of my gaping wound.
Tear off the pink veil of submission, of prettiness.
Rip up the dainty pink ribbons that constrain, control.
Break free of this pink construction of an idealised woman
and liberate my blood red
amazon warrior.*

*One-breasted female warrior
ready to fight,
to tear down the pink structures of confinement.
I am raw, powerful, see my bloody red wound!
I want to be seen, to show my scars proudly
as an initiation into womanhood
leaving behind the pretty submissive
little pink girl.*

*I do not need to have people feel sorry for me,
pity me,
see me as powerless,
submissive, quiet, non-confronting.
I can be a proud blood red amazon woman
free to be who I want to be.*

There is something scary and shameful about blood. Blood signifies the female. Blood initiated me from innocent girlhood to womanhood. It seemed like all the carefree joy of childhood disappeared with those first drops of menstrual blood. The summer I turned 12 I started bleeding. Although I had two older sisters I had no idea what was happening to me. I was scared and ashamed. For a week I lived in a nightmare of fear and anxiety, hoping it would stop until one morning I bravely confessed to my mother. In a matter-of-fact fashion, she showed me how to put on a sanitary pad, and thrust a book about reproduction into my hands. And that was my welcome into womanhood! Throughout my adolescence I was conscious of hiding my blood, forever fearful of the humiliation of leaving a red bloodstain on the back of my school dress. I was initiated into the female shame of blood. At childbirth blood accompanies life, but the baby is whisked away to be cleaned up and re-presented cleanly washed and wrapped, free of all the blood and mess of the birth miracle. We learn so early of the shame of our female blood. So perhaps it is no surprise that our experience of breast cancer is packaged in polite pink.

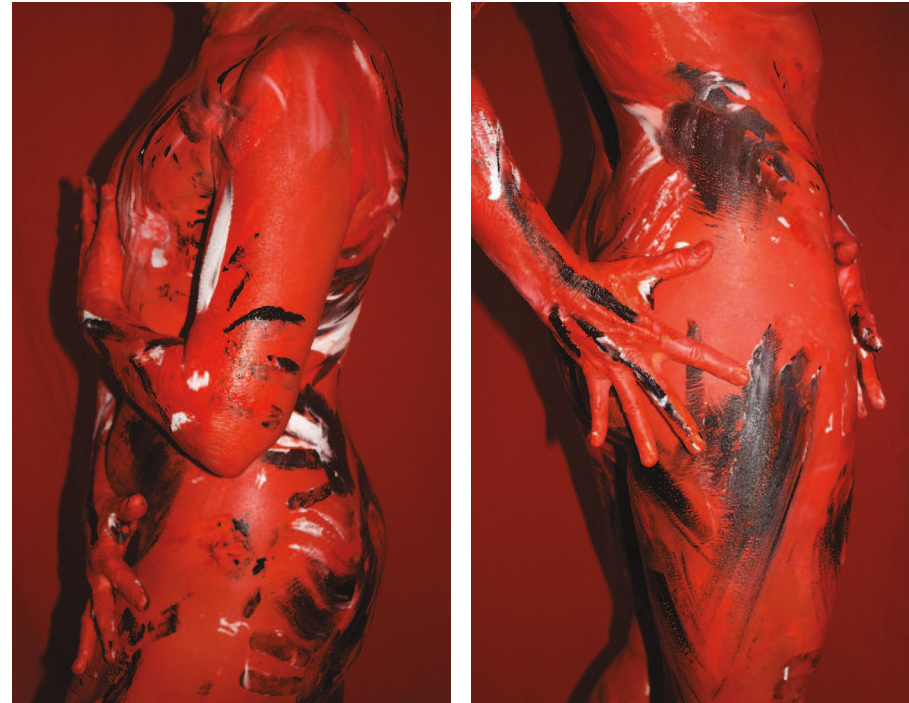


Image 5.7 & 5.8 Red painted body

As I gaze at these images I am struck by the beautiful strength conveyed by my red painted body. Although I feel a sense of vulnerability in revealing my nakedness, I also feel proud in revealing my painted body.

*Proudly adorned in red.
My passion, my visceral womanhood,
my blood,
my pain, my anger on show.
I will not be covered by society's
polite expectations.*



Image 5.9 Release

The process of painting my body red and imprinting it on paper enables me to connect with my anger and experience a sense of release as the red paint transfers from my skin to the paper. No longer feeling my anger as a separate huge overwhelming presence that threatens to engulf me I now feel connected to its energy and the possibility of movement. My art has given me a voice to express my anger. I had felt silenced by the prevailing view of

how women with breast cancer should act. I felt that I should feel grateful that I had survived, that I should celebrate my good fortune and, dressed in pink, present a happy cheerful face to the world. I should not express anger, as this negative emotion might jeopardise my recovery.

The promotion of a nineteenth century ideal of the angelic woman, who is expected to submit unquestioningly to adversity and to suppress rather than express justifiable anger is a key aspect of the pink discourse. Like other women with breast cancer, I confront the pressure to adhere to the quest of medicine and health care to stay positive, be courageous, be in control of my emotions, and to suppress any discussion of the possibility of death as this does not fit with the pursuit of survival (Batt, 1994; Broom, 2001; Hart, 2003). Whenever I try to express my anger at having breast cancer I feel myself silenced. I relate to the views of Barbara Ehrenreich (2009) that the repression of understandable feelings of anger can “weigh on a cancer patient like a second disease” (p. 43). I want to break free of this shroud of silence that constrains me to be a “good patient” and maintain the unwritten contract that requires me to buy into the quest for survival in order to receive support. Like other women with breast cancer feeling controlled and managed is a source of my suffering and the locus of my need for healing (Hart, 2003). Painting my body in red and imprinting it on paper allows me to break free of this imposed silence and gives voice to my anger. I act out my joy of expressing my anger by dancing over my imprinted image.



Image 5.10 Dancing feet

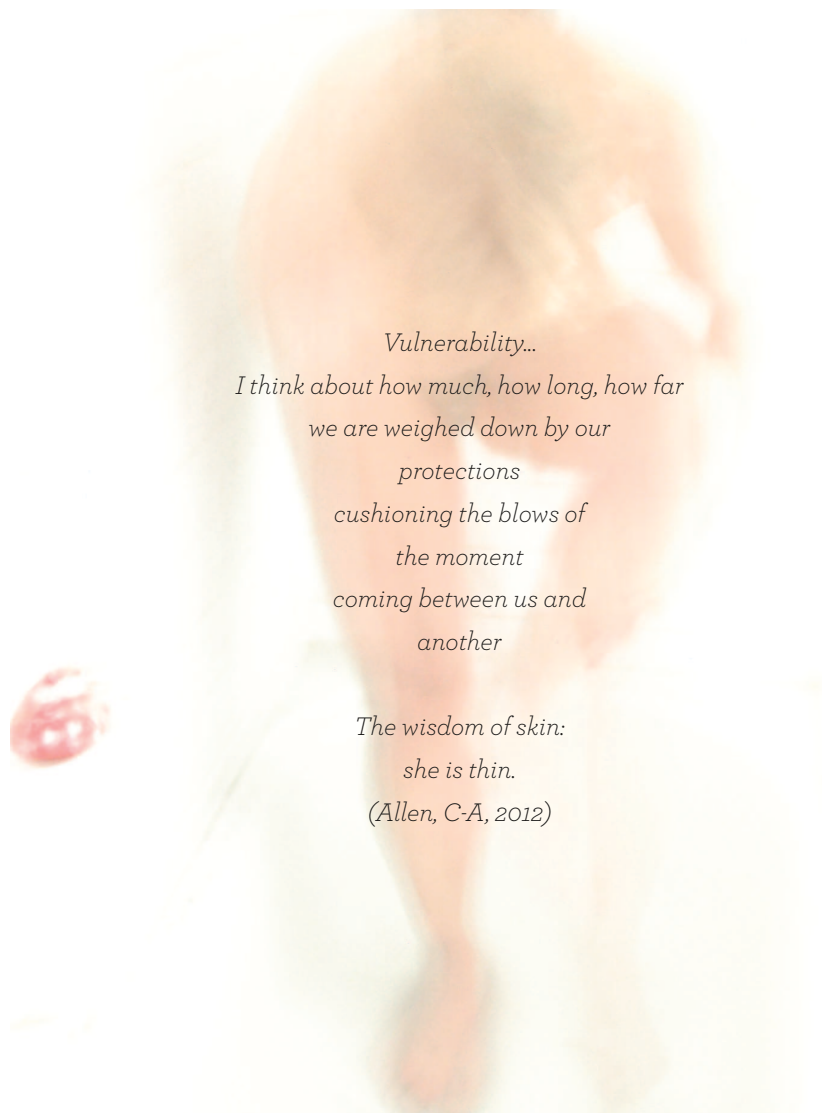
*Red wet stickiness
of anger released, dancing
gently breaks the bond.*

I am reminded of Rumi's poem

Dance

*Dance, when you're broken open.
Dance, if you've torn the bandage off.
Dance in the middle of the fighting.
Dance in your own blood.
Dance, when you're perfectly free.
(Rumi trans. Barks 2004, p. 281)*

I feel strong and wise, an Amazon warrior, enrobed in my painted red cloak of courage that covers my naked vulnerability. Can I retain this feeling of strength and wisdom once this cloak is removed? It is time to wash away the beautiful red robe of rebellion. The white tiled shower looks like the scene from a splatter movie, with splashes of red blood-like paint over the white tiles and bath. It reminds me of a suicide scene as the blood-red paint washes down the plughole. I feel cleansed as I wash off the red. Maybe I don't have to hold onto my anger? My pain? Maybe I don't have to rail against society's constructions. No longer covered in my paint cloak I feel vulnerable, exposed. Am I brave enough to face the world in my true nakedness? My naked flesh seems such a thin defenceless layer of protection. But perhaps I can face the world without this extra red coating of anger. A poem given to me by one of my co-enquirers seems to sum up my feelings.



Vulnerability...

*I think about how much, how long, how far
we are weighed down by our
protections
cushioning the blows of
the moment
coming between us and
another*

The wisdom of skin:

she is thin.

(Allen, C-A, 2012)

Now devoid of paint my scarred chest is visible. What can I learn from my scar? It seems symbolic that the removal of my left breast has brought my heart closer to the surface. Without the padding of my breast the sound of my heartbeat is loud. My scar is a visible mending of my wound through which my heart beats loud and strong. The idea of beauty in imperfection seems so at odds with the image of the pink lady. Pondering a different symbolism for breast cancer one, that holds the beauty, wisdom, and courage of women's experience of breast cancer, I create a series of art representations by applying layers of textured paint to a canvas and painting in gold over a stencil of curved shaped breasts. I create another image with the gold painted stencil and when I lift the stencil off the second artwork, the left breast shape becomes stuck on the paper leaving a stencil with only one breast. I create a third image using this stencil and paint over it in black, mirroring the image of the black space of my absent breast I explored in the previous chapter. When I look at these images I am reminded of the medical diagrams my surgeon used to illustrate my three bouts of surgery as my breast was gradually cut away.

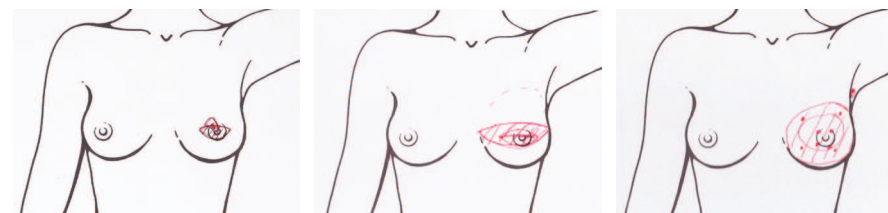


Image 5.12 Medical diagrams

This series of images seems to convey a narrative of moving from the grief of my absent breast to my red anger to acceptance of my changed body. I allow the images to speak to me.



Image 5.13 Golden breasts

*I stand proud my richly textured,
multi-hued beauty resplendent with round
full breasts exposed.
I am strong.
I am proud.*



Image 5.14 Gold stencil

*I feel lost, overwhelmed by the bloody mess as one of my
beautiful golden breasts is torn away.*



Image 5.15 Absent breast stencil

*I stand proud, black space of my absent breast exposed,
beauty in difference.
I am strong.
I am proud.*

*Proudly facing the world
Blood and mess of my life exposed
Breast torn away to reveal
Black space of possibility
Strong in my vulnerability*







Detailed description of an enquiry cycle

As I struggled with my grief and anger, I undertook a daily practice of making collage cards until I had made over 100 cards. Usually I just intuitively started to make a collage card without any particular intention.

Making art representation: creating a collage card

I am absorbed in my morning practice of making a collage card. I have an overflowing box of magazines and catalogues from which I select images to use. I choose a blue background on to which I paste a disembodied leg. Without thinking I paste two rows of pink ladies I cut from a BCNA magazine. I initially try to cut out the pink ladies individually, it is very finicky, and with my too-large scissors I keep cutting away parts of them. They become even more torn when I try to stick them on as they stick to my fingers. I feel frustrated, and picking the pieces from my fingers, I screw them up and throw them away. I then paste on the joined up foursome. This seems somehow symbolic of the lack of individuality in this pink lady emblem. The joined up pink lady foursome offends my sense of aesthetics as they jump out of the background in their rigid uniformity. As an afterthought I paste on the torn out pink lady angel figure.

Being with the art representation

As I contemplate this image my attention is drawn to the disembodied female leg encased in a lace stocking and wearing a bright red high-heeled shoe. The redness of the shoe is accentuated as the rest of the leg image is in black and white. This image has an erotic feel. Directly under the shoe is a small group of four joined-up pink

ladies. The large red-shoed leg looks like it is about to stomp on them. The pink ladies seem so helpless, stuck there while the woman's leg, with the red shoe, looks powerful, sexy, and strong. Floating at the top right hand corner overlooking the scene is a pink lady angel. As if she has somehow escaped from her group and gone to heaven, she is bigger with angel wings and a halo.



Image 5.16 Red shoe and pink ladies

Dialogue with the art as other

As part of this enquiry cycle I dialogue from the art representation. I enter into the different elements of the collage and speak from these.

I firstly speak from the woman's leg with the red shoe.

I am the leg belonging to a strong powerful woman who is comfortable in her own sexuality. I am not afraid to express my sensuality by wearing sexy lace stockings and red high-heeled shoes. I am liberated. I want to squash you pink ladies as you represent everything I am not. I am sensuous, powerful, and free, while you are neat, correct, and simple. You have no depth or texture; you are merely silhouettes. Without feet, you have limited ability to move. Without hands you cannot grasp, touch, or hold. Without eyes you cannot see the wondrous world, without a mouth you cannot speak. You have no way of sensing the world around you or of expressing yourselves.

The group of four pink ladies respond.

But we are together, connected as part of a group. We don't feel alone and isolated, vulnerable or exposed. We have so much in common that together we feel strong. No matter where we go in the world we can find others like us with whom we can connect. We have a strong sense of community and support. You may be strong but you are alone.

The woman's leg with the red shoe replies

I do not need others exactly like me to be strong. I can express myself. I am not afraid to express my female sexuality. I can step out in my high-heeled red shoes and take

on the world. I am so much stronger than you polite pink ladies. I am alive, energised, liberated, and free.

The pink angel.

I am hovering above you all making sure that all is good and in order. I am the omnipresent female critic ensuring that women behave in a feminine manner. Do not risk your reputation by dressing like a "raunchy hooker" in lacy stockings and bright red shoes. Join the pink lady movement—be happy, polite, constrained. Do not draw attention to yourself. Make sure you fit in.

The question mark.

You need to question all these assumptions. Keep exploring, keep questioning and you will find your way.

Coalescing threads of knowing into new understanding

Discarding the polite, pink, uniform of constraint.

Liberated from the shackles of expectations

*I am a sensual woman
strong in my femaleness.*

*There is a risk in breaking free of the group,
drawing attention to myself,
risking society's condemnation.*

*But it is through expressing my sensuality that
I am able to locate the complex layers
of my female strength.*

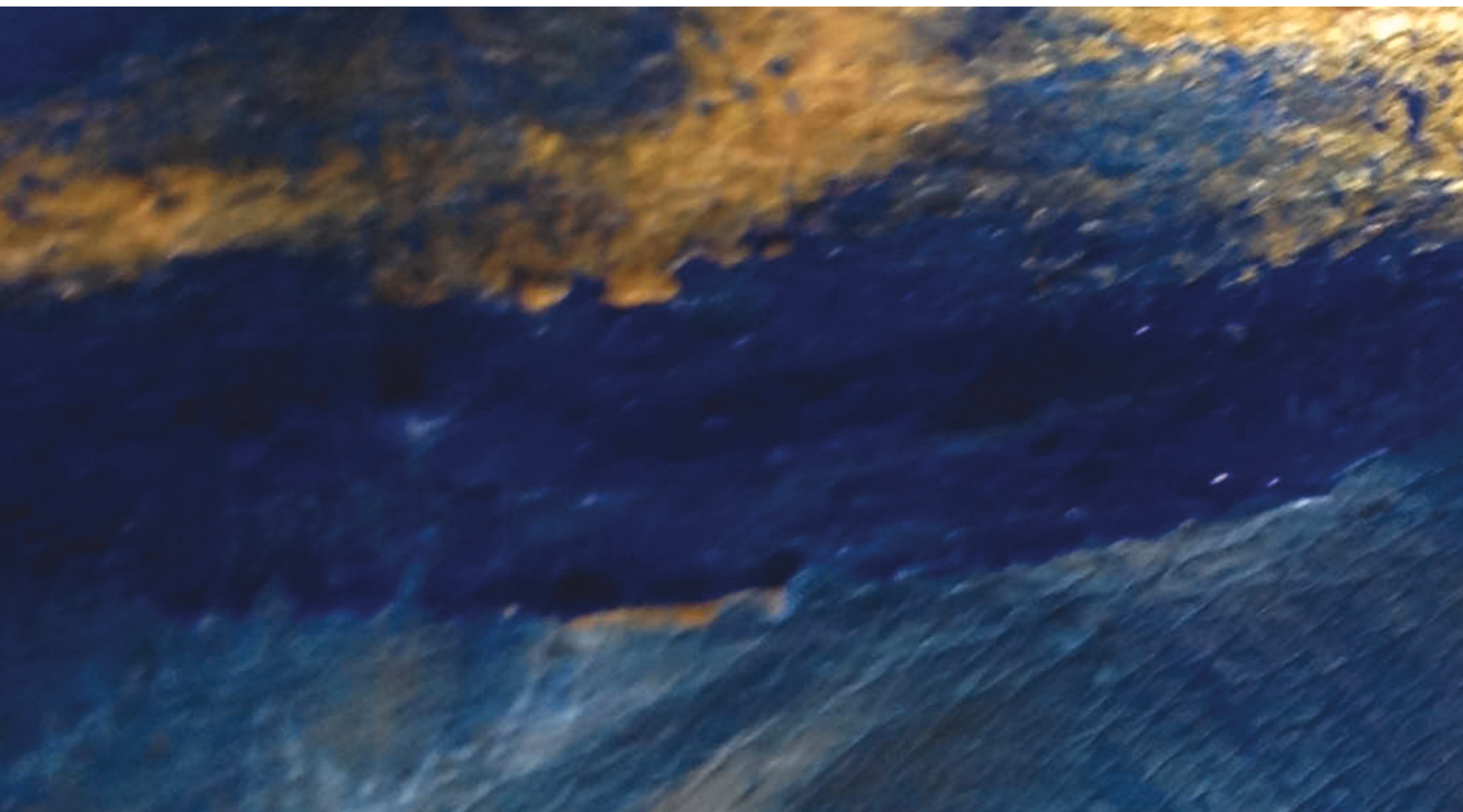
Conclusion

The pervasive pink of breast cancer marketing symbolised by the pink lady was the stimulus for the blood red to spurt forth in a visceral stream of outrage. With my increased sensitivity to breast cancer, the BCNA pink lady logo seemed omnipresent. I felt myself, my truth, my experience being overwhelmed by the societal pressure to put on a polite stoic front; to quietly pretend nothing had changed. I felt driven to resist this suffocating pink blanket of niceness by immersing myself in my own embodied experience of my corporeal female body.

Exploring the blood red visceral nature of my experience and being prepared to expose my vulnerability I began to take pride in my scar, the visible mending of my wound. Rather than a mark of shame, I began to view my scar as a sign of my strength and survival. The exploration of the red, was both energising and energy depleting. The red of my anger created the energy to start to drag myself out of the blackness of pain but this fight against the pink also took energy. It seemed to represent for me my lifelong striving to be true to myself rather than fit into other's constructions, to be seen as who I am. I felt deeply affronted by the imposition of this submissive pink 50s stereotype of womanhood that is embedded in the dominant breast cancer narrative.

In the final enquiry cycle blue entered as a background to this battle between the superficial one-dimensional pink fake feminine and the multi-layered blood red complexity of female wisdom. The blue question mark encourages further exploration. It is this blue that I will explore in the next chapter.





Chapter six

Blue



When the ocean surges, don't let me
just hear it. Let it splash inside my chest!

(Rumi, translated by C. Barks (2004, p. 145).

Introduction

In the previous two chapters I have described my arts-based enquiry in which new meaning emerged with a strong sense of colour; black for grief and fear, red for anger and passion. Although the colour black emerged first, red followed soon after in response to my outrage at the pink lady symbol. After several years of immersion in my arts-based enquiry dominated by black and red, the colour blue suddenly emerged in a moment of epiphany during an art-making session in which the white and blue colours of the ocean were revealed to me. From this moment my emotions were transformed and I felt driven to explore the colour blue, a particular bright shade of sky blue. It was only later on, looking back at my previous artwork I noticed that colour had been present in varying degrees but, my attention was so transfixed by the black, it had not been visible to me at the time. I used the method outlined in chapter three to explore the blue through a fusion of different modalities such as painting, collage, sculpture, installation, smoke drawing, and story-book making.

In this chapter I start with a detailed description of the art-making session in which the blue first emerged. This was a powerful moment in my enquiry and provides a good illustration of the possibility of moments of epiphany, when the process of making and exploring art allows a sudden insight or transformation to arise. It shows how my enquiry process cycled through the different steps using a range of modalities to enable me to come to new understanding. This enquiry cycle also provides an example of the impact of the art-making tool becoming an extension of my body as described by Merleau-Ponty (1962) and Michael Polanyi (1966). They both use the

example of the blind person's cane to describe this experience of incorporation when a tool becomes part of our body, to the extent that we are able to feel through the tool, as if our sensory perception capacities were now extended to the working ends of the tool. Paul Carter (2004) drew on these ideas in developing his concept of "material thinking" where we project ourselves into our materials and tools so that we can feel as if we are those tools and materials. In my enquiry the end of the paintbrush attached to a long stick becomes an extension of my body and embodies the sensation of painting with my nipple. I have followed this detailed description of one enquiry cycle with a creative synthesis of the findings from the other enquiry cycles in the form of a poetic narrative and collage.

Detailed description of an enquiry cycle

This enquiry cycle is initiated from an intention to explore my feelings of grief captured in my image of the black hole. This image was especially significant and initiated a number of enquiry cycles as I sought to explore its meaning. I brought the image to a group art studio session with the intention of exploring it further. As part of this description I have incorporated a reflexive commentary written about 12 months after the actual enquiry took place.

Making art representation: painting with a "wobbly stick"

As a warm up activity to a studio art session I paint on a large sheet of paper stuck to the wall using a paintbrush taped to the end of a metre-long stick. It is an exercise in the experience of abandoning control, of free painting and just allowing myself to

make marks on the paper. Initially this lack of control is quite frustrating then I relax into the experience and feel into the end of the stick as if it is an extension of my body. As I do this I am suddenly catapulted back into my experience of three years earlier of using my painted nipple to make marks on paper. I experience a similar sensation of making squiggly painted marks and splodges on paper with limited capacity to orchestrate the image. I feel my body flooded with grief as I am taken back to the night before my first operation to remove my nipple. The embodied feeling is so strong I almost collapse to the floor. I keep painting no longer seeing what I am doing through my tear-filled eyes.

Being present with the image

A companion assists me to explore the image I have created *Image 6.1 Squiggles*. The first thing I notice is the sense of energy and movement that I feel when looking at this image; it appears to pulsate with life. The dense black mass of squiggly lines at the bottom is familiar; it resonates with all the other images of the black space that I have created. The small circular shapes with their flowing tails are new; they have a strong sense of movement. My companion then invites me to look at the *Image 4.17 The black hole of grief* which I have stuck to the wall next to the other image. Inviting me to move a metre away she asks me what I see. I shift my gaze and am amazed to see the beautiful shimmering white, tinged with blue pulsating



Image 6.1 Squiggles

outwards from the black hole. After carrying around this image for over three years and being totally absorbed in the black space, the deep black hole of grief, I am totally taken aback to see this beautiful shimmering white that surrounds the black hole. It is only at this moment that this has become visible to me. It has a water-like almost transparent quality.



Image 4.17 Black hole of grief

I continue to gaze at this image but now I am focused on the white surrounding the blackness. Like the blackness it is also transfixing. It holds so much possibility. It reminds me of the times I have sat on a rock and meditated on a waterfall, gazing at the cascading stream of water and watching the veil of water, moving as one, crash down, until I change my focus to one drop of water as it separates from the sheet of water following its journey into the river below. As I continue to swap between these two ways of seeing from following one single water drop to seeing the veil of water moving as one, the change in my focus allows me to see and experience the waterfall in very different ways. Similarly the change of focus has allowed me to see and experience this image of the black hole of grief in differing ways.

As I speak of this to my companion, I feel myself moving outwards from the black hole and into the lightness of the water. I am still in the water but there is a totally different feeling to this water. Previously when I had looked at this image I had felt swallowed up by the black depths, now I feel held by the beautiful light filled water. I imagine emerging from the black depths towards the light, droplets of water falling from my body as I burst out of the water into the light. Finally reaching the light and air. After holding my breath for so long, holding my grief and sadness so tightly within me, I can finally breathe!



Image 6.2 Ocean without a shore

A sense of familiarity hits me as I write this. It reminds me of the video of the deep-water dive I received as an intersubjective response at least a year earlier, described in the enquiry cycle in Chapter 4. I go back and look at this enquiry cycle. At this time I was still focused on exploring the dark depths, and although I do acknowledge that I make it to surface “sucking in the air”, I do not explore this experience of breaking free into the light as I do here. This again shows how I kept revisiting similar material in different enquiry cycles and coming to slightly different knowing or understanding.

This experience of breaking through the black water into the light is transformative. It feels like I have broken into another world. Moved from the world of the darkness and death to the world of light and the living. I am reminded of Bill Viola’s exhibition *Ocean without a Shore*, which I recently saw at the National Gallery of Victoria in Melbourne. In this video installation, exploring the threshold between life and death, transformation and renewal, people are shown slowing walking towards the viewer. They are out of focus as if behind a screen, then suddenly they emerge through a sheet of water into the light. They stand and hold the eye of the viewer for some time before turning and going back through the water wall and walking into the distance.

When I viewed this exhibition, which was set up in a small dark room, I sat in this room for about an hour by myself totally mesmerised. The link below to a video provides a glimpse of this exhibition (<http://www.youtube.com/watch?v=zx5pRFQ2zgU>).

As I write this I reflect on the notion of immersion in the topic described by Moustakas (1994) as part of his heuristic research method. He described being so immersed in the topic of enquiry that it continually entered every aspect of his everyday life. This is a good example of how I carried my enquiry with me, how it entered my everyday life and how my daily experiences influenced and informed my enquiry.

As I explore these images I feel the sun shining through the window warming my back. I feel totally transformed. No longer dark, heavy, and stuck. I feel exhilarated, energised, refreshed, light, and alive. I am alive: alive to possibility. It is exciting. I am no longer scared of what might be. I can just live.

*Looking up from the depths
all is light,
pulsating with the energy
of new life created.*

This resonates with the haiku I developed as part of my enquiry into the black hole of grief, which shows that the potential for joy was at the edge of my experience, but I didn't fully embody this knowledge at the time.

*From the black hole of grief
absence, loss, lack of support
permission for joy.*

I want to explore this transformative moment further using another modality so I cycle through the steps of my enquiry method again.

1. Noticing emotion

Following this experience this newfound sense of lightness and joy still resonates in my body. I am keen to further embody and consolidate this transformed feeling.

2. Identifying a bodily felt sense

I tune into my body to locate the emotion. Where do I feel it? What does it feel like? It feels like a light filled energy centred in my chest and suffusing through my whole body. My body feels light.

3. Using movement to deepen my bodily felt sense

I stand in the yellow circle of sun streaming through the windows. I can feel the warmth of the floor under my bare feet. I slow my breathing and turn my face towards the light and look into the deep blue of the sky. I stretch my arms upwards and outwards as I embrace the sun. I curl my body inwards and then stand tall and stretch myself upwards. I make these movements bigger and bigger until I am squatting on the floor and leaping up with my arms outstretched. I then reduce the movements until I am again standing still in the sun. I start to walk slowly around the room. I do not know what I am going to do. There is a large wooden frame in the room I walk through this. My improvised movement gradually moves into art-making.

4. Making art representation: creating an installation

I continue walking through this frame as if it is a doorway into another world. I then notice some beautiful lacy materials, which I pick up. I move into the art materials room and pick up other materials: sheets of cellophane, tissue paper in different shades of blue, some white satin and blue silk, a heavy black blanket. I find a whole lacy mosquito net. I bring these materials back to the wooden frame. I move the frame a bit closer to the window and drape the heavy black blanket over it creating a black cave-like space. I need some more black material to completely cover the frame. I walk around scouring the studio for black materials I reflect on the familiarity of this focus on the black; it is comforting. I know this space. I use masking tape to join black plastic sheets. As the black plastic puckers under the inflexible tape, I am reminded of my own bandages, my scars, my own visible mending on my body. Inside this dark space I place a cushion to sit on. I create an opening; a small slit of light reveals the way out

into a light filled space. I am reminded of the words in Leonard Cohen's song *The Anthem*,

*"Forget your perfect offering
There is a crack, a crack in everything
that's how the light gets in."* (Cohen, 1992).



Image 6.3 Lacy light

I include an audio recording of this song in the dark space. Using the windows, with the sun streaming through, as the back wall, I construct a light filled space connected to the black space. I use the lace mosquito net and light lacy material to create the walls and ceiling of this space. I scrunch up the cellophane and blue tissue paper and place this with my earlier representations, of being in the beautiful blue, on the floor along with the silk and satin material. I want to create a sensation of being in the water, to construct an environment that reflects my earlier embodied experience of being in beautiful light infused clear blue water. My earlier feelings of aliveness, lightness and energy remain with me as I absorb myself in this construction.

5. Being with the art representation

I go inside the black cave-like space and sit on the cushion. As my eyes adjust to the

dark, I see that it is not black but a beautiful deep, dark, velvet blue. I press play on the recording of *The Anthem* song and sit quietly and meditate on what I hear – the music, the words, the soft muffled sounds outside my refuge. Rather than a sad, frightening place, it feels like a dark womb-like safe cocoon, a perfect place to meditate. I don't want to leave this darkness. It has a peaceful feel of shutting out the noisy crescendo of life. I reflect on the peacefulness of the dark space. This resonates with my new understanding, that the black can be a place to pause. This started to emerge in my enquiry into black. Now that I can actually sit inside this black space rather than just imagining being inside it, the experience is much more powerful. I want to stay here. It feels so safe and secure inside my dark cave away from everyone. I can just sit here quietly. I don't have to do anything, be anyone. I can just be: here in this dark refuge. I stay here for some time, focusing on my breath.

Seeing the crack of light through the narrow slit, I squeeze myself through the small opening into the sun-drenched light-filled space. It is such a contrast from being in the dark. The walls of lace and glass provide a sense of sanctity; it reminds me of looking at the light streaming through stained glass windows in a church. I feel all my senses alive—the light reflecting on the cellophane floor, the warmth of the sun on my skin as it filters through the lace and windows, the many different hues and shades of blue and the textures of the floor with tissue paper, cellophane, and silk under my bare feet. I sit here and dwell on the sense of lightness, energy, and peace.

6. Creating a dialogue with the art as other

I invite other members of the art studio group to enter my installation to experience the space I have constructed. One at a time they enter the black space and listen to the music. My rough structure forces people to crawl through the narrow opening into the light. Some have great difficulty in finding the opening and then making their way through to the light filled space. This seems appropriate, as it has certainly been a difficult and lengthy process for me to find my way through the dark to the light. Their responses vary, some find the black space claustrophobic and hurry through into the light, while others find it a quiet refuge to be savoured before emerging into the light. All comment on their different feelings as they move from the dark to the light. A couple said that they liked the peaceful feel of the dark space and found the light space too confronting, while others enjoyed moving into the light and sunshine.

I continue to move through my structure, from the dark to the light and back again noticing my bodily feelings as I do so. Perhaps the most significant thing I notice is how calming and restful the dark space feels, so unlike the overwhelming sense of despair and grief that I have previously associated with the black space.

7. Coalescing the threads of knowing to a new understanding

I create a haiku to encapsulate my emerging understanding

*Dark, light both provide
place of peace to pause, reflect,
contemplate my life.*

I realise that it is not possible to force myself, by sheer will, from the depths of despair into the light. When I am ready, when I have spent time exploring the dark space of pain, when I have found meaning in my loss, only then can I see the transformative light and be able to move from the blackness towards this light-filled energy. I am then able to experience the black space as a place of peaceful refuge, a place to meditate, away from the crescendo of the world. I now realise that rather than trying to banish the blackness, I can accept its importance provided I can also access the light. Both darkness and lightness provide a place for contemplation.

After holding my grief, sadness and anger so tightly,

I can finally breathe!

Held by the beautiful light.

Warmed by the shining sun

I feel exhilarated, energised, refreshed, light.

Alive to possibility.

Aquamarine/turquoise shape

golden light filled centre

a place of transformation.

Suddenly I can see

across the dark threshold

to life.

Walking along the beach

the water reflects the blue sky

a gentle breeze caresses my skin

contentment, joy, peace

at one with the world.

Memories of sun-filled days

playing at the beach.

I feel peaceful and happy.

the warmth of the sun on my skin

the cool blue water.

My body feels light

against the warm solid flat rock.

Blue sky above me

my breathing reflecting

the rhythm of the waves.

Diving under the water

Shafts of sunlight

through the blue water

Air bubbles float to the surface

Effervescent, sparkling like champagne.

I break through into the warm sunshine.

I float on my back

the beauty of the blue sky

above me.

Floating on a draft of wind

I drift above the sea

absorbed into the blue sky.

I paint myself this blue of the sky

flesh transformed to vibrant blue

Hollow chest

that was painted in black

now glows and glistens

in golden glitter.

Wet blue painted skin

connects to shiny paper surface

gold glitter slips and slides

paint seeps.

Texture of my skin

a calligraphy of my life

imprinted from my body.

Painted in vivid blues

*I feel lithe, athletic, like
Avatar movie characters
racing through the forests
at one with the natural world.*

*Different blues
of my blue painted skin
a beautiful seascape
blue of the summer sky
flecked with white fluffy clouds.*

*Spiritual searching,
captured in collage
reaching towards the light
a mystical light, peace
divine release and bliss
from darkness to light,
from ignorance and fear
to wisdom and strength.*

*I immerse myself into, and speak from this collage
You too can find peace, joy and contentment. Let go
of your attachment to how you think your life should be
just be
in your life as it is,
mindful
of every precious moment.*

You do not need to rush after your life.

*Allow
your life to emerge.
The beauty in the world
is freely available to you
all the time.*

*I create a concertina book.
Covering the paper with soft pastel
the story emerges
as colours of nature
interact with my feelings.*

*I was scared.
I thought I was going to die.
But facing death
wasn't so scary.
Just a slipping
into the light
leaving a faint trace
of my life behind.*

*I was scared.
Then I found
real peace
knowing I had
lived my life to the full
with no regrets.
Can I hold this wisdom?*

*A faint trace of my being here
lives on in the memories
of my children, my family and friends.
And now this seems enough!*

*I use papers and candles
to create images using smoke
swirling in the air
emergent, ephemeral
Immersing in emergence
my life unfolds
like smoke,
my spirit energy drifts and unfurls
touching randomly,
a faint trace;
my legacy.*

*Accepting my death
frees me to live life fully
open and present.*

*Lingering sense of shame
surprises me.
Curled inward, head bowed
Arms crossed protectively
I want to challenge this shame.*

*I want to celebrate the beauty
of my scarred chest.*

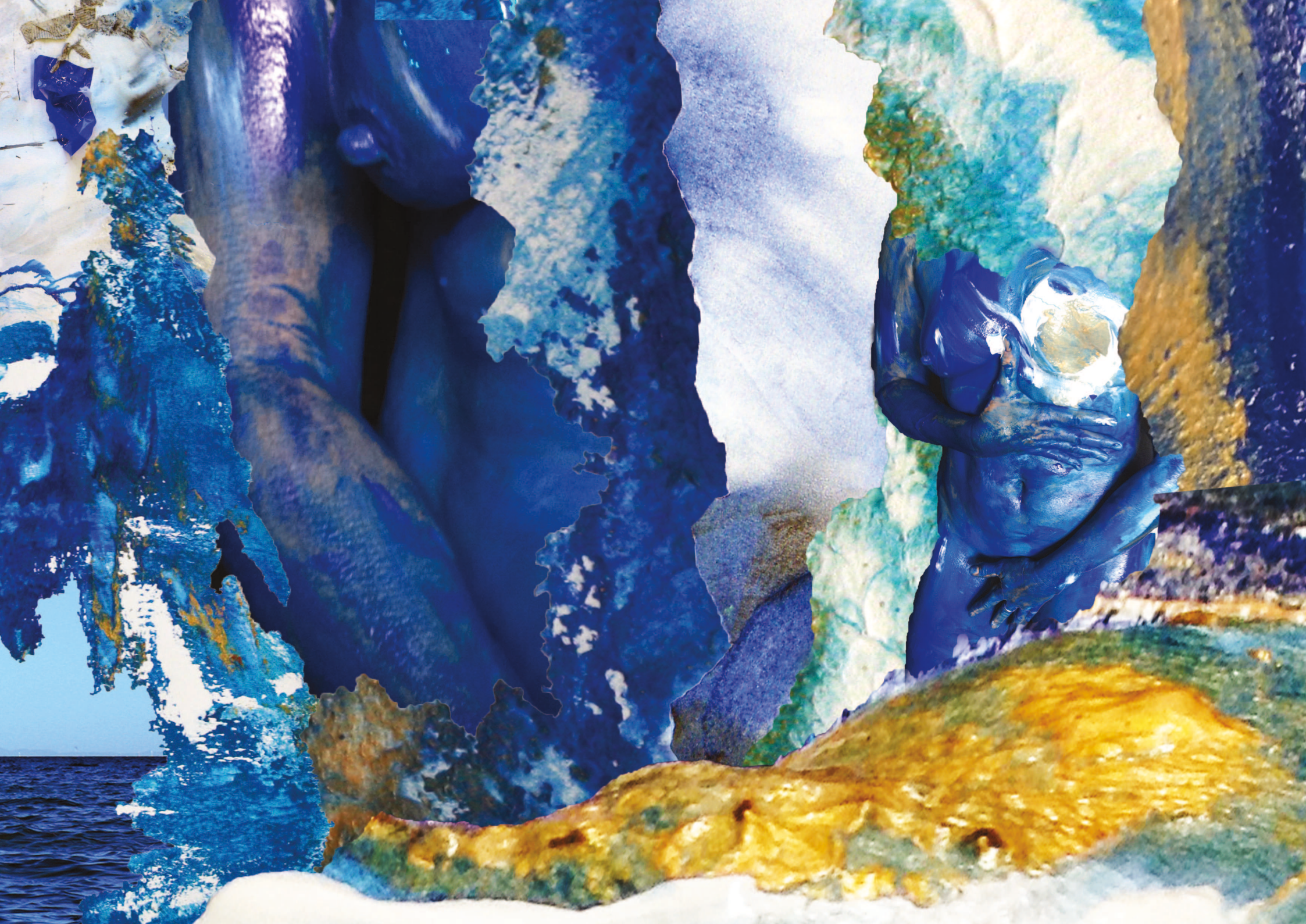
*I take photos at the beach.
the sun shining on my face
my naked chest.
Is this too confronting?*

*I wade into the water.
further and further into
the deep freezing water
it takes my breath away.
My hands are white and numb
I am so cold.
My head is freezing.
A man walking his dog comments
'you must be mad.'*

*My arms outstretched
I feel energized and alive
my skin tingling
a sense of elation
having challenged myself
to bare my one breasted chest.*

*I love being in the sea,
feeling the salt water and the air against my naked skin.
I feel strong as I leap out of the water
and reach for the blue sky
and golden sun above me.
I feel liberated and free.
I feel alive!*





Conclusion

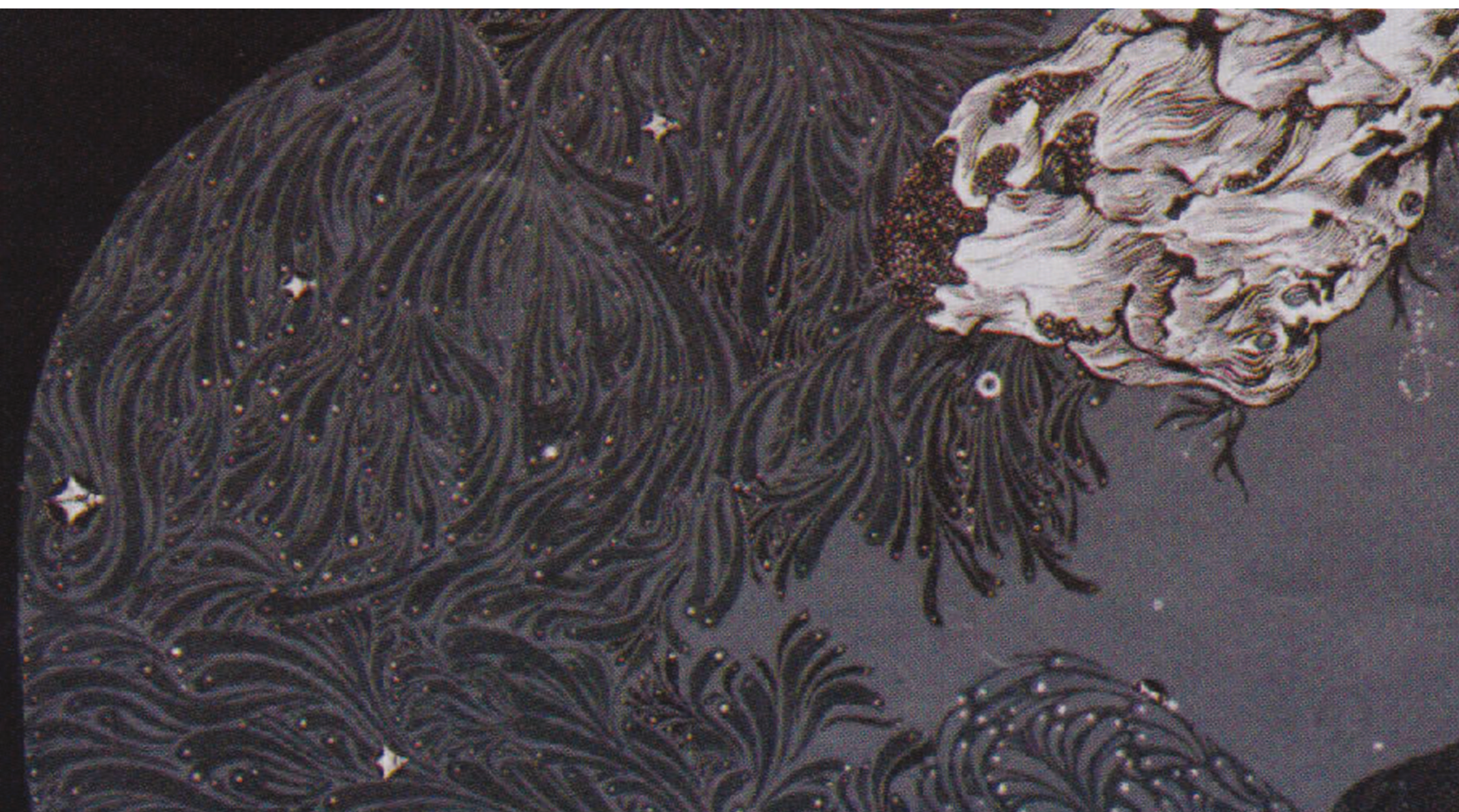
In this chapter I have presented a creative synthesis in poetic and collage form of six enquiry cycles using different modalities that were dominated by the colour blue. The colour blue emerged in a moment of epiphany allowing me to move from a place of grief and anger to a place of tranquil acceptance. Blue, as the colour of the sky and water, particularly the sea, became a common theme through my enquiry cycles and opened me up to the reinvigorating power of connection with the natural world. Water, which makes up about 70% of both the human body and the earth (Mayo clinic, 2013), allows me to feel the strong inter-relationship between the natural world and myself; I feel the tidal flow of connection between the world and myself. Through my enquiry I experienced the sense of entanglement with the world as illustrated in Merleau-Ponty's description of experiencing the full sense of the blue sky.

If I fully attend to the sky gazing into its blue, my body gradually adopts a certain bodily attitude in response to the spacious blue. My eyes and my whole body slowly yield, relax, and enter into a sensuous rhythm of existence that is already there and that is peculiar to the sky in its blue depths. In its contact, my body adopts a "certain living pulsation" that is not its own, but that it lives through and that also lives through it, and becomes my body's being of the moment. My living situation becomes one of blue. I can feel the blue profundity and become immersed in it because of a bodily openness that lets the sky pulse through me and, in the same trembling moment, lets my bodily sensing breathe life into the blue sky. This bodily-skyly sensibility

that tremulously runs through me and that is neither passively received nor actively willed makes me realize an 'anonymous self' that has already sided with, and is already open to, nature and my surroundings. (Merleau-Ponty 1962, p. 214-216)

Through being present in all my senses to the experience of being in nature—being in the sea, feeling the warmth of the sun, and being absorbed into the blue of the sky, I feel myself truly touched by the energy of the natural world. It is this sense, of being open to and transformed by the energy of the natural world that allows me to move to a place of acceptance of my changed body.





Chapter seven.

Women's story



I struggled with how to convey the stories of the participants in my enquiry in a respectful way that held their richness, authenticity, and honesty, and also in a way that reflected both the uniqueness of each individual story while at the same time illuminating the commonality of the experience of breast cancer and mastectomy.

Introduction

As part of my enquiry I worked with three other women, who have had a mastectomy, in a small arts-based group and in individual arts sessions. The group workshops and individual sessions allowed the women to creatively explore their breast cancer experiences using a range of modalities following the arts-based method outlined in chapter three.

The framework for the four half day group workshops comprised:

1. My body as it was, is, and will be, using visual arts
2. Giving my body a voice using voice expression
3. Sensation of my changed body using movement.
4. Gaze on my body—my own and others using collage.

In my follow up interviews with the women involved in this project, they all stressed that they had gained unexpected and profound insights through using creative arts. As one of the group participants said “It opened me up to looking at things in a more abstract, less concrete way, which was really good for me” (Personal communication, April 18, 2012). I was keen to respect the contribution made by the women to my own enquiry and incorporate their story in some way. At the outset the participants and I had initially talked of doing a group exhibition or presentation as a synthesis, however, much of our creative expression had involved voice and movement, which being quite ephemeral, did not lend itself easily to an exhibition. The other women also made clear that once they had completed the workshops and individual sessions it felt finished

for them. They were no longer interested in how to bring the project to a conclusion. I realised that this was really my concern as a doctoral student.

Initially I wrote an objective academic account of my work involving other women, citing “expert” references, as I discussed (under neat section headings), the establishment of the group, its size and composition, the recruitment process, the impact of my dual role as a researcher/participant, the workshop design, ethical issues, as well as an outline and discussion of each workshop. Reading this it was evident that the voices of the other women were barely present. How to bring their voices and experience to life? Jennifer Mullett (2008) writes of a similar challenge she faced in bringing the transformative energy of a series of women's arts based workshops to a broader audience. She eventually did so through song. Words, such as concrete poetry, the hanging letter sculpture, and poetry, have been a constant form of creative expression for me. It therefore seemed natural to continue with my use of narrative, using a short story form, as a way of capturing the women's experiences. When obtaining the consent of the three other women I guaranteed to show them the completed story and gave them the opportunity to request any changes.

The short story, as a form of creative non-fiction or fiction, is gradually being legitimised as an ideal vehicle to present the findings of qualitative research (Barone & Eisner, 2012; Caulley, 2008; Ellis & Bochner, 2000). However, the process of creating written representation, in a way that acknowledges my power as the researcher, to establish the “truth” is a contested and loaded arena. While traditional views of research have emphasised the importance of “sticking to the facts”, Thomas Barone and Elliot Eisner

(2012) contend that the line between fact and fiction is ambiguous and shifts with every encounter between the viewer and the text. By disturbing and disrupting the familiar, they argue that short story fiction can strengthen the research as it has the potential for “enhancing meanings of social phenomena that run counter to final, orthodox, seemingly settled interpretations and conclusions” (Barone & Eisner, 2012, P. 101).

I felt the weight of the responsibility of retelling the participants’ stories and of respecting their truth, so I thought that the most ethical way to approach this work was to transcribe the participants’ words as accurately as possible. After several drafts, however, I came to see another form of integrity. As I read more widely around the evocative power of fiction as a means of conveying the real meaning of a story (Barone & Eisner, 2012; Caulley, 2008; Ellis & Bochner, 2000), and read other short stories (Minge, 2007; Ostricker, 1999; Owton, 2012; Parry & Glover, 2011; Vande Berg & Trujillo, 2009), I began to feel more comfortable with writing in a more fictionalised way in order to express the essence of the participants’ stories. Like Suzanne Gannon (2004), who presented her academic research of women’s stories of their breasts, into a script and performance, I became less concerned with translating their actual words and shifted my focus to conveying the meaning of their experience as powerfully as I could. Rather than merely structuring and ordering the women’s words into a form of narrative, I spent time developing the fictionalised characters, their personality, qualities, and voice in order to find a way to communicate the essence of what I believed the participants wanted to convey.

In crafting an engaging short story I utilised a number of design elements associated with creative writing including the use of composite characters, plot, narrative drive, tone shifts, creating suspense, use of dialogue, and purposeful alteration of details, settings, events or characters, either for ethical or aesthetic reasons (Barone & Eisner, 2012, Caulley, 2008). I developed different characters through an amalgamation of the women’s experiences, in a similar way to Diana Parry and Troy Glover (2011) who developed a fictional performance text to convey the experience of people with cancer. Incorporating the women’s original art works and poetry I developed a form of autoethnographic layering (Rath, 2012; Speedy, 2011; Tilley-Lubbs, 2011). I fictionalised some aspects of the story in order to create a more flowing engaging narrative. By using composite characters organised around themes, rather than individual narratives, I strived to allow the women’s different voices to be present in a way that protected their privacy and provided me with the freedom to develop an engaging powerful story that encapsulated their ideas and experiences. Through this narrative approach I hoped that, rather than being talked about as passive victims, the participants would become the central protagonists in their own story.

Arriving at themes

I based the short story on themes that emerged from both the workshops and the individual sessions. The process of arriving at the themes from the group workshops occurred as part of each individual workshop and as part of a summation at the final workshop. The themes that emerged were:

- Facing mortality can bring choices of how to live your life more fully including the option to slow down.
-

-
- Feeling pressured from surgeons, family, and friends to have a breast reconstruction, as part of the normal breast cancer treatment, contributed to the experience of confusion and trauma.
 - The need to have space—emotional, psychological, temporal—and support, to come to terms with the changed body before making a decision about whether to have a breast reconstruction.
 - The pressure on relationships of the experience of cancer—friends, who do not know how to be with this diagnosis may withdraw, while partners, who are not able to get the support they need, may also withdraw or become overly protective.
 - The lack of support for lesbian women, particularly lesbian partners—the focus of all services assumes a heterosexual norm.

Themes that emerged from individual sessions were identified by the two participants at the end of each session and then in the review of all the sessions.

- Anger over the pink lady logo as not representative of their breast cancer experiences.
- Feeling disempowered by the medical system—not being heard or seen.
- Coming to terms with a changed body.
- The breast cancer experience is more than just dealing with a disease, it brings old lived patterns to the fore and provides an opportunity to change.

Rather than try to incorporate all these themes within the short story I decided to focus on four themes that emerged most strongly; all of which involve a power analysis.

- The pressure to conform to the normative body.

-
- Power imbalance between patient and medical experts – not being heard.
 - The anger over the dominant breast cancer discourse, which does not reflect their experiences.
 - The lack of support for lesbian women, particularly lesbian partners.

**Rather than follow the academic style guide, which I have used throughout this thesis, I have used the standard fiction format style for the following short story.*

*There is a community of the spirit.
Join it, and feel the delight
of walking in the noisy street,
and **being** the noise.*

*Drink all your passion,
and be a disgrace.*

*Close both eyes
to see with the other eye.*

*Open your hands,
if you want to be held.*

Sit down in this circle.

(Rumi, translated by Barks (2004, p. 3).

Reconstructing choice: A short story

*My body is pain
my body is less than me.
My body is me!*

Sinking into the plush leather sofa, Izzy and Mel sit with downcast eyes, surrounded by images of beautiful models, with perfectly shaped breasts, smiling down at them.

‘I don’t think I can do this again,’ whispers Mel.

Another couple shares the room. He is ruggedly handsome in his 50’s, with the assured sense of power and attractiveness that comes with the accumulation of wealth; she is beautiful, in her early twenties, the last vestiges of innocence still shining from her eyes. Sitting with their heads huddled over the magazine, he with a protective arm around her shoulders, they could be father and daughter. I hope they aren’t thinks Izzy as she watches him pointing to images of the breasts he likes.

Izzy and Mel make a striking couple. Izzy with her dark eyes, olive skin, and black mass of unruly curls betraying her Maltese background, contrasts with Mel’s fair freckled skin, and short red hair. They met over a year ago when holidaying in Europe. Mel was taking time out from her job as a public servant to recover from the death of her partner from breast cancer, while Izzy was getting over another broken relationship that was always going to end badly. But Mel is different; unlike her previous lovers, she is calm, forthright, and gentle. With her beautiful green eyes and enigmatic smile, she bewitched Izzy. Neither was looking for love, but they found it under the spell of an Italian summer.

They have spent an idyllic year together and recently Izzy moved into Mel's house. But now they have been wrenched into the harsh reality of dealing with Izzy's diagnosis of breast cancer.

'Fancy getting cancer in my milk ducts,' Izzy had fumed. 'I haven't had any use for them. They have never performed their purpose of carrying milk to nurture a baby. And now they've been invaded by cancer cells.'

The surgeon had recommended that Izzy have a mastectomy, and asked what type of mastectomy she would like. This seemed such a bizarre question and Izzy later confided to Mel that she had an image of going on-line and ordering the mastectomy of her choice, one with a pretty patterned stitching in purple perhaps.

'I assume you are going to have a reconstruction so you'll need to do what's called a 'skin-saving' mastectomy,' her surgeon had informed her. 'I'll try and leave as much skin behind so the plastic surgeon has something to work with to create a new breast.'

When Izzy just looked at her blankly, her surgeon said, 'well you'll need to decide soon. If you decide not to have a reconstruction I'll need to do a 'flat to the chest' mastectomy, that'll leave a neat scar across your chest.' In dismissal she said, 'My nurse will show you some pictures to help you make up your mind.'

Still reeling from the shock that she had cancer, and needed to have a mastectomy, Izzy found herself sitting in a small office while the nurse thrust a folder into her hands.

'See, you can have a mastectomy and have a neat scar like this one' she said, pointing to an image of a headless torso of a woman with two red slashes across her now flat chest. 'You can then wear a prosthesis in your bra and no one will know. Or you can have a breast reconstruction, which most women prefer to do'.

Another headless torso, this time with misshapen breasts with a scar across them and no nipple. Page after page is filled with these images—headless torsos of women's scarred chests with varying levels of deformity. It is so de-humanising. Oh these poor women! Being shown as if they are criminals in a series of mug shots. After a cursory glance Izzy flees in tears.

Later as she talked it over with Mel, Izzy expressed her confusion.

'Do I want to have a breast reconstruction? I have no idea. And if I do, there are more choices! I then have to choose what sort of breast reconstruction I want. This is all too much!' she wailed tears welling in her eyes, 'I have just found out I have cancer. And now I have to make all these decisions.'

That was a week ago. A long week, in which they tried to come to terms with the reality of Izzy's breast cancer diagnosis. Today they are meeting with the plastic surgeon, to get information about the different types of breast reconstruction. That's why they are sitting in this luxuriously appointed waiting room under pictures of women with beautiful enhanced breasts.

Like a used car salesman selling different models of the latest sports car, the plastic surgeon goes through the three different types of breast reconstruction. 'You can have a 'pedicle flap reconstruction'. I'll stretch your back or abdomen muscle over

to your chest and use it to form a new breast, because I won't have to cut the blood supply you'll have less chance of getting an infection and your new breast will look and feel more natural.' He adds quickly, 'the only real downside is that you'll have scars on your back or abdomen as well as at your reconstructed breast. But I can always do a breast implant if you want more bulk to the transferred tissue' he adds in a brighter tone. 'Another option is to cut tissue from the abdomen and use this to form a new breast. A lot of women prefer this as I can get rid of your tummy fat and create a flat stomach and a new breast at the same time' he says with pride.

'The third method is to use breast implants to create a new breast. This will require a couple of operations. I'll insert a tissue expander under the skin and chest muscle, which I'll gradually inflate by injecting saline over several months. Then once the tissue is stretched enough, I'll operate again and remove the expander and replace it with a silicone or saline breast implant.'

Mel jumps at the words silicone implant.

'Isn't that what all those poor women, who've been part of a legal class action against the implant producers, had done to them?' she asks in a strained voice. 'Wasn't the implant producer using industrial silicone in the implants and they leaked into the women's tissues.'

'Yeah,' interrupts Izzy, 'I've seen the pictures in a women's magazine of women who just wanted to have bigger breasts and ended up with scarred and disfigured flat chest walls with permanent lumps of silicone enmeshed into their tissue. They showed these pictures of these poor women. They looked terrible. I don't want that!'

Seeing their horrified looks, the plastic surgeon quickly recovers,

'Of course I'd recommend saline implants. You don't have much extra weight on

you, so implants would be the best method for you.' 'Mmm,' he stares intently at Izzy's nipples, 'you have good-sized nipples, that's good. I'll be able to make a new nipple from your remaining one, this might mean that you'll lose sensitivity in your nipple, but it'll look more normal. You're lucky, if your nipples were smaller I'd have to use some skin from your inner thigh to make a nipple but this will give a much better result.' He finishes with a flourish and large smile 'then to create a truly realistic breast we can tattoo on a new aureole and you'll look better than ever.'

'Who cares if my nipples no longer bring me any pleasure,' Izzy mutters to Mel, 'as long as I don't look deformed or different.'

Then with a magnanimous gesture, the plastic surgeon says 'Actually I can make you look even better. I can fix up your other breast as part of the treatment so it'll be covered under medicare. You can choose to have whatever size you want. I can make them bigger by inserting an implant into your other breast or smaller by reducing the size of your good breast. Just choose what you want' he says smiling, while passing a breast catalogue to me.

Avoiding eye contact with the couple in the waiting room, Mel and Izzy trudge off through the cold Melbourne winter day to the tram stop. 'I feel sick,' says Izzy, 'I don't even want his bloody breast catalogue. How dare he think I want to change my breasts so he can create his version of the ideal woman!'

'Yeah I reckon your breasts are just beautiful exactly as they are,' Mel says putting her arm comfortably around Izzy's shoulders.

'God I don't know what to do I'm so scared!'

'It'll be fine, you don't have to decide right this minute. At least they've caught it in time.'

Izzy can sense Mel's effort in trying to stay calm and not give in to her own fears. After all she has been here before. She nursed Roz, her previous partner, who she was with for 15 years, through surgery, radiation, and chemotherapy. Roz died within 12 months of diagnosis.

'Oh this is so fucked up! You've already had to go through all this with Roz, now it's happening again. I'm so sorry Mel. It's just not fair! 'Fucking breast cancer!' yells Izzy into the wind.

'It'll be ok,' says Mel softly, avoiding looking at Izzy. She doesn't want her to see her fear. Mel finds it hard to reach out and talk to others; she tends to bottle up her emotions. 'You'll be fine.' But I'm not sure if I will be she thinks.

Izzy too is lost in her own thoughts now. I'll do everything I can to ensure that she doesn't have to go through that painful journey again. I'm determined I'll beat this thing vows Izzy to herself as she feels Mel shrink inside of herself as they walk together lost in their own thoughts.

As they sit on the tram heading home Izzy looks around at the other women in the tram, surreptitiously checking out their breasts. Would anyone really notice if she didn't have breasts she wonders?

Izzy has always found her breasts to be a hassle. At thirteen, when she was more interested in playing sport with the boys in her neighbourhood, she was aghast to find herself suddenly sprouting breasts. Not delicate small budding breasts like the other girls, but large round curvaceous breasts belonging to a voluptuous woman, not the tomboy teenager she was. They imposed themselves on her like an alien life form. The boys, who had previously accepted her as one of their own in their games of football, now saw her differently through their furtive sidelong glances. Her breasts created an invisible force field around her that kept them at a safe distance.

They no longer tackled her to the ground and if they did grab her, their touch had a different feel and, with a self-conscious laugh, they would quickly let her go. Rather than part of the gang, she became their audience, as they showed off their prowess, always looking to see the effect of their athletic leap, or long kick. She became so self consciously no longer one of them, that she soon gave up playing football with the boys; her only choice was to join the admiring chorus of girls laughing coquettishly from the sidelines. Not fitting there either she withdrew into her own fantasy world, where she had lots of friends.

Izzy's ever-swelling breasts became a beacon for the gaze of boys and men. No matter how much she tried to hide them, she could feel the eyes of men burrow through her many layers of clothes to gaze wantonly at her breasts. They seemed to cast a spell. A spell she didn't want. She just wanted them gone.

Although others gained pleasure from their voluptuous beauty, she just felt their heaviness dragging on her neck, their obstruction when exercising. While she had to carry them around, her breasts didn't feel like they were hers. They were objects of other people's attention and holders of other people's stuff—envy, desire, curiosity. They stirred her mother's envy and her older brother's curiosity; he always wanted to see and touch them. She took on a slumped-over gait trying to deflect his gaze and the bathroom now became a combat zone that she had to sneak in and out of unseen rather than her previous haven of relaxation.

And now they are still causing her grief, putting her life at risk, her relationship at risk, stuffing up her future.

Before they arrive home Izzy has decided to have a double mastectomy. It seems a good deal, her breasts to secure a future free of breast cancer and thereby protect her relationship with Mel.

‘I think that’s overkill,’ her breast surgeon says in her calm authoritative voice, when Izzy tells her she wants to have a double mastectomy. Feeling overdramatic and foolish, Izzy doubts herself in the face of the surgeon’s powerful certainty. Izzy has always prided herself on being strong and fit and fiercely resisted being ‘unwell’ or needing doctors. Am I too, a hypochondriac like my mother Izzy worries? Am I guilty of overkill? Is it overkill to want to protect myself from a future occurrence of breast cancer and Mel from having to grieve the death of another partner? Feeling intimidated and close to tears, Izzy is too deflated to try to explain her complex reasoning to her all-knowing breast surgeon.

Izzy faces further questioning when one of her male friends demands, ‘why are you choosing to mutilate your body if you don’t need to?’ His use of the word mutilate cuts her to the core as it severs their former close friendship. It seems that others are personally affronted by her decision to remove her breasts to prevent breast cancer; that somehow she is breaking some social contract by choosing to have them removed. The possibility of not having a breast reconstruction seems to cause further offence. As she ponders her decision, she is confronted by a tangle of emotions.

‘My feminist beliefs should help me choose what to do’, she confides in a friend, ‘but then I worry that I am just doing what I think my feminist friends think I should do.’

Not knowing how to help Izzy, and feeling overwhelmed by her constant questioning of what she should do, Mel asks her friend Sue to catch up with Izzy for a chat. Sue, a solid no-fuss sort of woman who works in finance, has also just been diagnosed with breast cancer and has undertaken extensive research. Over a coffee at an inner city café, she regales Izzy with facts and figures about the life expectancy of women with breast cancer and the risks of the different treatment options. She too is weighing up

whether to have a breast reconstruction or not.

‘If I have a reconstruction, I just worry about putting my body through a lengthy eight-hour operation, then having to stay in hospital for three weeks while I recover’ Sue confides. ‘Whereas if I just have a mastectomy, its only a two-hour operation with a three-day hospital stay. But I don’t know what to do, I’m scared. I’m scared I’ll die having a reconstruction. That I’ll survive breast cancer but die having a breast reconstruction.’

Close to tears, Sue tells Izzy that at her appointment yesterday, her breast surgeon had shouted at her ‘Haven’t you decided yet whether to have a breast reconstruction?’

‘I was saved from making a decision about a reconstruction,’ Sue says with excitement when she and Izzy next catch up. ‘All the plastic surgeons went to a conference in Fiji’ she laughs, ‘but my husband thinks I would feel better if I have a reconstruction.’

‘But its not his body’, Sue continues.

‘He says he doesn’t care what I look like but he just thinks I’ll feel better about myself if I look more normal,’ says Sue. ‘I’m not doing it out of vanity as I’m past being concerned with how I look ... I just don’t want to be reminded of my breast cancer every time I see my scar. I want to put the whole cancer thing behind me.

‘Yeah, but I don’t think I’ll have a reconstruction’

‘But won’t you feel deformed?’ Sue exclaims.

Deformed! Mutilated! Such powerful language to describe my body without breasts thinks Izzy.

‘But,’ Sue adds, ‘I’m terrified of dying during complicated surgery, especially as it is not necessary to save my life. I should just get over my fear and do it!’

*I am incomplete
 I am sad
 I wrestle with the deformity
 I am incomplete
 Forget about it enjoy the moment
 But what does the future hold?
 I should get over my fear and just do it.*

As a 45 year old woman, Izzy discovers that she is surrounded by female friends, relatives or acquaintances who have breast cancer. With 1 in 8 women diagnosed with breast cancer in Australia this is not surprising.

*Shared experience
 of this sad state unites us
 but awakens
 my fragile mortality.*

Alice, a former colleague of Izzy's has also recently been diagnosed with breast cancer in her milk ducts. She has had a double mastectomy and breast reconstruction using saline implants. She tells Izzy that her time supporting women with breast cancer determined her choices.

'I always knew I would have a double mastectomy and breast reconstruction if I ever got cancer. Even though people ask me why I would mutilate myself in this way.' Her use of the word mutilate jars. Why do people use this term to describe a mastectomy.

Alice's experience of having breast reconstruction surgery is not smooth sailing

though and only adds to Izzy's fear and confusion. Over lunch Alice pours out her story of her breast reconstruction surgery in a desperate rush. It's as if she's afraid she won't have time to tell it all.

'After my surgery I knew I wasn't well, something was wrong, but the doctors didn't believe me, and sent me home anyway. I became really sick and went into serious organ failure as a result of an extreme reaction to the drugs I was on. I kept ringing the hospital and saying I felt really sick but they just told me that was normal. After a few days I was admitted to intensive care in serious danger.' Before Izzy can get a word in Alice rushes on, 'I had to work so hard to appear calm and rational as I knew that'd be the only way I'd be heard. I'd learnt how I had to relate to doctors from my years of working in hospitals with women with breast cancer. I knew not to act like a helpless patient but to case manage myself like a professional, to get my story straight, to sound sane. To engage doctors I had to be calm, speak quietly and not show emotion. So even though I was really, really sick I still had to try and maintain control. My plastic surgeon didn't want to hear that I wasn't OK. I had to focus all of my energy on presenting myself, and my story, in a way that he could hear me. I nearly died but he didn't want to know because it didn't fit with his expectations.'

'He screwed up by going away for the weekend and not leaving notes regarding my medication', Alice continues angrily. 'I think he was just worried that I'd sue him.'

Alice finally pauses for breath and takes a mouthful of her pasta and a gulp of red wine. Speaking in a quiet voice she then tells Izzy of a weird thing that happened to her before her surgery. She says that her breast surgeon, Vanessa, came and sat on her bed for a chat one night and asked her what she thought of Greg, her plastic surgeon.

Alice says she was taken aback. She didn't know if it was a trick question or not. But she had told her that she thought Greg was a typical plastic surgeon, highly skilled, arrogant, and charming. Vanessa had then confided that they had been at a training session together about managing mistakes, and were told about research that showed that if something went wrong, all patients want is for their doctors to acknowledge what had happened and say sorry. Vanessa claimed that Greg was adamant that he would never admit he had made a mistake and say sorry to a patient as he thought this would make him vulnerable to being sued.

Shrugging her shoulders Alice says, 'I don't know why Vanessa told me this; she just came and sat on my bed before my operation and told me. So I was prepared when he did make a mistake. I didn't expect him to acknowledge it.'

'The breast cancer bit was easy, the operation was easy, it's what happened after that was so bad. Knowing I was so sick and not being believed, not being listened to. For me the trauma was in not being listened to, not my experience of breast cancer', Alice says, a catch of emotion in her voice.

Listening to Sue and Alice doesn't inspire Izzy with confidence. Like Sue, she too gets a reprieve from making a decision as she has her mastectomy operation the week before Christmas when all the plastic surgeons are on their summer holidays. On Christmas Eve Mel and Izzy get the best Christmas present ever, when her surgeon informs Izzy, 'We got clear margins, your lymph nodes were clear. So for now you're in the clear. You can enjoy your Christmas.'

But it wasn't really much of a Christmas. Since coming out as a lesbian to her traditional Maltese family in her 30's, Izzy has had limited contact with them.

Christmas is always a hard time for her as she misses the big boisterous celebrations with her large extended family—being fussed over by her grandparents, chatting to her cousins, and playing games with her nephews and neices. She is still close to her sister, who always invites her to spend Christmas Eve with her husband and children. But it's not the same. With no children and no real sense of family, Izzy sometimes feels very alone in the world, particularly at Christmas. Mel, an only child, celebrates Christmas with her parents. And last year Izzy was invited along, but she felt like an imposter, Mel's parents kept telling her how beautiful Roz was, and how much they all still missed her. This year she just feels sick and sorry for herself as well as lonely. Her chest is sore, she feels grumpy and angry.

Looking at her breastless chest she wonders where her breasts went after they were cut off. She imagines them as two cherry topped crème brûlées being carried off on a silver platter. Like the picture of St. Agatha who had her breasts cut off by the pagan governor because she refused to accede to his sexual demands.

Where did they go?

When the surgeon cut them off?

What did they do to them?

What about the stories they contained?

Where did they go?



'I don't know what to do,' complains Izzy for what seems like the hundredth time. 'Should I have a reconstruction? Why would I? How would I feel if something happened to me during the operation?'

'Do you still think I'm beautiful without breasts?' Izzy asks.

'Of course I do,' Mel says with a hint of irritation,.

'I don't want to put you through waiting for me to come out of another operation, says Izzy, wondering if I have survived.'

'Do what you want, its your body, you're the one that needs to decide what to do. Don't worry about me. I've done it before I can do it again' Mel says stoically.

'I know what I want. I just want to go back to how we were before I had cancer.'

'Perhaps we should go back to Italy for a holiday.'

'I don't have any more leave left,' replies Mel practically.

Izzy can feel their relationship slipping away. Mel has been patient and uncomplaining in her support as Izzy navigates the various hurdles of the breast cancer treatment regimen. But Izzy's worried. Although Mel is loving and considerate, Izzy can feel Mel shutting herself off as she protects herself from further pain. Izzy wished Mel had someone she could talk to about her fears. Mel doesn't really open up to her friends and they haven't been able to find any support for female partners within the breast cancer services.

Mel keeps telling Izzy, 'I'll be ok, just concentrate on looking after yourself.'

But will she wonders Izzy? Will we survive the challenges of breast cancer?

Izzy remembers trying to find some support for Mel. She researched the web for support for lesbian women diagnosed with breast cancer and their partners. Finding nothing she had become outraged at the invisibility of lesbians. The Australian National Breast and Ovarian Cancer Centre Website has a section on supporting men whose partners have been diagnosed with breast cancer but no mention of women who have female partners. Under support for partners their website states:

More than 12,000 women are diagnosed with breast cancer in Australia each year. For every woman diagnosed there will almost certainly be a man in her life – a husband, partner, son, father, brother, or friend – who will also be affected. When a woman is diagnosed with breast cancer, she faces a challenging journey that can turn her life upside down. For the man who loves her, this can be a frightening new frontier, and a difficult and isolating experience.

'What about the woman who loves her female partner with breast cancer? Where does she go for support?' Izzy screams at the computer.

Confiding her concern about Mel with a group of their lesbian friends, they have a heated discussion about the different experiences of men and women faced with the reality of their partner having her breasts removed.

'Because we both share the same anatomy there is a different level of empathy,' says Jen looking lovingly at her partner Kat.

'It really hits home how horrible it'd be to have no breasts,' replies Kat.

'Yeah and breasts are so important in our lovemaking,' Zoe says smiling as she brushes her hand sensually over her partner, Julie's breasts.

'If men could put themselves in the position of imagining that they had a male partner who was having his penis removed, they might get a better understanding of how it is for lesbian partners,' Izzy says angrily, 'I'm sick of always feeling invisible. Of always having to explain my relationship to people like doctors, as if I'm part of some weird cult.'

But, apart from friends who tried to understand, Mel wasn't able to get the support she needed. Although she wasn't explicitly excluded from the medical system, she felt like she was tolerated, rather than fully embraced in the way that male partners are. The medical staff treated her as if she were Izzy's friend, rather than her partner,

who desperately needed support to survive the possibility of losing another person she loved to breast cancer.

After her operation Izzy felt raw, hurt, deformed, and yes, mutilated! Rather than the nice neat line across her chest, as promised, she had a lumpy jagged slash. She felt like a bag of wheat that had been cut open and then roughly stitched back together. Without nipples her chest looked even more weird. She felt like she had a tight band wrapped around her—she felt constrained and constricted as she struggled to breathe.

Izzy continually mulled over how she could make sense of her new body? A body without breasts? Breast cancer brings to the forefront our relationship with our breasts our own nurturing and sexuality. Our breasts are the signifier of our femaleness, and create the beautiful symmetry of the female body. But in western culture they are objectified by the male gaze and exploited to sell everything from sex to cars. A woman's breasts represent the conflictual views of female sexuality, of the Madonna or the whore. On the one hand they represent the role of the mother as nurturer, of the giver of life while on the other they are portrayed as erotic symbols of sexuality, used to titillate and objectify women.

Like Izzy, many women have complex relationships with their breasts—they may be too big and a focus of unwanted attention. Or not enough—too small, too saggy, not the right shape! Breasts are a very visible symbol of women's sexuality and beauty. We hold them up, pad them, lift them with wire, push them up, push them together, to make them appear more than they are. Or we flatten them, bandage them to try and make them invisible. Some women want larger breasts so have breast enlargements while others have breast reductions. Some women like to play

around with their gendered appearance and dress as men creating a masculine chest through tightly bandaging their breasts away. The idea of using a bandage to flatten chests seems ironic when viewed alongside images of women with bandaged chests following breast enlargement surgery: all these women with bandaged chests for such different reasons and outcomes.

Although she didn't like to admit it to Mel, no longer having breasts had brought Izzy some relief. She felt a sense of liberation in no longer having her D-cup sized breasts mediating between herself and the world. She felt safer in the world without her breasts.

Izzy had still not decided whether to have a breast reconstruction or not. She was aware that presenting the reality of her choice to the world could come across as a political statement—as a challenge to the pervasive norms of what a woman should look like. Some people reacted angrily when she told them she probably wasn't going to have a breast reconstruction. They seemed to take it as a personal affront,

After one such incident Izzy said in exasperation to Mel, 'Being a lesbian doesn't help! It just re-affirms for them that I am not a proper woman.'

Breast free

Restless with breastless.

My scars no longer mark an absence, but remind me

Re-mind me, draw me towards

a new way of seeing.

Look! Can you see what's not there,

*who's not here
what isn't*

(How much have I missed?)

*My scars are my warnings: don't be careless. Look into.
See beyond. Take care what you're
stepping on,
taking
over.
Phantom pains have taught me
to believe in ghosts.*

*The presence of absences.
How lucky for me these scars came
just in time.
Earlier, I wasn't ready
for this
richness.*

Although Izzy didn't really miss her breasts, she did miss her nipples. Under Mel's loving touch, her nipples awakened, they became sensitised and an important part in their love-making. Now they are gone. Izzy is left with a chest devoid of any sensuality. Where do I fit she wondered? She'd always imagined that without breasts her chest would just look like a man's. Like a man, she had looked forward to the freedom of being able to just strip her top off when sitting in the sun. When she shared this with Mel she was horrified.

'I'd be too embarrassed to sit with you if you took your top off in public' Mel exclaimed.

'Why?' asked Izzy in genuine surprise, 'does my chest still hold some sexual identity or is the lack of breasts too horrifying to see? Why should I feel ashamed of my scarred chest? What if it were a scar on my back? How would you feel then?' 'What makes a mastectomy scar so shocking—the absence of breasts?' Izzy says her anger deflating.

'Don't be so dramatic,' Mel says irritably, 'if you want to go topless do it, just not with me.'

'I don't see why I have to wear other people's discomfort, including yours,' retorts Izzy feeling her breathing quicken. 'I can't even go swimming anymore because everyone stares at me when I get changed.'

'Well maybe you need to not worry what other people think,' replies Mel calmly. Feeling herself starting to lose it in the face of Mel's composure, Izzy recalls her recent attempt to go swimming in the local public pool. While changing into her bathers she had found herself being stared at by a little girl who had pointed at her chest and asked her mother.

'Mummy why doesn't that lady have any boobies—she looks funny?' And her mother just looked embarrassed—she didn't even acknowledge Izzy as she said in a hushed voice, 'don't stare at the lady.'

The cutting away of Izzy's breasts seems to have cut away at the connection between her and Mel. Mel wants to help—she fusses around Izzy.

'You are still beautiful to me' she says as she tries to caress Izzy's body. But Izzy can't bear to have her touch her. Her body feels sore and sensitive. She feels raw, as if her skin has been peeled away to reveal her bloody weeping insides. She wishes Mel could understand, she just wants to be held and comforted. She knows

Mel is getting frustrated and losing patience with her. She feels a chasm growing between them as they both struggle to meet each others needs but not knowing how to.

Mel's pain is also raw and intense as she confronts her own past grief. The more Izzy reaches out to her the more Mel withdraws into her role as the practical nurse. She can do all the physical care but can't deal with emotions.

'I was able to help Roz' she says, 'she appreciated everything I did for her. Even though she was so sick during her chemo she didn't complain. Right to the end she stayed positive' declares Mel.

'Great,' Izzy mutters under her breath, 'trust me to have the misfortune of having a saint to be compared with!'

Roz did breast cancer the right way, the way that is depicted in the media. Where women with breast cancer are supposed to be stoic, uncomplaining and cheerful and feel grateful for the gift of breast cancer, while still looking gorgeous! Just like Kylie Minogue, Angelina Jolie, and Jane McGrath.

As their relationship starts to unravel, Izzy feels so alone. Alone in the world, a 45 year-old lesbian without breasts? Where do I go for help she thinks? Where does Mel? She searches out cancer support groups both online and in their area but they seem to be all about tea and scones and forced cheer. Izzy feels pissed off, angry, ugly.

'I don't want their tea and scones, good cheer, their stiff upper lip shit.' She tells her friend Kat, 'everywhere I go I feel accosted by pink breast cancer stuff.'

Izzy is astonished to find herself, a lesbian woman in mid 40's, engulfed in girlish pink. She becomes increasingly enraged by all this pink, and points out to Mel that

the breast cancer pink lady logo doesn't even have breasts!

'It reminds me of the sign for a female toilet' Izzy says in disgust to Mel.

'But at least they're raising all this money for research' explains Mel. 'Surely that's a good thing.'

'But it so disempowering' exclaims Izzy, 'I feel so exploited. All these companies exploiting women with breast cancer for their own commercial gain. It makes me feel sick.'

'It presents women as docile pretty victims' Izzy continues.

'But maybe that's the best way for them to attract money. Would you prefer them to use pictures of women with deformed chests to try and raise money' Mel retorts, 'I don't think that would work.' 'I don't know why you have to get so angry about everything and make everything such a big deal' Mels says in exasperation. 'Can't you just focus on getting yourself better? Why do you always have to make everything into a feminist cause?'

'Why can't you understand how this pink cancer stuff affects me. It makes me feel alone, isolated, exploited and weak. I want to draw on my strength,' Izzy responds trying to hide her increasing frustration and anger with Mel, 'it's the wisdom and strength of the earth mother inside me that'll get me through breast cancer, not this bloody pink lady bullshit!'

*I want to be strong, in charge
connected to my female wisdom*

*My wise earth mother
draped in the colours of autumn. Rather than being contained
in this pink straightjacket,*

*I want to get down and dirty
in the sweet, rich, moist fecundity of the earth.*

Out of the blue Sue phones Izzy, she has had a breast reconstruction. She had tissue taken from her stomach to make a new breast.

‘The operation was painful and it’s been a pretty long recovery, but I’m glad I finally had the courage to go ahead with the surgery. I feel much better, more complete. And my husband is happy too.’

Izzy has finally decided not to have a breast reconstruction. She and Mel broke up a year after her diagnosis. Their connection wasn’t strong enough to withstand the trauma of breast cancer. Mel realized that she just couldn’t go through the prospect of losing another partner to breast cancer and decided to call it off and asked Izzy to move out. Izzy has found a new flat to rent and is trying to get her life back on track. She feels alone and angry but realises that breast cancer made her and Mel confront the reality of their relationship; it highlighted the things they didn’t like about each other. The ghost of Roz hung over their relationship. Although she understands how hard it must have been for Mel, Izzy is angry that Mel wasn’t able to be there for her when she needed her. Perhaps if they had both been able to find the right support to help them through, things could have been different. But they needed people who truly appreciated what they were going through. Izzy needed people to appreciate her anger and confusion and the importance of her relationship. Being encouraged to dress in pink and have fun just didn’t help her. Being seen as friends rather than partners, by the medical system only made things harder for them.

Fighting for without fighting against

Inside coming out

Different strands

Mixed up

Messed up

Tangled up

Freed up

I don't want to have to be as strong as I have to be.



Chapter eight

Showing my story



Don't turn away I implore. Amidst the noise of clinking glasses, laughter and chatter, I feel you reach out. You give me your full attention, I feel you connect with my story. I feel your emotion as your own story bursts forth to meet mine. It feels good to know that I have created the space for you to see the experience of women with breast cancer in another way.

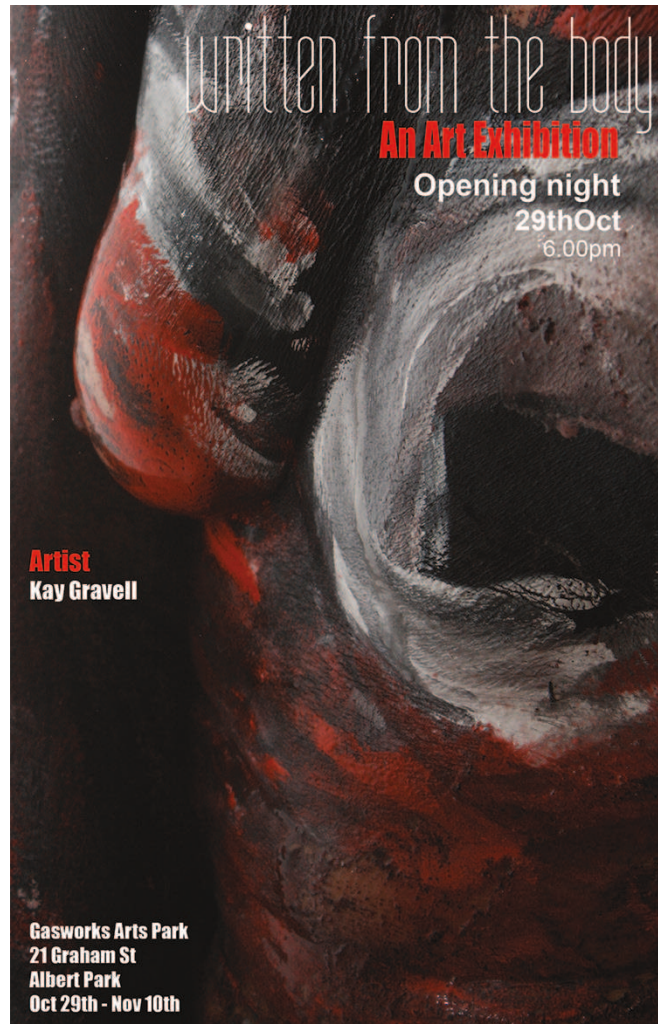


Image 8.1 Exhibition invitation.

I paint my body memory into text. Making art creates a powerful space for people to make sense of their experience of trauma or illness; to express complex emotions that are difficult to put into words. I am interested in the idea of bringing embodied meaning into words. Using my body as both a canvas on which to paint, and as a medium to create printed images, allows me to come to accept my changed body.

The meaning of my breast cancer journey gradually emerged through my art-making.

From a jumble of emotions and letters a narrative, in three colours, formed to convey the healing journey of one woman's experience of breast cancer; from fear and grief to anger and passion and finally to a place of acceptance and appreciation of the joy of living.

Introduction

As I moved through my enquiry I had a strong desire to take the artwork, initially created in intimate spaces, to a broader audience. My primary reason for wanting to do this was to show my own experiences of breast cancer. I recognised the importance of having my experiences acknowledged and legitimised by others as part of my own healing process. I felt so angry at not being seen, not having my experiences of breast cancer reflected in the public narratives; this was an opportunity to act on this anger. I wanted to create the opportunity for a dialogue of an alternative breast cancer narrative, one that reflects the mess, anger, and pain of my experiences in the hope that it might connect with the stories of other women and legitimise the range of women's experiences of breast cancer. Showing my own vulnerability through my own story, I hoped to pose questions that "might otherwise remain unasked" (Barone & Eisner, 2012, p. 133) so that others might be open to see women's experiences of breast cancer in a new light, and bring this new understanding to the way they respond, whether as friends, colleagues, or health professionals, to women with breast cancer

The process of organising the exhibition of my artwork, selecting what to show, determining how to present my work, consulting with the gallery curator, holding an opening night, and being present while people viewed my work, raised many unforeseen challenges which provided the opportunity for me to gain increased understanding. In this chapter I outline my motivation for wanting to show my artwork to a broader audience and elaborate on the challenges and opportunities afforded through the process of exhibiting my artwork in a public gallery. I have included my artist statement for the exhibition in Appendix three.

After opening night

I am sitting in bed. It's 2.00 am, after the exhibition opening night. I can't sleep. I feel deflated, vulnerable, with a sense of regret at having shown too much. It was an amazing night. A room full of friends and family looking at my art that was made in my home, now brought out into the full glare of a public space. People staring at photos of my naked body. My raw emotions on show.

The responses were rich and supportive. The common refrain "you are so brave, so courageous to show so much of your self your emotional pain, your grief." Do I feel brave? Not at the moment. During the night I felt euphoric; so loved and supported. But now I feel empty, deflated, exposed. Alone in the middle of the night my timid voice, my shy private voice is finding the space to say "oh, no what have you done?" I feel like I did, when as a young woman, I would awake full of regret and remorse the morning after a big night in which I had drunk too much, been out of control; that awful feeling of slowly recalling, in the harsh light of day, the embarrassing actions of the night before. Did I really do that? Lose control, reveal too much, and expose myself? That slow realisation creeps in. Oh no what have I done? Did I make a fool of myself? Can I go and pull down the images from the wall? Can I withdraw myself from the public gaze? My work is on show for another two weeks. To be now viewed by strangers.

I had this stupid grin on my face all night, almost a grin of hysteria. I felt both overwhelmed by the enormity of what I was doing while at the same time I felt slightly

dissociated from my artwork on the walls around me. I wanted others to connect with my experiences and also to affirm me as an artist. While people were in tears as they responded to the pain captured in my work, I felt detached from such emotions. I no longer feel this pain. I have moved on from the rawness displayed on the walls. When stuck in grief, fear, pain, and anger I felt driven to explore these emotions through making art, which was reflected in the colours of black and red. Once I connected with the joy of being alive, I no longer had such a desperate urge to keep creating art so there is much more black and red artwork than there is blue and gold, the colours representing my acceptance and joy. A few people commented that they felt my art was very dark. It seems to be confronting for people to be faced with the black. I sense that some would prefer I kept my blackness inside, hidden away. This distaste for exploring the dark side of experience seems to reinforce the tyranny of cheerfulness narrative. I wonder why it is seen as brave and courageous to show my emotions.

Sitting in the night, staring at the glow of my computer screen I reflect on why I wanted to show my artwork to a broader audience, what drove me to expose myself in this way?

Why have an exhibition?

My reasons for having an exhibition were varied, and changed over time, however, the desire to show my artwork, as a way of sharing my story, has been an integral part of my enquiry. As discussed in the previous chapters, showing my artwork to a supportive other, to facilitate a deeper exploration of my art representations, and

receiving their artistic response, has helped me to come to know more, than I otherwise would. As I became aware of the shame I felt about my one breasted body, and my sense of outrage at not being seen, the idea of showing my artwork to others beyond a supportive companion, surfaced as an important part of my arts-based enquiry. Additionally, in recognition of the power of the personal to bring about broader social change, I was committed to challenging the dominant breast cancer narratives and creating the opportunity for dialogue about alternative narratives.

Historically there has been a concern with the ethics of displaying the artwork of others, created as part of a therapeutic process (Wadeson, 1980) and even whether art created as part of a therapeutic process should be considered legitimate art at all (Alter-Muri & Klein, 2007). More recently, however, there has been an increasing recognition of the value (both at an individual therapeutic level and a social change level) in showing artwork created as part of an arts-based enquiry to a broader audience (Barone & Eisner, 2012; Finley, 2008; McNiff, 2011a, 2013b; Moon, 2009, 2010; Potash, 2011; and Stepakoff et al, 2011). Many arts therapists see the witnessing of art as integral to arts-based personal enquiry and contend that without this, the art experience and the art itself are not complete (Allen, P., 2007; Lu & Yuen, 2012; McNiff, 2013; Moon, 2009). Witnessing the artwork of another or of the self is described by Shaun McNiff (2013) as more than observation, it is an embodied process requiring “empathy, compassion, and creative perception” (p.38) developed through practice and discipline. This contemplative, often, silent attentive process is one of non-judgmental support; it is active but not interpretative. This form of witnessing has been incorporated into my enquiry process.

Despite having my artwork witnessed in this way I still had a strong desire to share my experiences more widely, to challenge the secrecy of women's experience of loss in relation to breast cancer. Bringing women's experience of grief and loss out of the shadows and its surrounding silence can be an important aspect of healing, especially if there is an associated aspect of shame or stigma, as can occur with women who have had a mastectomy (Batt, 1994; Saywell, Henderson & Beattie, 2000). The making and showing of artwork to an audience has been found to assist women with breast cancer to affirm and proclaim their present existence, strengthen their identity and increase their sense of connectedness (Collie, Botorff & Long, 2006; Luzzatto & Gabriel, 2000; Malchiodi, 2012).

I resonate with Leckie Hopkins (2003) when she asks in relation to her own breast cancer experience, "how do I story the raw life of this?" (p. 132). I too want to make sense of my experience, to find my own multi-faceted story, which spoke of my fear, anger, sense of loss, and shame as well as of my celebration of life. In time, as I reached out into cyberspace and into the literature of breast cancer narratives, I began to come across the stories of other women with whom I could relate; other women who, also angry about their invisibility, drew on their feminist understanding to challenge the simplistic "courageous survival narrative" (Hopkins, 2003, p.134).

There is a strong tradition of showing artwork as a way of publically sharing a personal story in a way that challenges dominant discourses (Murray, 2000). By showing my own story as honestly as I can, I hoped to join with other women (Acker,

1995; Ehrenreich, 2001, 2009; Kohlman, 2005; Krupar, 2012; Lord, 2004; Lorde, 1980; Nielson, 2010; Sedgewick, 1993; Spence, 1986; Vitry, 2010) in challenging the societal constructions around female bodies and breast cancer that reinforce the shame around my imperfect body. I too want to contribute to the growing practice of creating social change through art (Levine, S. 2011; Levine, E. 2011, White, 2009) with the acknowledgement of the important role of showing artwork to a broader audience as a major contributing factor (Finley, 2008; Stepakoff et al, 2011; Timm-Bottos, 1997). As Malchiodi (2012) contends, activist artwork by women with breast cancer can be a way of proclaiming "I am here" (p. 399).

The imperative to break through the pretty pink wrapping and show another view of breast cancer has perhaps been most powerfully expressed through photography. In 1980 the feminist poet Deena Metzger spread her arms wide and bared her unreconstructed chest adorned with a tattoo, this iconic image, titled *The Warrior* (image 8.2) became the first widely distributed photo of a woman showing her post-mastectomy body and became a symbol of women's pride in their scarred chest and a "landmark insignia of feminist iconography" (DeShazer, 2008, p. 33).

Soon after my mastectomy a friend gave me this image. It had been given to her when she was diagnosed with breast cancer but she said she now no longer needed it and wanted to pass it on to me. This act of passing on an image of strength and pride was a powerful reminder to me of the importance of women reaching out to each other in challenging the idealised versions of the female body. This photograph has accompanied me on my breast cancer journey and inspired a series of photographs of my own naked scarred chest (Image 8.3 joy in life). Another friend then gave me Jo Spence's (1986) photographic autobiography, in which she chronicled her breast cancer journey using her photographs to present her truth to the world.



Image 8.2 The Warrior



Image 8.3 Joy of life

The power of imagery to challenge dominant narratives was graphically illustrated when Matuschka's iconic self-portrait, *Beauty out of Damage*, which revealed her chest following a mastectomy, appeared on the cover of the 1993 New York Times Sunday Magazine. This image, which was seen as provocative, beautiful, confronting, and challenging of female notions of beauty, went on to become one of the most published pictures in the world appearing in hundreds of international publications, books and on TV shows and in documentaries. In 2011 it was chosen by LIFE magazine as 1 of 100 pictures that changed the world since the camera was invented (Sullivan & Burrows, 2011). In a letter to the editor, a woman wrote: "with one blunt image the New York Times made an artistic and political statement about cancer, women, and our culture's narrow view of what is feminine, physical and beautiful despite being 'imperfect' and 'flawed'" (New York Times, 1993). Artists such as Lynn Kohlman (2005) and sculptor Helene Hietanen (2002) have also used photographic images to capture their transformative breast cancer experiences.



Image 8.4 Beauty out of Damage

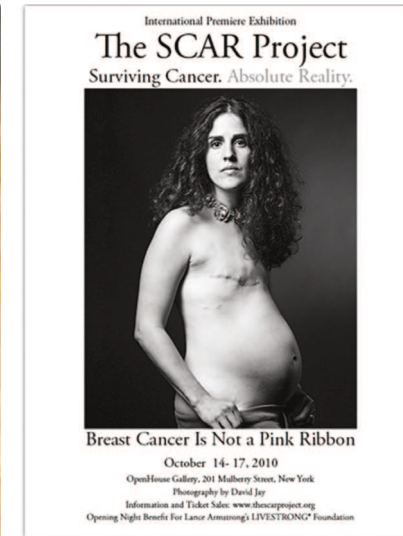


Image 8.5 The Scar Project

The Scar Project (2014), which uses beautiful photographic images, shot by fashion photographer, David Jay, to help young breast cancer survivors reclaim their femininity, their sexuality, identity, and power, continues this tradition of challenging the shame of not conforming to the normative view of female beauty. More recently the Grace Project similarly uses photography by Charise Issis, this time with older women who have undergone mastectomies, to turn the female nude trope on its head, transforming pieces of art history to illuminate both the pain and resilience of breast cancer survivors (Brooks, 2014). Performance artist Tutu presented a more confronting and angry perspective. "From the start, she wasn't feeling the 'pink and pretty' way

women are supposed to relating to this disease”, explained Ashley Savage (2014), of Performance artist Tutu, whose breast cancer story began in 2009 and is portrayed on her blog Cancer sucks (www.savageskin.co.uk/public/Cancer_Sucks.html).

Despite the work of these artists, breast cancer is still hidden behind a small pink bow and the image of a woman revealing her mastectomy scars is still seen as confronting and shocking. This was powerfully demonstrated when an Australian woman, Beth Whaanga, received international attention when, determined not to be ashamed of her post surgery body, she posted photographs of her body showing her breast cancer scars on her facebook social media page (www.facebook.com/underthereddress?fref=ts). She was horrified when more than 100 people “unfriended” her because they deemed the pictures offensive. As reported in the Guardian on 17th February, 2014,

The fact that she is a young attractive woman appears to have incited some of the censure directed at her . . . It seemed as if she was being punished: first for not staying in her ‘sexy/attractive’ box and then for not hiding away, ashamed and cowed, like a good deformed girl should” (Ellen, 2014).

Other women have risked public censure and used drama, film or performance to show their bodies as a way of depicting their breast cancer experiences. Susan Miller’s (1995) play *My left breast*, Sonia Báez-Hernández (2009) film, *Territories of the breast* and series of installations that incorporate fiber, photography, knitted and found objects (2014), and sculptural works of Alyson Baker (2012) all explore notions of the changed body following breast cancer treatment. Breast cancer has inspired a rich

tradition of women using arts to explore their confusion, pain, conflict, and identity brought about by their changed body within the context of the culturally defined gendered breast. In this tradition I too have created artworks, photographs, and short films to explore my changed body. It is this work that I wanted to share with a broader audience.

Organising the exhibition

Choosing the exhibition space

I could have held my exhibition in a friendly and supportive environment such as the MEICAT gallery space; however, I wanted to bring my experience of breast cancer, in all its complexity, out of the shadows and into the full glare of a public space. I did not want my artwork to be seen within a health or therapeutic context but as part of a normal community experience. I chose to exhibit my work at Gasworks Arts Park a community arts park, close to where I live. Gasworks Arts Park, a former industrial gas plant site, comprises artist studios, parkland, gallery spaces, and a community theatre. My work was shown in the public foyer gallery of the theatre. I accepted this space knowing that, apart from the opening night, in which I was able to speak, I would have minimal opportunity to create a context for the audience to explain my intention in showing work that could be seen as confronting. Given the experience of other women such as Beth Whaanga, who was censored for revealing her breast cancer scars, I was aware that the photographs of my scarred chest could receive a similar response. Every person, however, confronts art or art-based research “from their own

unique worldview” (Barone and Eisner, 2012, p. 113), I therefore accepted my limited ability to control the context and reading of my work. Despite this acknowledgement, the fact that many people would view my artwork in an incidental way as part of their visit to the theatre left me feeling vulnerable.

Opportunities and constraints of the space

The theatre foyer and hall, which was previously the turbine room, has been transformed into a large, airy, light, white walled foyer with high ceilings, plush carpet, and velvet curtains in ruby red. The space retains its former industrial feel through its painted rough brickwork and high ceilings with exposed pipes. The high ceilings and large windows create a sense of airy lightness, which I felt could hold the darker aspects of my work. The size and layout of the space provided the opportunity to display large artworks on its white painted brick walls, while the room’s red and white colour palette displayed my mainly black and white work, with red and blue accents, to good effect. The doors to the theatre are at the centre of the back wall opposite the large front entrance. I had originally wanted to suspend a large hanging sculpture from the ceiling in the middle of the room but was informed that this was not possible as the central area has to remain clear as it is a public walkway for the theatre. So I compromised my vision, something that as Tom Barone and Elliot Eisner (2012) point out, comes with the process of re-presenting art from an arts-based enquiry to a gallery with different goals. I created a smaller hanging sculpture to suspend in one of the corners.

Creating a narrative: What to include and what to omit

I wanted the artwork to tell the raw emotions of my story and in the tradition of other artists (Hietanen, 2002; Kohlman, 2005; Matuschka, 2014; Metzger, 1989), I also wanted to challenge the idea of the normative body by showing the reality of my one-breasted body. The decision to display my naked scarred chest was challenging, but my desire to confront the lingering sense of shame about my body, overrode my fear of exposure. I had initially planned to include an interactive piece critiquing the pink lady symbol, in which members of the audience, posted their own representations of breast cancer over a large pink lady sculpture, but I thought that this might be too confrontational for people who were just having a night out at the theatre. Given the widespread occurrence of breast cancer it was likely that the majority of potential audience members would have some personal experience of breast cancer and I didn’t want to disrespect personal memories of a loved one who might have died of breast cancer and who may have felt sustained by the symbolism of the pink lady. I realised the danger of alienating or excluding potential viewers if I was too strident or offensive (Barone & Eisner, 2012) so I sought to invite my audience to connect with, and share, my experiences, without being too confronting.

The timing of the exhibition was also influential in determining what artwork to display. My first exhibition, at the start of my enquiry, reflected the shock of my initial diagnosis. This exhibition, which occurred towards the end of my three-year arts-based enquiry, formed a creative synthesis of my meaning-making into my breast cancer experiences. I had come to a place where I was able to provide a coherent narrative that incorporated the many aspects of my experience culminating in a place

of acceptance reflected in the joyful photographs of me leaping out of the ocean proudly displaying my scarred chest. If I had attempted to exhibit my artwork while still immersed in the raw emotions of pain and anger, the artwork would have told a different story.

Pressure to be cheerful

Whilst organising my artwork for the exhibition I confronted some major challenges arising from the differing goals of myself, as an arts-based researcher wanting to stimulate questioning about contemporary experience, and the gallery curator, who was keen for me to offer an uplifting story for visiting members of the public. She kept stressing, that as a public community space, I needed to provide a “feel-good” experience for people who might see my artwork. She even questioned the use of black frames for my prints suggesting that, as the colour of mourning, black would be too depressing. Her attitude reinforced to me the pervasiveness of the imperative to be cheerful.

My resolve, to tell my own story in my own way, was strengthened by my experience of the Victorian Cancer Council Arts Awards exhibition, coincidentally held in the same gallery the week before my exhibition. These arts awards covered a number of different art modalities —visual art, writing, sculpture, and film—with categories for adults, adolescents, and children. The gallery curator had privately expressed to me her dismay at the depressing nature of much of the artwork displayed saying she had placed works that she felt to be dark and gloomy in less prominent locations. I felt it

important that different representations were given space in this exhibition. Although there were many entries that fitted within the more traditional feel-good genre there were also a range of artworks that gave voice to the pain, anger, depression, loss, and grief of the experiences of cancer. This was poignantly present in the works created by the young people and children living with cancer. I submitted the short film, *The black hole of grief*, which won first prize in the film category. This recognition of the artistic merit of my artwork gave me more confidence to challenge the curator in decisions around what to display. While acknowledging the need to act ethically, with an intention to not cause harm to people who might view my artwork, I was also determined to stay true to my primary motivation for exhibiting my work, and not trivialise the experience of women with breast cancer by censoring out the pain and anger.

Influence of the gallery criteria in the selection of artwork to be displayed

As well as creating a narrative that would engage others, I was also responsible for presenting artwork that met the aesthetic standards of the gallery. For me, some of my most meaningful artworks were the life-sized body prints I had created on large pieces of paper. I had created these with the intention of exploring my experience, and not as artworks to be displayed in a gallery. The paper had become creased and tattered over time. Whilst I thought this added to the meaning of the artwork, the condition of the artwork was deemed by the curator to be of too poor quality to be displayed in the gallery. Instead she pressured me to use the ones I had printed on canvas, even though these were not the ones that held the most meaning for me. Whilst my belief

in the power of my story had enabled me to advocate strongly on the content of my artwork, as an untrained artist, I did not have the confidence in myself as an artist to effectively challenge these limitations placed on me in relation to the aesthetic quality. In not being able to insist on the use of the artwork that held the most power for me I felt my story lost some of its authenticity.

The gallery format also influenced the modality of the work I presented, with a strong bias towards visual art. I was able to present a short movie comprising my images, spoken word and music, at the opening night, however because of lack of security at other times, this could not be displayed throughout the exhibition. Some of the artwork I created, as part of my enquiry, had been ephemeral—such as movement, voice, sand trays, and temporary installations. Apart from recording in my journal and in photographs, this artwork no longer existed in a tangible form and could therefore not be displayed.

Thus there were a number of criteria that the artwork had to meet in order to be displayed as part of a public exhibition. It had to be in a form and of a size that could be shown in the space; it had to meet the gallery's standards in terms of the condition of the artwork, the aesthetics, and the content (it had to be suitable to be seen by all ages). It had to convey a narrative that would engage a community audience and be suitable for incidental viewing by members of the public who might be passing through the gallery to attend the theatre. Within these constraints, I chose artwork that conveyed the essence of my experiences, reflected the diversity of my art-making, fitted best within the gallery space and which I hoped would open up a dialogue

Exhibition as a new artwork

One of the foremost characteristics of the exhibition is its ability to be a total work of art. Like a painting or photograph, an exhibition adheres to the same criteria as any work of art that strives to produce aesthetic equilibrium, defined by what it includes and omits, and attempts to contribute to a larger artistic dialogue connecting history and contemporary ideology (Cline, 2012, P 83).

One of the key works was a hanging sculpture, which comprised different sized painted letters of the alphabet hung in a random fashion. I worked on this hanging sculpture while preparing my other artwork for exhibition. Creating this sculpture involved cutting out and painting over 100 alphabet letters, which I then strung onto separate strands of fishing line. The repetitive work of cutting, painting and hanging the letters helped contain my anxiety about the exhibition. I created each strand individually, attaching the letters in a random fashion. When all the strands were completed I brought them together and attached them onto one hook. The strands became tangled and intermingled forming a unified piece of work, telling a story of meaning gradually emerging. This seemed to reflect the process of bringing



Image 8.6 Meaning emerges

the individual artworks that held different meanings, together to form a coherent narrative.

I had planned to create a chronological representation according to the different colours, moving through the emotions of grief and loss, to anger, and finally to joy and acceptance. However, aesthetic considerations and the dimensions and character of the space, largely determined the placement of the artwork. The strongest works, in terms of aesthetic merit, were located at key viewing spaces beside the theatre doors opposite the main entrance. This disrupted my understanding of the relationship between the artworks, for example, the series of nipple paintings, which I had envisaged being viewed first, were located in the far corner of the room. I had imagined that people would view the artwork in a certain order, starting at the entrance and working their way around the room. However, as I later discovered, people entered the exhibition at different points and moved around in a haphazard fashion, further disturbing my planned chronology.

When I had finished hanging the artwork I sat alone in the middle of the room and contemplated the exhibition. I felt moved by the sadness and struggle held in many of the images, but as I looked around and tried to get a sense of it as a whole, the overriding feeling was of balance and symmetry. The space with its white walls, high ceilings, rich red carpet and crimson velvet curtains provided a good background for the mainly black on white artwork. The deep red carpet provided the perfect foundation, resonating with the blood red imagery of my arts-based enquiry and highlighting the energy and rich visceral texture of the large red body print on the

far wall. The few gold letters interspersed amidst the bunched black letters glinted in the sunlight. The cascading letters clinked musically and cast beautiful moving shadows on the walls as they moved slightly in the faint breeze. I noticed the different textures—the plush velvet of the curtains, the roughness of the brick walls, the rich layers of thick paint, the grainy imprint of my muscular leg, and the shiny wet-look gloss of the photographs of my painted skin. The images made from, by, and of, my body interacted with this large public space to form a multilayered story. The main colours of this representation were the white of the walls, and red of the floor and curtains, with my artwork creating accents of black. Viewed as a whole, the exhibition held a sense of lightness and space, the darkness only emerged when I zoomed in on individual artworks. This seemed to reflect my feelings of my own sense of lightness as I regained greater distance from my experiences of grief, loss, and anger.

Similar in colour and texture, the plaster casts emerged from the shadows of the wall against which they were suspended, subtle memories of before and after. Their delicate presence was in stark contrast to the prominent position in which they were presented in my first exhibition, when they were displayed as the only pieces of artwork on the one coloured feature wall. This brought home the realisation of how far I had travelled in coming to terms with my changed body. As I have moved onto explore other experiences, the focus on my changed physical appearance has moved into the background. I sat there and created a dialogue between the different artworks of the exhibition, which I captured in the poem.

*Acceptance
of my vulnerability allows me to be open,
strong, light and free. The pain of the loss of my breast
now a subtle presence in the shadows.
Emerging from the shadows, the complex layers
and emotions now integrated
and co-existing to form a new narrative of
the celebration of life.*

Dialogue between the exhibition and others

On opening night the room was crowded with people—friends, family, colleagues and full of energy—people talking, laughing, and crying. People moved around the space some in quiet contemplation, some moved to tears, some reconnecting with old friends. It felt special to have so many of my friends and family present to witness my many-layered journey. I had asked a friend to record comments from people attending the exhibition as a way of capturing their responses to my artwork. The following comments were recorded on opening night.

The textures are so inviting.

I was speaking to Kay's cousin and she was in tears as she was so moved by the exhibition and it made me realise how strong and visceral this art really is; it really gets you in the guts.

Having worked with many people who have had serious illnesses I am amazed at how Kay has integrated her own therapy in art; her emotional and spiritual integrative journey we can see here.

I have never really seen the pink lady stuff like that but it is so true.

I think she is so courageous to share so much of herself so honestly.

I think it is beautiful, the writing and images together are so strong.

I find the painting reflects a resurrection from a significant level of despair to an exuberance of life, it is something that we can all share, some of us have already been through it, others may go through it. It is very profound.

I love the depth of the feeling and the fact that it is presented simply; it is complex in meaning and intent but very simple in form and I think that is a skilful balance and it is the depth of the emotion that comes through.

When I listened to these comments the next day I felt seen and understood. My friends and family were able to connect to the different emotions of my breast cancer. I felt acknowledged not only in my experiences of breast cancer but also as an artist. I had felt driven to show my artwork as part of my personal healing and as a way of creating a different breast cancer narrative, however, until now I was less aware of my desire to be recognised as an artist. Having previously been told that my artwork was

not of a high enough quality to be judged on its artistic merit, I felt proud in seeing it displayed on the walls of a public gallery and on receiving comments from audience members such as “*I think Kay has a real talent and I think she is very brave. I love it.*”

Dialogue with the audience

I decided to immerse myself into the exhibition art representation and speak to the audience.

Here I am. I want you to see me, to acknowledge and understand my story. I invite you into my vulnerability. It feels scary, laying myself bare, opening myself up to your gaze. I have no control over what, or how, you will see. Will you be a voyeur and focus on the nakedness of my body? Or will you connect with the emotion of my journey? I want you to be able to see all the different shades and textures of my story, the pain and grief, the anger and passion, and the acceptance and joy. I don't want your pity. I want you to acknowledge my dignity, my vulnerability and my strength.

Why do I need your acknowledgment? For me to see my own story should be enough. But it isn't. I need you to see me. I want to be able to reach out to you as I feel your gaze—to feel a sense of connection. At times I feel superfluous; you thrust my pain to the background as you chat of everyday life. Don't turn away I implore.

Showing my personal experiences in authentic, honest detail with enough space for others to engage created a sense of connection. I felt seen, my experiences now acknowledged and legitimised. From the shadows into the light, the different strands

of my story were brought together in one place at one time; my enquiry now felt complete. Showing my story to others, sharing my experiences was a key part of my journey. Having had this experience I can now concur with Bruce Moon when he writes:

The act of creating is not an end in itself. It is not enough to paint, dance, or sing in isolation. There has to be an audience, someone who sees the drawing, watches the dance, or listens to the song (Moon, B., 2009, p. 99).

Another perspective through a creative response

I later received an intersubjective poetic response from my supervisor which she formed using my own words of my description of the experience of the exhibition.

The exhibition

Part 1 Organising the exhibition

*I wanted to be in the glare of the public
to be really seen
in my community
in the foyer
of a large white
renovated theatre
by all sorts of people.*

*I was told
I couldn't get in the way of the public,
that I needed to tell
a suitable story
with good materials
and well stretched canvasses.
Not the scrappy,
torn and creased story
told on large pieces of poor quality paper
that held so much meaning for me.*

*Part 2 setting up
I chose suitable art work
that opened up a story
That I told in the shadows of the corners,
and in full light
on the walls.*

*Part 3. Being present to the exhibition
I sat in the centre
feeling the balance of the red, black gold and blue.
I see
visceral textures
the sensation of skin.*

*I see
moving letters
cascading towards the floor
mainly black, with accents of colour
creating shadows where I think the meaning is held.
I see casts
Both white, one with two breasts
the other with only one
holding memories of before and after.
I see
My black hole of grief
No longer overpowering me.
I see
big body prints, muscular legs,
my body curled in and open wide
I do not feel vulnerable, but strong,
powerful and comfortable.*

*Part 4. On the night
A room full of people
I was overwhelmed
grinning
with hysteria?
Feeling disassociated from my work*

*I have moved on from this art
 No longer with a desperate urge to make
 Some said I was brave
 Others said it was too black.
 I felt I needed to be seen
 and acknowledged,
 so when people turned away to talk
 I felt superfluous.
 When you reached out towards me I felt connected.*

Part 5. After opening night

*I can't sleep
 I feel deflated, vulnerable
 regretful.
 What have I done?*

Meaning making has been described as an ongoing process of storying as we integrate new experiences into our understanding of who we are (Collie et al 2006; Frank, 1995). This response highlights the complexity of developing stories about ourselves. Showing my artwork to others provided a space for me to tell my story, a story told from my body. Reading this poetic response I now see that showing my artwork to others allowed me to see my own story more clearly. Seeing the different textures and attitudes of my body, seeing the different parts of my journey and the connections between them has enabled me to create a new storyline that incorporates

my changed body. This response highlights the tension between the importance of being seen as a way of coming to acceptance of my changed body, and the feeling of vulnerability that comes with showing my nakedness.

Most powerfully this response brings to my attention the constraints I placed on myself in telling my story, *"I couldn't get in the way of the public. . . I needed to tell a suitable story . . . with suitable artwork, not the scrappy, torn and creased story . . . that held so much meaning for me."* Although I wanted to tell my own unique personal story all stories are told within, and therefore influenced by, existing discourses. My exhibition was not only influenced by breast cancer discourses but also by discourses around art and the role of community galleries. In creating narratives with which to story bodily experiences, the impact of audience and the availability of particular discourses must be acknowledged (Hopkins 2003). My decision to show my artwork in a public space meant that I was subject to both subtle and not-so-subtle forms of censorship, both from the gallery and from myself, which influenced the story I told. As Jeanette Winterson (1990) writes "Every journey conceals another journey within its lines: the path not taken and the forgotten angle" (p. 10).

Although I had wanted to show the raw story of my experiences of breast cancer in contrast to the pretty pink cheer, I realise now that I presented my artwork to fit the prescribed expectations of aesthetics and quality. My neatly framed artwork censored out some of the mess of my experience. I recognise the tension I held between my desire to be seen as "a proper artist" and my desire to tell my authentic story. I wonder how different the experience would have been if I had had the confidence in myself

as an artist to insist on showing my original body prints, with the paper partly torn, complete with smudges and accidental paint drips that better captured the raw energy of the making. Perhaps this more vulnerable, naked, and less-curated and aesthetically formed story is the concealed journey.

Conclusion

In responding to the particular characteristics of the gallery space, the chronological order of the narrative was disrupted and I came to see my artwork with fresh eyes. The relationship between the different pieces of artwork and their relationship with the space all combined to create a new art representation, able to tell a new story, which provided the opportunity to come to new understanding and meaning about my breast cancer experiences. The realisation that the changes to my body were no longer of central importance to me, reflected in the changed position of the plaster casts between the two exhibitions was particularly significant.

My exhibition provided the opportunity to take my personal story out into the world as part of a social change agenda in the hope that this might change the way people viewed women's experience of breast cancer, to see it as rich, complex, and full of meaning. For me, the imperative to be seen, to share my breast cancer experience, to have it acknowledged and legitimised, and to display an alternative breast cancer narrative drove me to show my artwork, even as I questioned whether it was "good enough". In showing my artwork, I joined a rich tradition of feminist artists and performance artists who have challenged "oppressive representational practices"

(Garland Thomson, 2002, p. 12) and brought out of the shadows other breast cancer narratives that acknowledge the pain, mess, anger, and grief in the hope that this may influence the way women with breast cancer are seen and supported.







Chapter nine

Discussion

Words

*Words thrown into the air
create a life of their own.
Twirling and twisting
into new meanings.*

*Words can gently envelope you
in a loving embrace
entertain and amuse you
talk to you through history
and shape a dreamt future.*

*Words can gobble, chomp, and devour
grab you round the throat
choke you
And like a hot knife slice
through your heart.*

*Words can form into packs
and terrorise you
hang from the ceiling*

and smugly mock you.

*They can form an oppressive black cloud
that squeezes the life from you.*

*Words can make themselves incomprehensible
making you feel stupid.
Their incessant chatter
can fill a room
so you can't hear yourself think.*

*But what are they?
Only noises emitted from our mouths.
Why do we give them so much power?
Why do we cling so tightly to words
as if they hold authentic meaning above all other forms of expression?*

*Words
They can be the glue that joins
two hearts or the ammunition that shatters
a love asunder.*

Introduction

I began this enquiry into my experiences of breast cancer overwhelmed by my feelings of pain, grief, fear, shame, and anger focused around the loss of my breast, and with a longing to find a way out of the place of indecisive stuckness about whether I should have a breast reconstruction. Wanting to find meaning in my breast cancer experiences and acceptance of my changed body, I had no clear direction of how I might proceed, apart from a commitment to ground my enquiry in embodied knowing through art-making. Making art was a process of self-survival, a way of exploring my feelings without being overwhelmed by them. I could relate to the suggestion of Shaun McNiff (2011b) that sometimes it is important to “simply make spontaneous expressions with the goal of seeing what will emerge” (p.392).

At its simplest, making art provided me with something to do which provided the momentum to move beyond my feeling of stuck immobility. My urge to make art is reflected in the words of Barbara Fish (2013), “I paint when I am afraid, when I am confused, or need to investigate something deeply” (p.210). Initially I turned to making art hoping that by following where the art led me, I would come to some new understandings, which would assist me in my decision-making. Like Laury Rappaport (2013) I found making art confirmed my intuitive sense that to deeply understand and write about my experience I needed to engage in a process of direct self-enquiry, “that included a method beyond words” (p. 202). Over several years I Immersed myself in making and exploring art using a range of different modalities. Working individually and alongside other women I undertook numerous enquiry cycles following the steps

outlined in my methodology. Being “willing to give up control and follow the surprise of what is emerging” (Levine, 2013, p. 128), I was able to access rich embodied knowing and profound new insights.

As I faced the pressure to have a breast reconstruction, I came to realise that I also needed to interrogate my own understandings of my body, which had been informed by my earlier feminist consciousness. I felt a need to supplement my embodied knowing with an intellectual investigation of different discourses of the body. This allowed me to develop new understandings of the female body informed by phenomenological and feminist philosophies. Through my reading, connection with other women, and my own arts-based method I was able to draw on all forms of knowing—experiential, presentational, propositional and practical—in coming to new understandings of my self and my way of being in the world.

I am now faced with the question of how to bring together the many threads of this enquiry, one that has largely been informed by experiential and presentational knowing, to a neatly formed synthesis. I feel immobilised by the familiar sensation of stuckness as I struggle to convey the complexity of my circuitous rambling into a coherent form. To return to the knitting metaphor of my methodology, without a clear pattern to follow, I continuously joined together threads of different colours and textures, using varied stitches, and following my intuitive sense. Occasionally I unravelled what I had done and started again as an alternative pattern emerged; as I inserted more threads, a more intricate design was formed. Although there are still loose threads hanging, my knitting now feels complete, but how do I retrace my steps,

the many unpickings along the way, to show how I have formed this creation? I feel a strong sense of connection with Corinne Brown (2013) as she poses the question. “Can embodied artistic enquiry be captured in text?” (p. 225). The challenge to convey what I now know in my body through words is articulated by Jacques Derrida (1978) as he dreams of a writing that could directly access the body:

A pen that would be a syringe, a suction point rather than the very hard weapon with which one must inscribe, incise, choose, calculate, take ink before filtering the inscribable, playing the key board on the screen, whereas here, once the right vein has been found, no more toil, no more responsibility, no risk of taste, nor of violence, the blood delivers itself all along, the inside gives itself up. (p. 8)

Like Jacques Derrida (1978), I wish I could just tap into my veins and allow my embodied knowing to pour forth onto the page into some form of decipherable text. In the words of Laury Rappaport (2013), “through the artistic process, I was able to make discoveries and have insights that could not be known otherwise. Art provided a language to capture, witness and unfold this somewhat mystical inner experience. Words alone could not provide this” (p. 203).

In this chapter I attempt to convey what I have come to know about how the arts assisted me in coming to new understanding about my experiences of breast cancer (propositional knowing) and how I might use this as a form of practical knowing to assist other women with breast cancer. I feel emboldened by Shaun McNiff’s (1998)

oft-repeated advice to “trust the process”. It was through my art that I was able to weave new meaning from threads of new knowing, so it seems natural to return to my art in order to unravel the design.

The power of an image

Two key images accompanied me throughout my four-year breast cancer enquiry. The images both held such rich content that they sustained continual exploration using different modalities and arts-based procedures, allowing multiple layers of meaning to emerge. One image, *The black hole of grief*, was created from my body and held within it my breast cancer experiences from the depths of grief to the exhilaration of the celebration of life. The other image, *The pink lady*, is a symbol to promote breast cancer awareness and fundraising in Australia. There is extensive literature on the use of images as a means of developing personal insight, transformation, and in arts based research (Allen, 1995b, 2013; Gilroy, 2006; Knowles & Cole, 2008; Lett, 2001, 2011; McNiff, 2000, 2008, 2013a), however there is limited discussion of the power of a single image to sustain an in-depth enquiry over time. In the following section I explore how these two key images facilitated my coming to new meaning and understanding.

The black hole of grief

The image of *The black hole of grief*, created from my own body, is a close-up photograph of my painted chest taken soon after my mastectomy. The image was created in a moment of improvisation when I painted my body as a means of

connecting with the phalanx of emotions following surgery to remove my breast. As I edited the photographs of my painted body I was drawn to the space of my absent breast painted in black and encircled by a sweep of white. I zoomed in and created a cropped image.

Exploring grief through an image

This image seemed to distill my feelings of grief and loss, powerfully painted onto my body. As I wrote in my journal at the time,

Gazing into the inky blackness, I feel transfixed, as I try to see meaning in its murky depths. The more I gaze the less I see nothing is reflected it's a black hole absorbing all the light holding me in its icy grip.

Perhaps this image held such power for me, as it was a photograph of my painted absent breast, my scar, my wound. Over four years I undertook numerous enquiries, both alone and with others, as I responded to this image using a range of different modalities such as sculpture, movement, painting, and poetry. It was as if the image gave voice to my wound, to my absent breast. As I discovered during one of these explorations, the removal of my breast had not left me with a flattened chest as I had envisaged, but a hollowed out space. By continually exploring this black hollow space I confronted the existential issues of my own mortality and search for meaning. I felt driven to keep exploring this black hole even though I was terrified of drowning in the blackness. I captured this sense that this image held important meaning for me when I first contemplated it and wrote a poem that included the following stanzas.

*The concaved black emptiness
stares out at me
like an unblinking eye.
A large black pupil
holding hidden depths
of unknown meaning.*



Image 4.17 The black hole of grief

I had a strong sense of urgency to explore this blackness, but I was also aware of the power of the image to cause me harm if I did not approach it carefully (Springform, 2008). I was frightened that if I dived into it I might drown in my grief so I circled around the blackness dipping my toe into it, approaching it from different directions, using different modalities such as movement, collage, sculpture, voice, and paint to explore it. This image, made from my wound, held my breast cancer experiences—my feelings of grief, loss, and fear. It was a form of container that I could carry around with me, and continue to explore without becoming overcome by emotion. My experience resonated with Barbara Fish (2013) when she wrote, “In images the intolerable can be contained, approached, and even confronted” (p. 210). The image contained so much more than I could ever put into words; it became a symbol, or a shorthand expression, of a range of bewildering and painful emotions.

In a similar vein Debra Kalmanowitz (2013) created an image of “a bottomless pit” to

represent her experience of working within the field of political violence and the effect that the stories of torture, dehumanisation, loss, and suffering were having on her. Her experience of her image seemed to closely reflect my own as she wrote, “The image provided me with a sensual experience I could not shake. In a pit with no way out and burdened with memories, I was buried, and alive” (p. 143). This is very similar to my description of feeling *Stuck in a deep black well of despair . . . The taste of death in my mouth*. She too acknowledges the power of her image. “The pit held a deep sense of desperateness and helplessness—I myself would almost have drowned had I not pulled myself out (at that time) looking no further into this image” (p. 143). Although my image held similar power and potential to pull me under, I was able to keep exploring it through the use of different modalities; this provided me with a safety net of being able to look into the image with sideways glances.

As I looked into my image I felt drawn to dive into the blackness to discover new meaning, however, as described in the detailed enquiry cycle in chapter four, I too was fearful of drowning, so I resisted the request of my companion to enter into it, feeling it too unsafe to do so at the time. However, by using different multimodal procedures incorporated into the MIECAT method of enquiry, this image was able to continually sustain me and provide a source of new knowing as I continued to initiate numerous enquiry cycles in response to it. The different procedures allowed me to explore this image “bit-by-bit” to come to incremental knowing in a safe way. For example, I created an improvised movement with my doctorate colleagues in which they held up a large circle of black material that I could gradually move through; experiencing the feeling of being able to explore the blackness safely without diving headfirst into it.

This image seemed to hold the essence of my sense of loss and grief. My experience resonates with Pat Allen (2013) as she maintains that in order to use art as enquiry it is important to engage in “the act of living fully with the image, enacting the gestures, the postures, handling the images until their truth enters our body as fully as our mind” (p. 17). As I continued to explore the image I came to understand that it not only held my experiences of breast cancer, but also held a lifetime of grief and loss; with each enquiry cycle I seemed to unearth new understanding of previous experiences of grief. The words of Lorri Neilsen Glenn (2013) resonated with me, “Art grounds our grief in form; it connects us to one another and to the world” (section 5, *Threading Light* 86-88)

I had a strong sense of recognition when reading James Elkins’ (2001) description of people’s responses to Rothko’s 14 huge untitled canvases painted largely in black that are held in the Rothko chapel in Texas. In his research into why people cry in front of pictures, James Elkins found that:

People cry at a painting either because they are too *full*, complex, daunting or somehow too close to be properly seen . . . or because they seem unbearable empty, dark, painfully vast, cold, and somehow too *far away* to be understood (2001. p. xi italics in original).

Rothko’s chapel canvases, although often described as entirely blank, were the most often cited pictures that brought people to tears (Elkins, 2001). James Elkins talks of initially being underwhelmed, when he first saw these canvases comprising

subtle textures of black on black, “the paintings looked worn and flat and dull—like pots scrubbed too hard with steel wool” (p.6). He realised, however, that the more he looked the more he saw and felt, although he acknowledged that his training as an art historian limited his ability to be truly present with the images in an open and naïve way.

Confession books in the chapel now have over 5000 entries recording viewers’ responses to the canvases, 32 of which James Elkins (2001) included in his book. I felt a sense of identification as I read some of these responses. “I think Rothko was trying to learn how to live with pure unrelieved darkness (p. 9). “The paintings are like black holes, absorbing every glint of light” (p. 10). “You might say he shows us, in the most profound and general senses, what loss looks like” (p. 15). “If you step too close you might find yourself *inside it*” (p. 18 italics in original). Although I am not claiming that my image is comparable to Rothko’s paintings, for me it holds a similar power of loss, intensity, and pull to draw me inside it. Jacqueline Lichtenstein (cited in Elkins & Naef, 2011) captures this power of being drawn to a particular painting because it “gives my sight a tactile dimension” (p. 86).

Another example of the power of textured black to create a strong emotional response is that of the U.S. Vietnam Veterans Memorial, created in 1982 by the 23-year old designer Lin, which comprises 58,256 engraved names on a polished black granite wall. Although now appreciated for its simple, emotional power, at the time it was seen as controversial because of its black colour and lack of ornamentation; some public officials and opponents went so far as to blast the design as “a black gash of shame,”

“a scar,” (Kent, 2007, para. 5). It is interesting that this black sculptural wall dedicated to the memory of the dead was seen as shameful and a scar; it makes me wonder at my own perhaps subconscious intention of painting my own scar in black. As in this memorial, black is representative of death in Western cultures, so my act of painting my scar in black in memory of the death of my breast now makes sense.

An important part of my arts-based enquiry was responding to the urge to stay with this image. Through mindful contemplation and continual exploration of the black hole I was able to stay with my emotions of fear, loss, and grief. The Buddhist philosopher, Thich Nhat Hanh (2012) advises, “When you have enough energy of mindfulness you can look deeply into any emotion and discover the true nature of that emotion. If you can do that you will be able to transform that emotion” (p. 89). The importance of prolonged contemplation is reinforced by William John Thomas Mitchell (2006):

Any picture is at least potentially a kind of vortex or ‘black hole’ that can ‘suck in’ the consciousness of a beholder, and at the same time (and for the same reason) ‘spew out’ an infinite series of reflections (para. 1).

In a manner reminiscent of Merleau-Ponty, William John Thomas Mitchell argues that pictures should be considered to be living things, which are able to respond to, and change, the viewer. This capacity of an image to change the viewer is also highlighted by James Elkins (1996) as he writes “Seeing alters the thing that is seen and transforms the seer” (p. 12). However in order to be changed the viewer is required to not just look but to really see; to utilise a form of phenomenological viewing (Mitchell, 2005). However, we rarely do this as part of our everyday lives, instead:

Most images pass by and through us so quickly that we scarcely notice them. They are fast food for the eyes, and mostly junk food. But some of them demand more attention, and even the trivial or overlooked ones have this potential waiting to be tapped. (Mitchell, 2006, para. 1)

Not only visual images can hold this power. Michael Franklin (2013), a potter, describes his arts-based enquiry process into his experience of prostate cancer through his mindful practice of creating and contemplating clay pots. I felt a strong connection with his arts-based process when he described the moment when a key art piece, a particular hand-built primitive-fired clay vessel, emerged after six years of making 80 pots and numerous drawings and paintings. To him, this vessel, which he named *cancer tumour*, was an enlarged, diseased, end-stage cancer. His experience of exploring this vessel resonated with my experience of exploring the image of the black hole of grief.

Engaging with this particular pot became a wrestling match, literally beating me back with its strong presence. Even though the imagery was painful to look at, there was magnetism to its truthfulness. The rawness and accuracy of the image beckoned me closer, and so I kept moving my awareness in as we re-created each other. (Franklin, 2013, p. 90).

Michael Franklin (2013) describes how his relationship with this clay vessel “awakened understanding of hidden truths related to disease and death” (p. 91). Similarly as I continued to engage with my image, it provided a portal through which I could

explore and come to new understandings of not only my experiences of breast cancer and grief but of many of my lived patterns of how I am in the world. Being able to depth this image through numerous enquiry cycles allowed me to stay with the painful emotions of feeling stuck in the blackness of fear, grief, and loss. To stay in this space of unknowing, however, required a strong resistance to both, my own desire to move on from this place of pain, and to the social pressure, “to gain closure”, “to get back to your life”. In fact what I found was that I just wasn’t able to see past my grief until I was ready. I was shocked to discover that I was not able to see the beautiful blues and gold of a response provided to me by my companion (Image 4.17 Isle of curvaceous sensuousness) as, at the time, I was only able to see the blackness that mirrored my own image of the black hole of grief.

This has implications for my arts therapy practice. It has reinforced my commitment to allow my clients to determine their own personal enquiry and not attempt to move them forward into resolution, as is often the focus of more traditional psychotherapy. The dominant therapeutic approaches of solution focused therapy (de Shazer & Dolan et al, 2007), single session therapy (Talman, 1990), and cognitive behaviour therapy (Simos, 2009) all resonate with Arthur Frank’s (1995) restitution narrative. These psychotherapy approaches represent different paradigms and values in relation to healing, and focus on positive action and behaviour as a means of change rather than deep and lengthy exploration of the chaos and discomfort of not knowing. The messy complex space of sensuous encounter tends to be rushed over in favour of a cognitive understanding and positive action. Using arts, to explore this key image, allowed me to continue to explore painful emotion and come to a place of personal

transformation. As Michael Franklin (2013) writes, “embodied narratives take time to simmer and emerge” (p. 91).

My enquiry also highlighted that the experiences of loss and grief do not follow the five stages of grief as outlined by Elizabeth Kubler-Ross (1969) of denial, anger, bargaining, depression, and acceptance, which she developed while working with terminally ill patients. Although her framework is being increasingly challenged as more people explore and recount their personal lived experiences of grief (Cameron, 2008; Harris, 2011; Holland, Currier & Neimeyer, 2006; Owton, 2012; Terry, 2012; Vande Berg & Trujillo, 2009), it is still part of the dominant grief narrative in the West and is held up almost as a scientific truth.

While there are similarities, it is important to acknowledge that everyone’s grief unfolds differently. Alice Terry (2012), in her poignant description of her journey following the death of her daughter, states that she never experienced denial or anger, but rather found herself swallowed by despair, pain, and anxiety, and a sense of rupture from herself, her life, and the world. I seemed to just become stuck and ashamed, although I did experience anger and outrage when I felt my experience was not being acknowledged. In contrast Helen Owton (2012) writes of her experience of grieving for her father as a child as one of denial and suppression of her feelings, feelings that did not surface fully until triggered over 20 years later. Leah Vande Berg and Nick Trujillo (2009) vividly capture, through the use of different voices, the different responses to grief. Although we may be able to relate to other people’s experiences it is important to remember that each person’s lived experiences of grief is unique.

Although it was not possible for me to move through this black space before I was ready, I kept confronting the discomfort of others and the pressure to move on and just get over my breast cancer experience, to be thankful for being alive and celebrate what I had gained from my experience. I felt pressured to take on the identity of survivor, in which “the breast cancer patient is seen as feminine, deserving and devoted to a medical cure” (Kaiser, 2008, p. 80); an identity that sits more comfortably with the biomedical narrative in which illness is diagnosed, treated, and cured (Batt, 1994; Frank, 1995). I seemed to confront this discourse of positivity wherever I turned: personal relationships, breast cancer support groups, media coverage, and the medical system. It seems to have infiltrated the whole breast cancer institutional system. But I couldn’t move on I felt stuck in my grief. My enquiry has highlighted the importance of challenging the “tyranny of cheerfulness” (Ehrenreich, 2001, 2009) and taking the time to explore the fear, loss, and grief of breast cancer.

The lack of space, or indeed permission, for women with breast cancer to acknowledge their real feelings in confronting a disease that can be fatal can have a major impact on their lived experience (Cobb & Starr, 2012; Crompvoets, 2012; Hart, 2003; Herndl, 2006; Hopkins, 2003). My experience reflects that of other first hand accounts of breast cancer (Butler & Rosenblum, 1991; Hopkins, 2003; Hozman, 2005; Lorde, 1980; Lord, 2004; Williams, 1993) in that my fear and grief influenced my everyday living and social relations. However, there is limited possibility, either within social relations, or more importantly, within the health system, to confront this fear of death. The focus is on being a good patient, to be positive, strong, courageous, and to invest in the survival narrative in line with the “battle for life” quest of modern medicine (Hart, 2003;

Kaiser, 2008; Thomas-MacLean, 2004, 2005). Given the stressful nature of oncology care it is perhaps understandable that health care professionals encourage this upbeat positivity as a cheerful compliant patient is much more manageable, less time consuming, and less emotionally draining than a distraught, angry, or even sad patient (Bode, 2010; Hart, 2003). However, this avoidance of acknowledging my very real fears of death left me feeling alone and alienated

Finding the light through an image

For over three years I remained focused on the circular black space in the *black hole of grief* image, which allowed me to fully explore my grief, mortality, and meaning of life. Throughout this time I had been unaware of the white surrounding the black. As I described in chapter six I had a moment of epiphany in which, with the help of my companion, I was able to change my focus and for the first time see this white surround. I had an experience, reminiscent of that described by James Elkins (2001), of sheer joy that hit me like a bolt of lightening and brought me to tears.

Visual artists Libby Byrne (2014), who explored her diagnosis of multiple sclerosis, and Raelean Hall (2013), who explored her grief over the death of her mother, both used a process of continual revision of a particular artwork as a way of exploring lived experience. Like me, these artists stayed with a particular image over time to explore deep emotional experience that allowed them to confront existential questions of life and death. While I used different modalities to respond creatively to the image of the black hole, these two artists explored their experience through a continual process of

revision and reworking of their images. For all of us, however, the artwork became a “vessel for the exploration and containment of questions of existence” (Byrne, 2014, p. 220) or as Theresa Van Lith (2014) writes, “the art became a place to consider the question, What is it like to be like this?” (p. 26). It is interesting to note that in all three art pieces the areas of white held the moment of transformation and for myself and Libby Byrne (2014) the white was connected to our capacity to breathe, “I may not know how to heal or even to pray and yet in the white marks on this image I was aware of the gift of my breath” (p. 223).

Although seeing the textured white inflected with tinges of blue was the initial trigger for my release from the black, a vivid blue, the colour of a summer sky and clear water, came to represent this moment of transformation. I continued to explore this vivid blue colour using different modalities, which reinforced the importance of my connection to nature, to the sea and sky, as a pathway out of my grief to a place of acceptance and joy. Through my enquiry cycles into the blue I developed a greater capacity to accept the impermanence and the limitations of my life. I came to accept that it is enough to leave only a faint trace of my life behind.

By understanding that in the natural world both light and shade, night and day, darkness and lightness are equally necessary, I was able to see that I do not need to fear the black: both darkness and lightness provide a place for contemplation and connection with the world. The sensory knowing that emerged from my highly sensitised attunement to touch through my embodied art-making, heightened my sense of connection to the sea and the sky: feeling the warmth of the sun and the

refreshing coolness of the water on my skin allowed me to feel alive and energised. This sense of being one with the natural world, having a reciprocal connection with the world, brought me spiritual fulfillment making it possible for me to arrive at a place of peace, contentment, joy, and acceptance of my life as it is right now.

This one image created from my painted scar provided me with the resource to journey through my grief and fear of death and come to a place of celebration of life. Through this image I, like other artists (Byrne, 2014; Franklin, 2013; Hall, 2013; Kalmanowitz, 2013) discovered that a particular artwork is able to hold the complexity of lived experience. Or perhaps, as William John Thomas Mitchell (2006) suggests, any artwork has this potential if afforded prolonged contemplation. My arts-based method based on a phenomenological way of viewing enabled me to immerse myself in this image over a prolonged period thus allowing it to continually offer up new knowing.

The pink lady – the urge to be seen

Buried in my story is the universal longing to be seen; firstly by myself and then by others. Being seen is a precondition of feeling a deep sense of connection with others. Brené Brown (2012b) argues that meaningful connections can only be earned by sharing your truth with the world, a concept she calls living wholeheartedly. In recent years, particularly with the advent of personal blogs, there has been an avalanche of personal stories from women with breast cancer. Written from many different perspectives a common theme appears to be an urge to be seen. I too responded

to this urge to share my story through both my personal blog and my exhibition. I relate to Eva Karpinski (2010) when she suggests that, “one of the motivating factors in producing those accounts may have to do with a sense of self as fractured by cancer and longing for a restoration of narrative coherence” (p.111). Through her analysis of breast cancer narratives through text and photography, Mary DeShazer (2013) explores the drive for breast cancer patients to be seen and acknowledged; to narrate their own experiences and to have control of their own story. She found that the woman’s story is often captured through a particular image—Dina Rabinovitch’s hat, Stephanie’s running shoes, Anne Leibovitz’s photos of Susan Sontage’s shell collection. The pink lady, the symbol for BCNA, the peak Australian breast cancer consumer support organisation, represented my experiences of not being seen.

The pink lady silhouette first appeared in 1998 as part of the *Field of Women* public awareness and fundraising event, an initiative of Lyn Swinburne, the founder of BCNA. This first event involved the planting of 10,000 pink silhouettes (representing the number of Australians diagnosed with breast cancer that year) on the lawns in front of Australia’s national Parliament House in Canberra. This event has since evolved into a major annual campaign with activities across the country, and is gradually spreading to other countries across the world. The use of the pink lady silhouette was a deliberate attempt to focus on the woman rather than the disease (BCNA, 2013b).

I was largely unaware of this symbol until my breast cancer diagnosis when I became acutely sensitive to its presence. As described in chapter five, my first conscious connection with this symbol occurred soon after my mastectomy when I confronted

an enormous inflatable pink lady in the city centre that triggered my outrage. As the enormous pink lady towered over me I felt small, vulnerable, and angry. This moment fueled numerous enquiry cycles as I tried to make sense of my recurring emotions of vulnerability and anger.

This pink lady image seems to distill the gender imbalance of a patriarchal world. In the Western world the colour pink carries with it the expectations of femininity, which are imposed on girls from the moment of birth as most hospitals still adhere to the custom of wrapping a baby girl in a pink blanket and a boy in blue. As Amanda Dunn (2013) writes, "The colours are not in themselves the problem but rather the insidious loading that goes with them. Pink is often accompanied by butterflies and cupcakes and princesses and fairies; blue by trucks and dinosaurs and tools. Pink is passive; blue is active" (para.9). If the image were a different colour, red perhaps, maybe it would not hold such power of traditional notions of female disempowerment for me. However, as well as the colour, the actual image further reinforces the passivity of females. With her legs stuck together as one, and with no hands or feet, the pink lady represents immobilised passivity and a sense of powerlessness. She certainly doesn't depict any sense of strong independent agency for me. With no breasts, "upturned bob" hairstyle, and flared skirt she appears more reminiscent of a prepubescent young girl than a mature woman.

In its ubiquitous presence, the pink lady appears to hold the three elements of the dominant breast cancer discourse—the importance of being cheerful, upbeat, and positive; the allocation of individual responsibility and the emphasis on detection

rather than prevention; and the focus on traditional notions of femininity. This breast cancer narrative had a profound impact on how I experienced breast cancer. Unacknowledged, unlegitimised, and invisible, I felt alone, deviant, and vulnerable.

The impact of this pink lady narrative on women's breast cancer experience was reinforced to me when the two women, with whom I worked on an individual basis, both started their first sessions by drawing an image of the pink lady. They both described how they found this image insulting and disempowering in its call to "fit in with a certain breast cancer story".

It was the pink lady, and all it represents, that was the stimulus for the blood red to spurt forth in a visceral stream of outrage that allowed me to connect with my corporeal body. Helen Cixous (1991) implores women to "Write your self. Your body must be heard" (p. 335). Painting my body in red paint and imprinting it to create images on paper allowed me to give voice to my body and challenge the pink discourse that surrounded me. It was through using arts that I was able to give my body, my body which had lost a breast, such an "emotionally engaged, sexually alive part" (Hopkins, 2003, p.133), a voice. As with the black hole of grief image, using different procedures and modalities, allowed me to explore my feelings of outrage and vulnerability through this image of the pink lady until I finally arrived at a place of acceptance of my identity as a mature one-breasted sensual woman.

Tyranny of cheer – the invisibility of grief

The pink lady symbolises the call to be cheerful and thankful of survival: it excludes the grief of women suffering the effects of cancer or of those who have lost loved ones to the disease. Death is an aspect banished from mainstream representations of breast cancer, which are hegemonised by the bright image of the survivor (DeShazer, 2013). Those who do not conform to this cheerful narrative of positivity at all costs become invisible. It seems that the dominant pink cancer narrative follows an arc that initially views women as victims when they are first diagnosed, and once they are treated they are defined as stoic survivors, trapped in a tyranny of cheerfulness and conscripted as soldiers for the cause.

This is illustrated in the poetic response (using her words) I gave to one of the women with whom I was working.

*Fake Feminine
Pink girlie image
Controlling in its cloyingly syrupy
fake feminine.
Support the cause
Embrace the pink
Go on the walk
Conform.*

I see the panic under the tea and scones.

*I have a fear
I'll have to take on the fake feminine
be engulfed in this pink cancer stuff.*

*Bickering, we as a family, feel we should
do the breast cancer walk
It's not me, it's not us!
We abandon the walk
And enjoy lunch instead.*

Although some may find comfort in participating in mass walks that recognise the death of loved ones, many find little solace in the platitudes that their loved one lost their fight with cancer and in fact are often left with a lingering sense of shame that the person did not remain positive and fight hard enough. The need to cheerily maintain

the high morale and positive attitude of crusaders against the enemy of breast cancer comes at a cost, the key one being denial of the true experience of cancer. This was poignantly highlighted by cancer patients and their loved ones interviewed as part of a documentary on Radio National:

"My aunt viewed her cancer as a battle and we, her family and friends, became her willing foot soldiers."

"We talked about everything except that she would die. When she died she had a pile of books titled you can beat cancer next to her bed."

"Her battle meant that she could never acknowledge the possibility of defeat which meant I could never say goodbye."

"We seem less prepared for death than ever. If we don't battle, what is left is just the uncertainty of death and is that too terrible to face?"

(Townsend, 2012, August 5).

Immersion in this "tyranny of cheerfulness" (Ehrenreich, 2001, 2009) does not allow women to connect with their authentic feelings, and invalidates experiences that do not conform (Angel et al. 2010; Wilkinson & Kitinger, 2000). The culture of cheer creates a standard against which all responses to the disease are measured, it demands compliance and conformity, and even minor deviations quickly begin to signal another additional pathology. The pressure to be in a constant state of positivity

may also prevent some women with breast cancer from reaching out for required help, when they are feeling depressed, sad, or angry, thus intensifying their sense of isolation and alienation at a time when they are particularly vulnerable (Sulick, 2010).

For those who are believers, the pink movement can mobilise feelings of togetherness and solidarity, hope and faith in biomedicine, and self-pride among breast cancer survivors. It is seductive in its appeal to participate in fun activities, while dressed in pink, at the same time as being able to feel self-righteous about promoting and contributing to a worthy cause. While it is important to acknowledge that positive success stories can be inspiring and helpful in supporting some women with breast cancer, they can also be alienating, particularly to those who experience ongoing effects of cancer or have a poor prognosis. The focus on positive thinking may lead to a sense of failure and guilt if things do not go well (McGrath, Jordens, Montgomery & Kerridge, 2006).

The importance of challenging this perpetual upbeat positiveness was highlighted in editions (issue 61 and issue 62) of *The Beacon* magazine (BCNA, 2013a, 2013b). Leanne's story in issue 61 (BCNA, 2013a) that she felt totally alone in her experience of not feeling positive and happy about her breast cancer was met with a flood of responses in the next issue. Whilst the BCNA editorial acknowledged that this was a "story we rarely receive for the Beacon" (BCNA 2013b, p. 2), it became the focus of all the letters to the editor. Below is a sample of responses that highlight the importance of breaking our silence and challenging this dominant narrative of perpetual cheer.

In my experience, everyone appears so happy and positive after their diagnosis and I did not feel I had permission to really say how I felt after my diagnosis. Eleven years later, I still don't. It was comforting to hear Leanne's story
(Robyn, NSW, BCNA, 2013b, p.2).

I really identified with this lady and cried heaps when I read her story, as it is exactly how I feel. The guilt for not feeling like celebrating my survival is enormous
(Averil, WA, BCNA, 2013b, p.2).

These responses draw attention to the needs of women with breast cancer to be able to publically share feelings of suffering, anger, and sadness; feelings that challenge the dominant discourses of positivity and celebration of survivorship that simultaneously encourage women to proclaim their status as a women living with breast cancer via pink t-shirts and ribbons while disguising the true nature of their changed bodies via reconstruction and prosthesis (Crompvoets, 2012; Kaiser, 2008, King, 2006; Nelson, 2009; Thomas-MacLean, 2005). The language of survivor, commonly used in breast cancer, is not usually used for other forms of cancer or serious illness. With my background in working with women who have been abused, the word survivor is strongly associated with sexual assault. Charlee Brodsky and Stephanie Byram (2003) encapsulate my views when they write:

It is a terrifying, lonely, sometimes shameful experience to look and feel so different ... the word 'survivor' grates on my nerves. We all live with our various

misfortunes, having AIDS or osteoporosis, living without health insurance, being in bad marriages, or raising difficult children. We are all survivors. Why should breast cancer be any different? (p. 124)

In order to make sense of cancer, Arthur Frank (1995) argues that it should be seen as a part of human experience that needs to be lived fully in all its complexities, pain, anger as well as unexpected joys, to become meaningful.

Allocation of individual responsibility

The dominant pink breast cancer narrative not only enforces a climate of perpetual cheer, but also constructs breast cancer as the responsibility of the individual. Like other women, I found myself being shamed into taking responsibility for my cancer and punishing myself with a "disturbing sense of self-blame" (DeShazer, 2008, p. 235.). If only I had led a healthier lifestyle, had been more vigilant in monitoring my breasts, had made more effort to ensure it was detected earlier, then perhaps I would not have got this disease. The influence of Louisa Hay (1984a, 1984b), the "positive thinking guru" who argued that cancer could be caused by not managing emotions properly, is still pervasive.

As a woman with breast cancer, I found myself feeling guilty that I had caused my cancer in some way, which left me feeling powerless and lacking confidence in my own body. In encouraging greater vigilance and discipline over the body, this narrative perpetuates discourses of the body based on the mind/body separation, particularly discourses of the body as a machine, and the body as a battleground as discussed

in chapter two. Attention is drawn to the moment of diagnosis and the effectiveness of screening and early detection. The focus of research that results from all the fundraising is on medical treatment, particularly drug therapy that benefits the large pharmaceutical industry.

Confronting the shame of not being “normal”

Shame needs three things to grow exponentially: secrecy, silence, and judgment. And when you start naming the cause of your shame and talking about it with people who have earned the right to hear these stories in your life, it dissipates, because shame only works when it keeps you in this false belief that you are alone (Brown cited in Bouris, 2014, para. 4).

The pink breast cancer discourse, of which the pink lady is a powerful symbol, is represented by the hetero-feminine, resilient, beautiful, repaired, and reconstructed body, a body which is responsive to medical treatment and safe from the spectre of recurrence. This idealised version of the female body can be seen in the pressure placed on women in Western countries to have a breast reconstruction following a mastectomy. In Western countries this pressure to conform to the normative body is largely promulgated by women to constrain women and is a good example of Foucault's thesis of the docile body in which women become enmeshed in the collusion of forces that sustain their oppression. Under the guise of raising awareness and fundraising this pink industry promotes the need for women with breast cancer to maintain and retain traditional notions of femininity through a focus on normative

body ideals through promotion of breast reconstructions, use of wigs, and attention to make-up and clothes. The absent breast is flawlessly concealed by prosthesis or reconstructive surgery. The promotion of celebrities such as Kylie Minogue and Angelina Jolie, in airbrushed fashion shoots in women's magazines, further reinforces an idealised beauty that is unobtainable for the average women with breast cancer.

The centrality of body image perpetuated through the pink breast cancer discourse is so powerful that a common response to breast cancer is a concern over the impact on body appearance rather than on whether the person will live or die (Hart, 2003). In contrast to other life-threatening diseases, in which mortality is understood as the fundamental threat, much popular and professional discourse about breast cancer focuses on body image. The reality that the disease is potentially fatal has typically been eclipsed by the intense concern over the loss of the breast and the impact this will have on the woman's sexuality and femininity (DeShazer, 2013; Fitts 1999). The loss of the breast is viewed as a signifier of loss of femininity, which is often then, framed as disability, with the risk of disease (spreading or returning) transitioning to the risk to bodily and gender integrity through exposing disfigurement (Cromptvoets, 2012).

A number of studies (Cromptvoets, 2006a, 2006b, 2012; Erikson, 2008; Cobb & Starr, 2012) have shown that the dominant social constructions of the female body influence the manner in which women experience breast cancer, including their decision-making in response to treatment options. The routine use of words like “disfigurement”, “mutilated” and “lop-sided” to describe women's post-mastectomy bodies, reinforce women's own sense of their bodily imperfection. I am continually shocked when I have

regularly experienced others referring to my scarred, breastless chest as mutilated. The fact that other women, including those who have also had a mastectomy, often use this word to describe the post-mastectomy body is another powerful example of Foucault's (1979) notion of internalised discipline and the docile body.

It is not surprising then that women in the West, particularly white, middle-class women, succumb, in increasing numbers, to the pressure to have a breast reconstruction (Cobb & Starr, 2012; Jagsi et al, 2014). Not only is surgical reconstruction offered to women as a means of recapturing their former feminine identity, enabling a sense of optimism that both body and self "will get back to normal" (Crompvoets, 2006a, p. 75), but it is sold as part of the treatment phase. A breast reconstruction is not seen as a cosmetic addition but as an integral part of the treatment of breast cancer. "In *looking* well and normal a woman presents herself as 'recovered'" (Crompvoets, 2012, p. 4 italics in original). The power and pervasiveness of this construct of normative femininity is evidenced by the shame many women feel about their scarred chest following a mastectomy (BCNA, 2010) and the effort that goes into presenting the body so that no one may discover the truth about a breast amputation. "As women are expected to 'get back to normal', with no visible mark of their loss, society gives no permission to grieve for the amputated breast and provides no space in which such feelings can be explored" (Crompvoets, 2012, p. 12).

The pressure to have a reconstruction is evident in a special edition of the Beacon (BCNA, 2010) on breast reconstruction; of the 14 articles in the magazine, 13 are women's stories and professional advice in support of having a breast reconstruction.

There is only one small article written by a woman who had decided not to have a breast reconstruction, and she had "decided against it as I was 60, had been separated for many years and had no special man in my life at the time" (BCNA, 2010, p. 6). The idea that women can choose to reclaim a sense of beautiful sensuality without conforming to the normative view of a female body with two breasts is rarely acknowledged. In fact as I have experienced, the shift to normalisation of elective cosmetic surgery is leading to an increase in breast reconstructions (Jagsi et al (2014) and "a predictable inversion of the domains of the deviant and the pathological, so that women who contemplate *not using* cosmetic surgery will increasingly be stigmatized and seen as deviant" (Morgan, 1991, p. 28 original italics).

Furthermore the inclusion of women who have had mastectomies, into the arena of cosmetic surgery may increase the power imbalance between patients and medical experts. Many women, including two from my group, recounted how they felt bullied and pressured by plastic surgeons into having further complicated and potentially dangerous surgery at a time when they felt particularly vulnerable. Many cosmetic surgeons strive to sculpt their own idealised version of the perfect breast, despite the women's desire to just obtain their previous appearance (Cobb & Starr, 2012; DeShazer, 2012, Jacobson, 2000). Lynn Kohlman (2005) describes how her breast surgeon refused to use small implants to create breasts that looked like her former small breasts despite her objections. In my own experience, the plastic surgeon offered to operate on my healthy breast in order to ensure I had two perfectly matched breasts; she even asked me what size I would like as she could make my new breasts to order.

Shelley Cobb and Susan Starr (2012) have coined the term, “the makeover metaphor” to describe the cosmetic transformation movement and argue that in recent years it has subsumed the military metaphor for breast cancer, by “re-articulating the experience of breast cancer diagnosis and treatment as a kind of self-improvement boot camp” (p. 85). Women often frame the opportunity for a cosmetic makeover, with the goal of creating an improved version of the body, as a form of compensation for contracting a potentially fatal disease, as illustrated in the views of a woman writing in *The Beacon*:

I chose a free TRAM flap . . . as it would give me a ‘tummy tuck’ that would reduce the apron of flesh left after a caesarean section some 32 years ago ... Initially it went well and looked great; a flat tummy and a perfectly shaped breast. (BCNA, 2010, p. 5)

Whilst the cosmetic surgeons cleverly market their products, in doing so they often undersell the risks and disadvantages of this surgery. On one level it can be seen as inexplicable why a woman who had already undergone life saving surgery would then choose to risk her life by having much more complicated and dangerous surgery in the hope that this would allow her to recapture her former feminine sense of self, or in fact attain a more improved version of her self. One of the women in my group was aghast at the contrast between the careful and comprehensive outline of the risks her surgeon gave her when explaining potential relatively minor Achilles surgery and the flippant cursory attitude of the plastic surgeon when discussing a potential 8-hour breast reconstruction operation. When she pointed this out to him, he replied “Oh some surgeons are just like that” (Personal communication, January 14, 2012).

It appears that more often than not, there are complications that arise from breast reconstruction surgery, including skin necrosis, infection, expander and implant leakage, capsular contracture (hardened scar tissue forms around the implant distorting the shape and hardening the implant), movement of the implant, symmastia (where the soft tissue connects both breasts), muscle weakness, scarring and infection of the donor site: stomach, thigh, or back (Alderman et al. 2002; Breuing & Warren, 2005; Ehlers, 2012). In the special Beacon edition on breast reconstruction women described a range of complications arising from their breast surgery:

“Part of the wound on my breast turned black ... part of the flap had died and was infected . . . I was left with a gaping hole, had to have a skin graft, dress the wound three times a day for two months and take antibiotics” (BCNA, 2010, p.5).

“My first experience was horrible, I felt like Frankenstein’s monster ... the second time the donor site was my bottom—I couldn’t sit up for a month ... and walking was pretty difficult” (BCNA, 2010, p. 7).

“I frequently ended up with painful infections . . . Despite everything I am really pleased with the final product. It is sad that I can’t feel touch in those areas anymore and they can also be quite uncomfortable at nights. However, the alternatives just didn’t appeal to me” (BCNA, 2010, p. 9).

Women described horrifying experiences of multiple operations required to chop away necrotised tissue, while still avowing that they loved their new breasts. It appears that many women collude with plastic surgeons in minimising their discomfort, pain, and less-than-desired-for results. For some women, any breasts even hard, misshapen, asymmetrical ones with no feeling are better than none, as at least they allow them to look normal in clothing, normal to the public gaze (Cromptvoets, 2006b). The cost, however, of this imperative to have a normative body with two breasts is poignantly illustrated in this woman's account.

My own second mastectomy, performed at the time of breast reconstruction, was prophylactic. My surgeon said he could not offer a 'good match' unless both breasts were reconstructed and I allowed myself to be swayed to his belief. Now I regret sacrificing my healthy breast ... If I had to do it again, I would not trade a healthy, functioning breast just to try to achieve what a surgeon calls 'a better match'. It is a lasting regret. I could have breastfed our son if I had resisted that surgeon's coercion. (Johnson, 1981, p. 101)

Amidst the plethora of breast cancer stories that present a relentlessly upbeat tone and espouse the opportunity to have perfect breasts and a flat stomach, I found it difficult not to succumb to feelings of shame about my imperfect body. My sense of shame that I no longer looked like a normal woman was amplified by my indecision as to whether to have my body "fixed" through a breast reconstruction. I continually confronted the condemnation of others offended by my consideration of retaining my "mutilated" one breasted body. Brené Brown (2012a) contends that shame is such a

powerful emotion as it evokes fear that if we don't do as we are expected or as we are told, we will be flung from the social nest. This began to make sense to me as I endured the incredulous comments of others, "why would you even think of not having a breast reconstruction when you can so easily have two breasts and look normal again?" (Personal communication, January 21, 2012). Brené Brown (2012a) further argues that shame is underpinned by vulnerability, which she defines as allowing ourselves to be truly seen.

In time, as I reached out into cyberspace and into the literature of breast cancer narratives, I began to come across the stories of other women with whom I could relate; other women who, also angry about their invisibility, drew on their feminist understandings, to challenge the simplistic "courageous survival narrative" (Hopkins, 2003, p.134). Although the cyber world is filled with women telling their own stories "on the personally enriching opportunities that breast cancer offers" (Bode, 2010, p. 95), I did link up to a number of women who shared my feelings of outrage at feeling invisible because their experience did not conform to expectations. Through a sea of pink I gradually came across an alternative narrative that embodies a feminist critique of the sexualisation and objectification of the female body.

Written in 1980, Audre Lorde's *The Cancer Journals*, is often cited as the most powerful feminist critique of the normative feminine body discourse. She argues that the focus on a women's appearance reinforces society's stereotype that women's sense of self is intrinsically linked to what they look like. Pre-empting Barbara Ehrenreich's (2001) later call to arms against the tyranny of cheer, Audre Lorde (2007) expresses justifiable

anger at her breast cancer experience and rails against the assumption that breast cancer leaves women unchanged. Rather than trying to hide her experience behind prosthesis she instead chose to proudly display her one breasted body.

Rather than the pretty feminine image that symbolises the pink breast cancer discourse, the feminist narrative celebrates the absent breast encouraging women to take pride in their scarred and changed bodies as a direct challenge to the idealised normative body. Susan Miller (1995) in her play *My left breast*, depicted her mastectomy scar as both a symbol of her sexuality and her aliveness. Rather than being a site of marginalisation, due to its difference from the normative body, she transformed her scar into a site of pleasure and power. This feminist discourse mobilises a sense of empowerment and acceptance and is represented by iconic images such as Matuschka's (2014) self portrait, *Beauty out of Damage*, (Image 8.4) and Deena Metzger's (1989) *The Warrior*, (Image 8.2) as discussed in the previous chapter. The feminist call to reclaim her scar is highlighted by Deena Metzger's poem, which is included on the Warrior Poster:

I have designed my chest with the care given to an illuminated manuscript.
I am no longer ashamed to make love ... I have the body of a
warrior who does not kill or wound. On the book of my body,
I have permanently inscribed a tree. (www.deenametzger.
com/poster/poster.html retrieved 12th November 2013)

Photography was also used by Lynn Kohlman (2005), a former Vogue model and fashion photographer to "present herself as the beautiful public body of cancer"

(Horwell, 2008). She embraced and displayed her wounded body, "determined not to hide behind her scars ... I have finally realised, my breasts gone. I am beautiful" (Kohlman, 2005, np). Lynn Kohlman's experience as a model and advertising designer enabled her to fashion her scarred chest and head (sutured with titanium staples) into a reconfigured iconography of beauty, with an "androgynous street edge" (Karan, 2005 np). More recently professional fashion photographer, David Jay, through his Scar Project, which beautifully portrays young women baring their mastectomy scars, has added a more ambivalent portrayal of women showing pride in their bodies. All these images provide an alternative representation of breast cancer, one that acknowledges the grief of loss and celebrates female beauty and strength, rather than the prepubescent, disempowered, immobilised image of the pink lady.

Although the value of showing or exhibiting artwork created in the process of arts-based enquiry or research is still contested (Jones, Koh, Veiss & White, 2010; Potash, 2012), it provides a key element of my enquiry. Through allowing myself to be vulnerable, to be truly seen, I am able to challenge the shame that I felt around my imperfect body. In her *Ted* talk Brené Brown (2012b) reinforces the views of my audience in describing vulnerability as a form of courage. "Vulnerability is not weakness it is courage—emotional risk, exposure, uncertainty it fuels our daily lives our most accurate measurement of courage, is to let ourselves be seen" (Audio visual).

I now understand that the yearning to be seen, in a way that reflects my lived experiences, is what drove my desire to show my artwork. The exhibition of artwork produced as part of an arts-based enquiry is often viewed as an innovative way of

presenting or disseminating findings (Keen & Todres, 2007), however, my exhibition was an integral phase of my enquiry: one that brought me not only new knowing, but a sense of completeness. My exhibition provided me with an opportunity to publically challenge and vent my outrage at the exploitation of the simplistic superficiality of the pink breast cancer narrative. I no longer felt alone and isolated because others witnessed and connected to my story. My exhibition allowed me to: share my experience thus reducing a sense of isolation (Haisler, 1987; Spaniol, 1990); highlight the need for social change (Potash, 2011; Stepakoff et al, 2011); have others bear witness (Allen, P., 2007; Lu & Yuen, 2012; McNiff, 2013b; Moon, 2009); and provide a platform for other issues and voices to be heard (Kalmanowitz, 2013). As Mary DeShazer (2013) points out, “if viewers witness traumatic or memorial images in private spaces, then grief and remembrance may remain individual, but if they/we witness such images in public exhibitions or venues, then mourning and remembering become communal” (p. 203).

As discussed by other writers (Batt, 1994; Larsen, 2013; Saywell, Henderson & Beattie, 2000; Seftel, 2001, 2006; Steiner, 2006), bringing my experience of grief and loss out of the shadows and its surrounding silence and challenging the shame and stigma so often associated with breast cancer was an important aspect of my own healing. The act of showing artwork to an audience has been found to assist women with breast cancer to affirm and proclaim their present existence, strengthen their identity, and develop an increased sense of connectedness to other women with breast cancer (Collie, Bottorff & Long, 2006; Luzzatto & Gabriel, 2000; Malchiodi, 2011). I too felt connected through this shared drive to be seen and heard. Writing of their experience

of supporting women with breast cancer to show their artwork, Collie et al (2006) state “even when they expressed terror, shame or anger, they were seen and heard” (p.765).

As well as challenging the pink lady view of breast cancer, my desire to show my artwork in a public exhibition also reflected my wish to be seen as an artist. As an untrained artist, I lacked confidence in my artistic ability and had never considered myself to be a “proper” artist. The idea of showing or exhibiting artwork produced as part of arts therapy sessions brings into focus the interface between art, as an aesthetic creative pursuit, and arts therapy. Art produced as part of an arts therapy process is seen in an ambiguous light. There is debate about whether it should be considered to be art at all, and secondly, whether it should be shown outside of the therapeutic context in which it was produced (Levine, 2013; Malchiodi, 1999; Potash, 2012).

Like all art produced as part of an arts therapy process, my artwork was not driven by an aesthetic ideal with an external audience in mind, but was created as part of a process of enquiry into an aspect of lived experience. However, this different intent does not mean the artwork produced is not art, particularly when viewed in a postmodern context, which blurs the distinctions between various forms of art, such as fine art, arts and crafts, folk art, and outsider art (Alter-Muri & Klein, 2007). My motivations to have an art exhibition to show artwork created as part of a therapeutic process, fitted with those identified in the literature: seeking understanding by others of a particular experience; gaining acceptance by a community; obtaining approval; and identifying myself as an artist (Bayles and Orlando, 2011; Thompson, 2009). Until I was actually present at my exhibition on opening night, however, I had not realised the importance

of being seen as an artist and felt gratified when my audience commented on the quality of the art itself. However, my greater satisfaction came on hearing comments like, “I had never seen the pink lady in that light” (Personal communication, October 29, 2013) indicating that my exhibition had given them a new insight into the dominant breast cancer narrative.

I have come across a range of breast cancer marketing symbols that I do not find offensive; they appear to capture the essence of the disease without using such loaded traditional feminine symbolism inherent in the pink lady. Symbols such as two interlinking purple and dark blue circles of Breast Cancer Support WA (<http://www.breastcancer.org.au/>), or the interlinking purple chain of the UK Breast Cancer Organisation (<http://www.breastcancer.org/>). In fact I really like the original BCNA image which was used for *The Beacon* magazine from its inception in 1998 until the Spring edition of 2001 as explained in email communication from Lyn Swinburne, BCNA founder and creator of the pink lady symbol.

Originally BCNA had a different logo, which was sort of a stylised female form in silhouette. When I came up with the concept for the Field of Women in Canberra, my concept was originally to have 10,000 silhouettes of a woman's face in profile. Trouble was I couldn't decide on her hairstyle, so then the idea came to me that the symbol should be for all women. The concept of the cutouts was powerful because when the individuals were strung together, they joined hands



Image 9.1
Original
BCNA logo

(as in a network). The other important thing was that when joined together they formed a heart shape in the gaps.

*I chose a really bright strong pink in acknowledgement of the strength of women. Believe it or not, there was not much HOT PINK around at that time (1998). Also the NBCF was using a gentle, soft pale pink in those days, so this was a way we could differentiate ourselves. I cut out the original pink lady shapes in hard cardboard and painted them bright pink ... later I took a small group of them to Anderson Park (my local park in Hawthorn East) and planted them in the grass. They looked stunning and I knew they would work well. For a while we used both logos. It became clear to me after a short while, that the pink lady was THE powerful image. PUMA, for example, came to me for an early licensing arrangement. They wanted to use the pink lady on their swing tags, so that was a pretty strong message. People knew BCNA because of the Field of Women, which had been very prominent in the media. We kept the female outline on the front page of *The Beacon* for a while, but really that was dropped too in favour of our brilliant pink lady, which says it all!*

(Lyn Swinburne, personal email communication, November 30, 2014).

So in an image intended to be a strong, powerful symbol of women with breast cancer, I saw a passive, disempowered girl. This is a good example of how I bracketed in all my preconceived notions, values, and experiences when I viewed this image. The fact that this image is so often associated with the traditional breast cancer narrative that calls for positive cheer and traditional notions of femininity along with my feminist values has no doubt influenced my interpretation. Whilst I continue to feel outrage

at the pink lady symbol, I have come to acknowledge the risks in using a more real portrayal of women, one that holds the sensual energy epitomised by the breast. Marketing of breast cancer has been successful because of the strong symbolism of the breast, which speaks of both sexual desire and maternal nurture. Women have learnt through the ages of the dangers of inciting unwanted sexual attention through the portrayal of their bodies and feminists have fought hard to challenge the objectification and exploitation of women's bodies. Perhaps the use of the pink lady offers a safe alternative, one that can appeal to everyone, including men without any danger of provoking a sexualised response.

I confronted the reality of this feeling of invasion through my public blog, which attracted voyeuristic responses and sexually provocative spam. Naively I did not think of this audience in the use of my language, so its not surprising that posts with titles such as *nipple painting* and *buying my first bra* received the most hits. In discussing feminist playwrights who attempted to challenge patriarchal inscriptions through an embodied narrative, Mary DeShazer (2008) acknowledges the risk that "some audience members will respond as voyeurs rather than compassionate witnesses." (p. 80). The fear of being subject to sexual intimidation or voyeurism is what so often imprisons women in their silence. Brené Brown (2012a) in her study of shame found that the best means of combating shame is to break the silence and bring the source of shame into the light.

I was prepared to risk being the subject of the voyeur's gaze as a means of challenging the societally imposed shame of my non-normative body. The pink lady image incited

such a strong emotional response I was inspired to use arts to explore my feelings of anger, vulnerability, and shame which enabled me to come to new understanding of myself. Through the intersection of my own arts-based enquiry, my reading, and connection to like-minded women I gradually moved from feelings of vulnerability, anger, and shame to feeling strong, proud, and beautiful. My last enquiry into the pink lady described in full in chapter five, allowed me to finally accept myself as a mature, sensual woman.

An intersubjective response I received from a companion during my enquiry encapsulates my experience of engaging with the pink lady.

Let the pink bleed
I'm becoming who I am
Let me be red (read).

Rediscovering my sensuality through touch

Touch is semeful in that it is full of meanings—physical, emotional, intellectual, spiritual—and those meanings are socially and culturally specific and located. Far from being a simple, muscular response/action, touch locates us in the world, connects us to each other, and enables us to operate effectively as embodied individuals and social subjects. (Cranny-Francis, 2011a, p. 476).

My engagement with the pink lady symbol allowed me to confront the shame of my non-normative body and express my anger at not being seen, however, it was through my focus on touch that I was able to fully embrace my one-breasted body. The touch of the cold wet paint on my skin, the touch of my body on the smooth paper, and the tension as I broke the painted bond—the physical sensation of touch, as well as the social meaning of touch, as my hand caressed my remaining breast, became central to my arts-based enquiry.

Perhaps because my enquiry involved my feelings about my changed body, I was drawn to use my body to create my art; my body was a canvas, paintbrush, and print block as I made a series of body imprints. This art method, which came to me in a moment of improvisation while exploring my feelings of anger (Gravell, 2009), was my starting point for exploring my experiences of breast cancer. As I explored the process of painting and imprinting my body, I became aware of the impression of touch formed from several modalities including pressure, skin stretch, vibration, and temperature. Through mindful awareness of touch, in all its meanings, I was able to

explore the impact of my changed body on how I understood myself as a sensuous, older woman. Touch focused my attention on the intersubjective space in which meaning is constituted as encapsulated by Anne Cranny-Francis (2011a):

We know ourselves and the world through the sense of touch, crucially including our ability to touch ourselves and *to make something of that touch*. At the point of touch . . . we know both the self and the other, including the other that is also the self (p. 468 italics in original).

In western philosophical and cultural thought the sense of sight is usually given pre-eminence over the other senses (Paterson, 2007; Pirovolakis, 2013), however, philosophers such as Michel Serres (2007) maintain touch is the source of consciousness, while influential phenomenologists such as Merleau-Ponty and Husserl argued that we are more intimately involved with our own bodies through our sense of touch than we are through sight, sound, taste, or smell. Husserl (2012) wrote in his unpublished Ideas II, §37, “I do not see myself, my Body, the way I touch myself” (p.155). He argued that the immediate experience of the lived body appears to be founded on the sense of touch in contradistinction to the rest of the senses. “The Body as such can be constituted originarily only in tactuality and in everything that is localized with the sensations of touch: for example, warmth, coldness, pain, etc. ... [The Body] becomes a *Body* only by incorporating tactile sensations” (p. 158-59 italics in original).

A critical aspect of the sense of touch is that to touch is also to be touched, thus touch always creates a dialogue, a communication both before and beyond text. Anne Cranny-Francis (2011b) writes “We cannot limit and control our touch by strength of will because we are always, already touching” (p. 591). The visceral character of this dialogic nature of touch is captured by Michael Serres (2007):

I touch one of my lips with my middle finger. Consciousness resides in this contact. I begin to examine it. It is often hidden in a fold of tissue, lip against lip, tongue against palate, teeth touching teeth, closed eyelids, contracted sphincters, a hand clenched into a fist, fingers pressed against each other, the back of one thigh crossed over the front of the other, or one foot resting on the other . . . skin on skin becomes conscious, as does skin on mucus membrane and mucus membrane on itself. Without this folding, without the contact of the self on itself . . . we would live without consciousness; slippery smooth and on the point of fading away (p.22).

This description contrasts with that of earlier philosophers such as Husserl and Merleau-Ponty, who tended to describe touch in a less visceral way and focus on the hands as the instruments of touch, rather than the skin as a whole. By avoiding sensual areas such as the lips, the tongue, genitalia, and breasts, they didn’t explicitly account for the gendered and sexual nature of touch. When I touch my hand with my hand I experience myself as an animate, sensing organism incorporating both the subjective and the objective—I can feel the texture of my skin, the temperature, the elasticity and even the bodily structure of my veins and bones that lie beneath my skin. When I

touch my nipple with my hand, I experience myself as a sexual, sensual woman; my touch locates me as a sexed and gendered being within a social and cultural world.

Through my arts method my skin became the focus of my sensory perception. So much of our experience is written on our body through our skin, as James Elkins (1999) writes, “perhaps the forms and possibilities of skin are the words and the grammar of sensation” (p. 36). While the other senses (smell, taste, vision, and hearing) are localised primarily in a single area (such as vision in the eyes or taste in the tongue), the sensation of touch can be experienced anywhere on the body, from the top of the head to the tip of the toe.

The skin, the largest organ in the body, is our touch receptor and is the primary connector between our inside and outside. The common assumption, however, that our skin provides a neat envelope for our body has no neuropsychological basis (Paterson, 2009). In terms of sensation there is no simple inside of our body, as our sensations reach outside of our skin boundary. This interconnection with the world through touch is picked up by Stephanie Springgay (2003) as she writes, “through touch the boundaries between self and other are blurred in a fluid, temporal space” (p. 7).

In my art-making I tried to maintain a heightened awareness to touch. Imprinting my painted body highlighted the significance of the sensory knowing that emerged through touch, particularly in my relationship with the art materials. As Rita Irwin and Stephanie Springgay (2008), note “touch becomes a mode of knowing through

proximity and relationality and poses different ways of making sense of the world” (p. xx). I came to understand that this direct experience of myself in my world, described by Christine Seeley and Peter Reason (2008) as “sensuous encountering” was the grounding for my other ways of knowing. The potter, Mary Caroline Richards (1989) captures my experience of sensuous knowing that emerged through my relationship with the art materials:

Potter and clay press against each other. The firm, tender, sensitive pressure which yields as much as it asserts. It is like a handclasp between two living hands, receiving the greeting at the very moment that they give it. It is this speech between the hand and the clay that makes me think of dialogue. And it is a language far more interesting than the spoken vocabulary which tries to describe it, for it is spoken not by the tongue and lips but by the whole body, by the whole person, speaking and listening (p. 9).

The intimate connection with the art materials as I imprinted my painted body onto paper and canvas highlighted the ambivalence and confusion I felt about myself as a sexual woman. My diagnosis of breast cancer soon after I left my husband, moved to the city, and began questioning my sexual orientation had left me feeling like an isolated outsider. I felt ungrounded and unsure. With no strong sense of connection to family, friends, home, or secure employment, I felt adrift in the world, looking in on other people’s lives from the outside. I no longer knew where I fitted. Not only did I have to struggle with coming to terms with my aging body at a time when I was trying to establish a new sexual idea of myself but I had to deal with the fact that I now had

only one breast.

Stephen Levine (2013) suggests that we form the self continuously through creative acts; it was through the intimate act of creating art on, and from, my body that helped me to gradually gain a sense of integration and “narrative coherence” (Karpinski, 2010).

[In]touch with the natural world

As I continued to smother paint over my naked body, over my breast and the space where my breast had been, I began to feel a sense of sensual awakening and connection to the natural world. I repainted my body in vivid blue and transformed the space of my absent breast from black to gold. A heightened sensitivity to touch, the touch of the sun warming my skin, the caress of the cool breeze, the coolness of the crystal clear water allowed me to feel alive and energised. I felt a sense of recognition with Caroline Peterson (2014) as she writes,

Within cancer distress as with much illness, there is a profound separation from the individuals’ known world, known freedom, and frequently severed relationship with the natural world ... healing emerges as remembrance of a connection with a wider world—a more natural world where the sun expressively dawns (p. 76).

My sensuality is expressed through my intimate connection with the natural world. As a living being I am sensibly attuned to and harmonised with my surroundings,

in deep communion with my environment in an ever changing weave of relations to earth and sky, and all things. It this recognition that we are “flesh of the flesh of the world” (Abram, 1997, 2011), that underpins a growing agitation about the impact of environmental degradation on our wellbeing, and has initiated questioning about the possible links between the increasing toxicity of our environment and increasing rates of breast cancer. Audre Lorde (1980) was one of the first feminists who actively promoted the link between breast cancer and environmental causes and highlighted the connection between corporate profit and breast cancer.

There has since been a long line of feminist writers (Brophy et al., 2012; Eisenstein, 2001; Klawiter, 2000, 2008; Steingraber, 1997; Williams, 1991) who have continued to highlight the link between cancer and environmental toxins and call for increased research into cancer prevention. It is argued that the cancer establishment is far more interested in treating breast cancer than preventing it, largely because prevention involves the restriction of a range of carcinogenic products on which our capitalist system has become dependent (Brown, Morello-Frosch & Zavestoski, 2011; Carson, 1962; Ibarluzea et al., 2004; Klawiter, 2008; Nielson, 2010).

Feminist advocates view women with breast cancer as being subjected to corporate rapaciousness using images of ruptured silicone implants to represent the violent disregard of industrial corporate greed. The pink fundraising campaigns have been very effective in raising the profile of breast cancer and dramatically increasing the funds allocated to breast cancer research, however, the rate of breast cancer in industrialized countries such as America and Australia has continued to rise

dramatically, from 1 in 20 in 1964 to 1 in 8 in 2010 and is much higher in developing countries (Australian Government, 2014; Brown et al, 2011; Ley, 2009). In fact it could be argued that the highly successful pink campaign, so effectively promoted and maintained by energetic well-meaning women, has been a valuable diversion from looking at the more important and challenging issues of the causes of all forms of cancer, particularly in terms of the links between cancer and environmental degradation and first world wealth. Considering the powerful interests vested in maintaining the current biomedical focus, including large multinational corporations involved in the chemical, pharmaceutical, and medical-industrial arenas, it is not surprising that breast cancer activists have struggled to change the research agenda (King, 2006, Klawiter, 2008, Ley, 2009).

Reminiscent of Merleau-Ponty’s description of the blue sky to highlight our sensual entanglement with the beauty of the natural world, Nancy Johnson (1981) uses a similar description of our entwinement with the world as she writes of her and her two sisters exposure to radiation from bombing experiments in Nevada and their consequent diagnosis with cancer.

I was a victim of fall-out when I was a teenager and stood outside watching the beautiful yellow sky . . . Did we three stand under the same yellow sky, or did we drink the same contaminated milk or chew on a blade of grass thick with poisons: rolling on the lawn on hot summer nights after the big mushroom’s death particles bathed our homes and gardens with ‘safe-level fall-out’ (p. 8).

Colour of autumn - a new coalition

My experience of breast cancer has sensitised me to the impact of the increasing toxicity of our environment. While my arts-based enquiry, with its focus on touch, has re-awakened my sensuality and enabled me to celebrate the beauty of my imperfect body, I still feel the grief of the earth's pain. The link between breast cancer and environmental degradation has the potential to bring together a strong coalition of feminists and environmentalists. The powerful forces of pharmaceutical and chemical companies, along with the support from well meaning charitable and fundraising industry, have created a very successful public relations campaign that has effectively developed a strong awareness of breast cancer.

If the feminists, focused on the critique of the traditional notions of femininity and the normative body, could join forces with environmentalists, focused on preventing the destruction of the environment, the high level of awareness of the pink branding of breast cancer could be used to focus on the link between cancer and environmental degradation. In North America there is a growing environmental breast cancer movement that engages scientific discourse in arguing that the toxic substances found in air, water, food, products, and our everyday environments at work and at home contribute to the development of breast cancer and other health problems (Ley, 2009).

This movement directs attention to the politics of cancer prevention. Breast cancer is viewed as both a product and source of profits of a global cancer industry, and

resources are targeted at mobilising outrage against corporate greed, irresponsibility and lack of accountability, and replacing the emphasis on biomedical research and early detection with demands for corporate regulation and cancer prevention (Klawiter, 2008; Ley, 2009; McCormick, Brown & Zavestoski, 2003). Unfortunately, it is difficult for this coalition of community activists to challenge the powerful vested interests and high profile personalities of the present day pink cancer industry. Attempts to highlight the link between the lack of corporate regulation and cancer are being expressed in "Stop the cancer where it starts" tours that take place in several locations across the U.S.A. However, the number of people who participate in these tours number in the 1000's, while the number of people who participate in the range of pink activities during Breast Cancer Awareness Month across the world number in the millions.

The female body is often used as a metaphor for the natural world—mother earth. There is a growing movement that brings together the feminist critiques of the body and concern for the environment that have arisen from feminist breast cancer activism (Bigwood, 2007; Ley, 2009). Known as ecofeminism, this movement connects all forms of hierarchical binaries promulgated by patriarchal society's dualistic thinking in which the self/subject is privileged over the other/object such as mind over body, masculine over feminine, civilization over nature, human over animal (Warren, 2008). Although concerned with all forms of oppression, ecofeminism is particularly focused on the exploitation of nature to meet the incessant demands of capitalist industrial growth.

Feminists have argued that it is the patriarchal structure of capitalist society that sees the feminine earth subjected to exploitation and destruction to feed the greed of the masculine industrial machine. Breast cancer can be seen as a powerful allegory for the environmental destruction of mother earth. As breast cancer is caused by an invasion of mutated cells undetectable by the human eye, so too environmental degradation is caused by the invasion of a range of invisible chemical toxins that infiltrate the air we breathe, our oceans, rivers, and waterways. Breast cancer is “fixed” by cutting out the cancerous cells and reconstructing new breasts, so that not only is all evidence of the disease made invisible, but the beauty of the woman can be seen to be enhanced by the construction of improved breasts. Likewise the natural landscape, which has been cut away for the exploitation of minerals can be “enhanced” through revegetation and landscaping while leaving invisible toxins to continue to poison the earth and water.

The symbolism of mother earth as an alternative representation of female wisdom was developed by one of the women with whom I worked. As she criticised the imagery of the pink lady she drew a representation identifying the depth of her multilayered female strength.

The top layer is the earth but underneath the surface there are all these other layers. Just like for me you can see my outside layer but I have lots of other layers underneath my skin. I feel I have such a strong female wisdom at my core and it is this that I am able to tap into when I need it. (Personal communication, March, 25, 2012)



Image 9.2 Autumn layers

In response to this image I created a poem.

*I want to be strong, in charge
connected to my female wisdom.
My wise earth mother
draped in the colours of autumn.
Rather than being contained
in this pink straightjacket,
I want to get down and dirty
in the sweet, rich, moist
fecundity of the earth
and feel alive.*

My final piece of artwork is a series of body prints mapping, through colours, my exploration of my breast cancer experiences. Initially I painted my body white and made a series of body prints to represent the sanitisation of the medical system that I confronted on my initial diagnosis. I then went through the same process using all the colours: black, pink, red, blue, and gold. Finally I painted my body with all the colours of my cancer experiences. My multihued body now reminded me of the colours of autumn. This seems a fitting synthesis to my enquiry. Autumn represents my connection to the earth, to the natural cycles of life and death, to transience and impermanence, and to an integration of all my experiences. Autumn colours convey the complexity of female wisdom, the natural cycles of death and re-birth and the beauty of the natural world of which we are all enmeshed as flesh of the flesh of the world. The colours of autumn symbolise working towards the wellbeing of the planet.

What I now know in relation to my enquiry questions

I started this enquiry with a desire to make sense of my changed body, and use creative arts to help me to come to a decision about whether to have a breast reconstruction, and if not, to explore how to live as a one-breasted woman. The use of arts-based procedures has allowed me to engage in dialogue with my multi-voiced self and to gradually come to new meaning about my experiences of breast cancer, my post-mastectomy body, and my way of being in the world as a one-breasted woman.

Do I want to have a breast reconstruction?

Through my arts-based enquiry, as well as my exploration of other women's breast cancer narratives, breast cancer discourses, and conceptualisations of the body, I have come to the decision that I do not want to have a breast reconstruction. Clarity around this decision has gradually emerged and consolidated through my extensive reading and many arts-based enquiries. My breast cancer experience has not just affected my biological body; it has also affected my whole lived experience—my physical, emotional, psychological, and social world. Adopting a phenomenological approach provided a means to describe and understand my subjective experiences of breast cancer; it allowed me to describe changes to agency, embodiment, interaction with the social, cultural, and physical environment and other individual features of my illness.

Although largely viewed as a broken machine in need of repair by the medical system, I have resisted this depiction, and through my arts-based enquiry have arrived at a view of myself as always whole, but continually forming in relationship with the world in which I exist. In the words of Margaret Somerville (2007), using an emergent methodology has allowed me to emphasise “the irrational, messy, embodied and unfolding of the becoming self” (p. 225). My enquiry and reading has also enabled me to challenge the traditional feminine notions of the normative body grounded in the dominant breast cancer discourse. I now feel comfortable living as a woman with one breast and challenging those who view my one-breasted body as a “mutilated body” (Braidotti, 1997, 2002).

How do I live as a one-breasted woman?

As well as facing the challenge of a life threatening illness, the removal of my breast brought my sexuality into focus as I navigated the gendered and sexualised social and cultural world as a one-breasted woman. My lived experience of breast cancer was a rich tapestry in which my personal story intersected with the dominant political and social discourses of breast cancer that are grounded in differing understandings of the body as explored in chapter two. Reminded by Dorothy Broom (2001) that breast cancer is a social drama and not just a personal tragedy, I have made sense of my own individual experience within the context of different discourses (Stoppard, 2000; Hopkins, 2003). In developing my own narrative in black, red and blue with which to story my bodily experience of breast cancer I acknowledged the influence of the available breast cancer discourses, each of which represent breast cancer through a particular discourse of the body.

I am aware that my multi-self being is formed through dramatic interaction with the political, social, cultural, and natural world, or as Judith Butler (2003, 2004) argues through performance of repeated acts and behaviours. Drawing on Merleau-Ponty's idea of the body she writes “One is not simply a body, but, in some very key sense, one does one's body” (Butler, 2003, p. 393). This idea of the self forming through dramatic interaction is further developed by Pam Paterson (2008), a woman with a disability and an amputated breast, as she asks, “while such a body as mine is constrained by historical conventions ... Is it possible to expand the cultural field through transgressive performances? Can the grotesque work successfully to deconstruct a confining aesthetic and the normalized body in culture?” (p. 389). Like me Pam Paterson explores the meaning of her “grotesque body” (Wolff, 2003) through the use of multimodal arts using her body as a site for sound, gesture, and image that “activates the materiality of the body, generates emotion and can permit the re-storying of experience in/through a narrative of transformation” (p. 389).

“By responding *in* and *through* art” (Prior, 2013, p. 166 italics in original), I have been able to explore my experience of my body and now feel more confident in performing my body in the world in its transgressive reality. I now feel less constrained by political, social, and cultural conventions. Although I acknowledge the important role of early feminists such as Audre Lorde (1980) and Jo Spence (1986) in challenging the traditional notions of femininity, which are still very much a part of dominant breast cancer discourses, unlike them, I do not feel the need to continually bare the evidence of my breast cancer to the world as a form of feminist protest at the exploitation of women by patriarchal capitalist forces.

Whilst my decision to not have a breast reconstruction may be seen as a challenging the pressure to conform to idealised notions of the normative body, I still at times choose to look as if I have two breasts by wearing a prosthesis as similarly I might sometimes put on make-up to present a particular view of myself to the world. At other times I choose to not wear a prosthesis, which makes the reality of my one-breasted body visible to others, but I do this because I feel comfortable in my body and not as a deliberate political statement (Crompvoets, 2012; Jain, 2007, 2010). I disagree with the views of Audre Lorde (1980) that attempting to hide the changed body through the wearing of a prosthesis does not allow women “to come to terms with their own pain and loss, and thereby, with their own strength ... which forecloses the possibility of reaching whatever enlightenment might be at the core of the breast cancer experience”(p. 49).

My body performance in constructing my sexualised and gendered self in the world is further complicated by my sexual orientation. As a lesbian woman, I face additional challenges presenting myself in varying ways that confound both traditional notions of femininity and stereotypes of lesbian women (Jain, 2007, Sinding et al., 2010). Eva Karpinski (2010) critiques personal breast cancer narratives (Kingston, 2009; Znaimer, 2007) for perpetuating a heteronormative view of women’s experience of breast cancer, “by silencing references to lesbianism (in Laurie’s [Kingston] elision of her favourite singer Melissa Etheridge’s sexuality) or flaunting sexist stereotypes (in Libby’s [Znaimer] fear of looking butch with her new growth of hair)” (p. 114).

By challenging normative constructions of the female body by deciding not to have a breast reconstruction, while at the same time, varying my appearance through choosing to wear or not wear a prosthesis, I am able to live as a proud one-breasted woman according to my own values and beliefs and thus challenge both butch dyke representations of lesbians as well as traditional notions of femininity.





What can I do with what I now know from my breast cancer experiences

Through my arts-based enquiry I have been able to form rich experiential, presentational and propositional knowing. By prioritising my immersion in creative arts and trusting in the pathway that emerged for me, I have come to new understanding about my own and other women's breast cancer experiences. Having been immersed in this enquiry for over four years, I feel I have formed practical knowing which I can use to benefit the lives of other women with breast cancer.

Integration of embodied arts-based methods into my arts therapy practice

My own arts-based enquiry into my breast cancer experience has been transformative and enriching. My struggle to try to articulate the enquiry process I followed has allowed me to gain a much stronger grasp on embodied knowing and the power of art-making, which I can bring to my arts therapy practice, clinical supervision, and teaching. In particular, I will bring an understanding of the importance of sensory knowing that can arise from a close attention to the intersubjective relationship between the sensing body and the art materials. My experience of drawing on the image of the black hole to enable me to stay with strong, difficult emotions has shown me the importance of allowing others to find safe ways, through art-making, of staying with strong emotion. I have also gained a greater appreciation of the importance, for some, of prolonged contemplation and the pause in arts therapy. The pause as a means of moving into

mindfulness is a guiding principle of my practice of Insight Dialogue (Kramer, 2007) and is also used by Shaun McNiff (2014) as a way of reconnecting with mindfulness to the present moment, "the pause slows everything down so that important things can emerge and be experienced" (p. 45). Through my own experience of being assisted by an attentive compassionate companion, I have developed an appreciation of the importance of bringing my whole self to the arts-based enquiry, of being present to both the arts and the other as highlighted by Stephen Levine (2009):

The most important of these gifts is the capacity to be present. The practice of the arts requires presence above all else: 'being there' in the emphatic sense. The openness and receptivity of this presence allows images to enter our space. Presence makes imagination possible (p. 152).

Providing support for women with breast cancer

Although my initial motivation for this enquiry was to develop meaning from my own breast cancer experience, I have never lost sight of the additional goal of assisting other women. There is a growing acknowledgement of the beneficial effects of using arts to help women with breast cancer (Oster, Astrom, Lindh, & Magnusson, 2009; Reynolds, Lim & Prior, 2007; Singh, 2011). I relate to the views of Beth Ferris & Youpa Stein (2002) that, "the creative arts help people living with cancer to 'unfold the cramped self, uncover losses and strengths, and gain the courage to begin a process of reclamation of story and life' (p. 47).

I would like to utilise the learning I gained from my participation in the arts-based group to offer similar programs to other women, particularly in relation to their acceptance of their changed body and decision-making around whether to have a breast reconstruction. Ideally I would like to develop a relationship with a mainstream hospital, such as the Peter McCullam Cancer Centre in Melbourne, to ensure art-making is integrated into support services for women with breast cancer, through the training of social work and breast cancer nurses. I have already made connections with the social work team and am optimistic that this can be achieved.

I initially wanted to develop a public website as part of my doctorate enquiry that could be available to women who were looking for a space to explore their experience through art, and also looking for information and support. In recent years there has been an explosion in women using blogs to explore their own breast cancer experience through personal narrative and art as well as an increase in online information and support through a range of peak cancer support bodies. I still believe there is a need for a more interactive online space that could encourage intersubjective dialogue using arts but perhaps this is only really possible in a closed group.

Bringing the lived experience perspective to health services

Bringing a phenomenological understanding to illness allows an appreciation of the impact of breast cancer on the whole life world of a person, not just on their malfunctioning body part. The medical system is still dominated by the biomedical

discourse and restitution narrative (Frank, 1995). In viewing patients as broken machines that need fixing, patients are disempowered and little acknowledgement or support is given to them to understand the impact of their illness on their personal, emotional, or social worlds. There is a growing movement towards a more holistic approach within medicine with advocates such as Harvi Carel (2011, 2013) supporting a phenomenological approach and Rita Charon (2008) promoting the idea of narrative medicine.

I am keen to undertake work with breast cancer services in my local city of Melbourne to develop a more holistic response to women with breast cancer. I plan to develop an information pamphlet for doctors that can encourage a better understanding of the women's lived experience of breast cancer, which would contain some simple information on how to respond to the patient as a person, rather than as a disembodied object. I have been involved with a training program for General Practitioners and I am currently working with one training organisation in incorporating these ideas into their training programs. I have delivered a number of workshops to doctors and nurses in which I have used creative arts (films, images, and poetry) to present the perspective of the lived experiences of a woman with breast cancer as a means of increasing their awareness, and will continue to do this.

As a woman living in a same-sex relationship, I found little support for either myself, or my female partner, that connected to our lived experience. The cancer support services assume a heterosexual norm and any information provided to women identifying as lesbian is provided as a clumsy afterthought. I would like to work with mainstream

support services such as Breacan and BCNA in developing more appropriate information kits that are inclusive of women who identify as lesbian. Using my short films I have contributed to a project with Breast Screen Victoria in developing a more supportive and inclusive service for lesbian and transgender women.

Providing an alternative breast cancer discourses

The task of challenging the dominant breast cancer discourse of positivity, cheerfulness, and traditional notions of femininity is important and ongoing. The fact that the writing of Audre Lorde (1980) is still so relevant and pertinent nearly 35 years later is evidence of how far we still have to go in developing a more sophisticated understanding of the causes and treatment of breast cancer. Wherever possible I will continue to promote alternative breast cancer narratives through my art-making and writing. Through this enquiry I have become increasingly aware of, and outraged at, the links between breast cancer and environmental degradation linked to our individualistic, capitalist, consumerist ideology in the West. I believe there is an opportunity to exploit the high profile of the pink breast cancer marketing to develop increased environmental awareness of the cost of our first world lifestyles. Until recently I was not aware of the existence of the environmental breast cancer movement in the U.S.A. and I'm interested in investigating the possibility of assisting in the development of a local movement in Australia.

Personal Life

This enquiry into finding meaning in my breast cancer experience has been circuitous, challenging, confronting, enriching, and deeply transformative on many levels. I have

continued to explore my interest in Insight Dialogue meditation practice alongside my doctorate enquiry and have found increasing intersection between my arts-based enquiry process and the Insight Dialogue approach. Looking back over this journey, the importance of regular art-making as a way of making sense of my life stands out. I will continue to use the arts as a way of finding meaning in my lived experience through a commitment to a regular arts practice. Finally, my exploration of feminist phenomenology and ecofeminism has increased my appreciation of the integral connection between the human and non-human world and has provided me with a renewed commitment to devote my energy to the achievement of a sustainable world: one which views the earth as sacred; recognises humanity's interconnectedness with and dependency on the natural world; and embraces all life, human and non-human, as valuable.

Conclusion

This enquiry has been grounded in my body. In coming to new meaning about my lived experiences of breast cancer I have attempted to speak from my body about my body. As Pam Paterson (2008) writes, "research for me is experiential, in and through the performing body-as- becoming-as-self" (p. 388). I have attempted to heal myself from the inside out and the outside in. Situated within a review of different discourses of the body, my enquiry centred on an understanding of the feminist phenomenological body as a continuously forming shape-shifting entity intermingled and coconstructed with the social and natural world as a basis for my embodied knowing. My arts-based enquiry foregrounded the "sensuous encounter" (Seeley & Reason, 2008), particularly

as it relates to the sense of touch between myself and the art materials. Touch provides the bridge between my experiencing, emotion, and movement into art-making. Touch grounds me in the present moment, allows me to heighten my sensory awareness, and provides the space for new knowing to arise within my body.

From a desire to find clarity in my decision as to whether to have a breast reconstruction I have taken a circuitous, rambling voyage through the colours of cancer from the black of grief, to the red of anger and outrage, the blue of acceptance of my imperfection and the celebration of life and finally to the colours of autumn symbolising female wisdom and concern for mother earth. Connecting back to the discourse of the body as flesh of the flesh of the world as articulated by Merleau-Ponty, I came to understand that not only does this understanding of the body underpin my arts-based enquiry process but also provides the philosophical foundation linking breast cancer with environmental degradation and thus creates a bridge between breast cancer activists and environmental activists to form a coalition in fighting for a more environmentally sustainable way of life and I hope, a reduction in the incidence of breast cancer.

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Appendix 1

Letter of Approval from MIECAT HREC

Melbourne
Institute for
Experiential
&
Creative
Arts Therapy

"Human kind is
being in search
of meaning"
17th August, 2010 Plato

15 Victoria Street
Fitzroy, VIC 3065
Tel: +61 3 9486 9081
Email: admin@miecat.org.au
URL: www.miecat.org.au

Kay Gravell
PO Box 1438
St Kilda Sth 3182

Dear Kay,

Re: Ethics Application

A collaborative inquiry exploring 6 participants' lived experience of their body following a mastectomy.

Thank you for submitting your ethics application. It was reviewed by the HREC at its meeting on 29th July, 2010.

The committee has approved your ethics application pending the following amendment:

- **Item 10:** That recruitment emphasises word of mouth rather than a more formal selection process
- For our records we ask that you submit an ethics application with this change and signed by you. Please forward to the office as soon as possible.

We wish you all the best in your research.

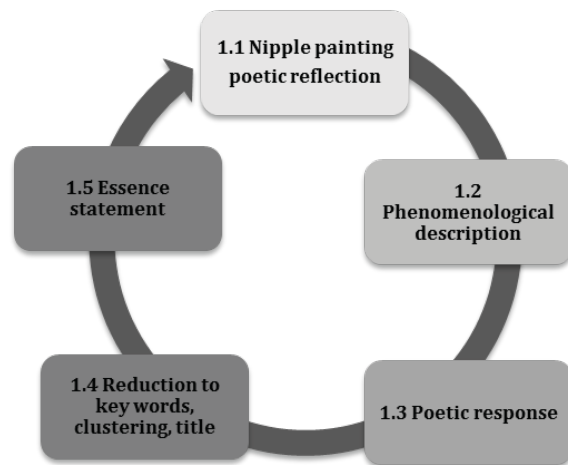
Yours sincerely,



David Davis
HREC Committee Chair
MIECAT Inc

Appendix 2

Alternative inquiry process for nipple painting enquiry



1.1 Creating nipple art

Alone in my flat on the night before my first operation as I reflect on the idea of having my nipple removed, I decide that I want to celebrate my nipple in some way. My nipples are such a vital part of my womanhood. They have nurtured my babies and are a source of sensual pleasure. Such a small innocuous piece of human flesh that holds so much significance and symbolism for me. I decide I want to experience the sensation of my nipple one last time, to allow it to leave a mark behind. I cover my nipple with black paint and using it like a brush I make a series of images on white

paper that I have stuck to the wall.

Nipple Painting

*Tomorrow my nipple is being cut off.
The perfect symmetry it provides my breast
will be replaced with a scar.*

*My nipple is a site of such strong sensation.
In response to emotion, sexual arousal, touch, temperature
it changes shape, colour and texture.
It is a barometer of my inner and outer world.
A constant reminder of my womanhood.*

*As I walk forward
my nipples are the extremity
of my physical boundary;
like a cat's whiskers
they are a radar
sensing the atmosphere ahead of me.
How do I celebrate my nipple?
Commemorate it?
Connect with the emotion of its loss?*

*I have a desire to somehow retain
its character.*

To allow it to make its mark.
To feel its physicality.

Like a paint brush
I move my paint smothered nipple
across the paper making a series
of abstract marks.

I immerse myself in nipple painting.
My nipples become tender, sensitive. The abrasive movement
across the paper becomes
more painful.

As I paint slashes of black
the shooting pain through my nipple
feels like
a knife cut.



Image 4.3 Two faces



Image 4.4 Couple with
bird Mirka Mora 1958

1.2 Being with the representation: Reflective contemplation

As I contemplate the images I feel myself drawn into the intense gaze of one image in particular, Image 4.3 Two faces of fear. It has the quality of a Mirka Mora, painting with large deep intense eyes conveying an expression of ... trepidation, fear, apprehension, knowing? I am amazed when I google Mirka Mora to find an image that has a strong resonance with my image. Image 4.4 Couple with bird The image of two faces has brought my sister, Ann, back into the forefront of my life. She died within a year of her breast cancer diagnosis when she was only 35 years of age. Will I die this quickly too? Whilst she has always stayed with me as a strong presence, I feel a renewed connection to her.

I have always experienced a strong sense of survivor guilt about my sister's death. Three years before her cancer diagnosis, Ann had been in a terrible car accident in Canada. A young man, drunk and driving a stolen car had crashed through a busy city intersection in Winnipeg Canada and picked Ann out from the crowded kerbside and smashed her against a wall. She was very lucky to survive and spent a year in hospital and was left with a permanent disability with most of her left buttock gone and her pelvis smashed. After being rejected as too old to adopt a child, she and her partner had decided to try and have their own child. She borrowed my book on the Billings' method of ovulation (Billings, E., Billings J. & Catarinich, 1977) to assist her in becoming pregnant. I had been using the book to prevent getting pregnant. That week she found out that she had breast cancer and I found out I was pregnant with twins. It seemed so unfair and unjust. I struggled to accept our differing destinies. But she didn't! Throughout her painful cancer treatment she was still able to celebrate my

pregnancy and the birth of my twin sons. She died before their first birthday. How can I draw on her strength through my own breast cancer experience? How do I not feel overwhelmed by my fear of death?

I decide to depth my inquiry by doing a phenomenological description of Image 4.3 Two faces of fear.

1.3 Phenomenological description

On a rectangular white piece of paper there are two semi-circular black shapes; they are **linked** together by a round **smudge** shape. The **left** semi-circular shape has areas where the paint has almost run out; there is just a fine **shadowy** line in places. Inside this shape there is an **incomplete** circular shape with another round black blob **stuck** inside it. There is a faint line **connecting** it to the other similar shape in the second semi-circular shape. This small semi circular shape has a very similar appearance to the one it is nearly **touching**. Rather than a blob stuck in the middle of it, it has a **strong stroke** of **thick** black in the centre of it. This **thick** stroke touches one end of the small semi-circular shape and almost bisects it although not quite. There is a gap of white between this mark and the edge of the small semi circular shape. In the second large semi-circular shape on the right of the page there is a thick **dense** black oblong shape on the upper right. This shape **fades** out towards the end. Beside this shape there is a longer faint line that forms the outer edge of the semi circular shape and another **heavy black slash cutting** across the **bottom** line. The paint has a rich texture. Above it there is a black dot. Around the large shapes there are several smaller

splodges of **black** paint. There are several **faint** almost **invisible** lines as the paint has **run out**. There is a lot of white paper which gives it a light filled appearance.

1.4 Reduction using key words, clustering and titling

I intuitively select key words (highlighted in yellow) from my poem describing the process of making the art and from the phenomenological description. I select words that resonate with my felt experience of tracing my paint covered nipple across the paper. Whilst thinking of my experience of being diagnosed with cancer I make groups of from both sets of key words. I then indwell or reflect on these clusters and give them titles.

Stuck in deep black sludge	Connection through touch	Almost gone – energy exhausted	Fear of pain
thick	connecting	run out	slash
deep	linked	fades	cutting
smudge	touching	left	intense
stuck	stroke	faint	
black	strong	invisible	
heavy		shadowy	
		incomplete	
		bottom	

Table 4.1 Clustered key words and titles

Looking at these words and titles I feel an overpowering sense of desolation, exhaustion and fear. Just the words breast cancer has such powerful symbolism of suffering and

death in our society, made stronger for me as my sister died of breast cancer. At the same time there is a sense of hope revealed through the power of the sense of touch in enabling connection to my emotions, to my sister and to others.

1.5 Essence Statement

Through the blackness of my fear, pain and sense of loss I can reach out to touch my sister and feel a sense of connection.

Appendix 3 Exhibition Artist Statement

Artist Statement Kay Gravell Written from my body

*I am writing from my body, every crevice, curve,
mound and wrinkle transformed into a
calligraphy of my breast cancer story;
a story of the wisdom of the female body.*

I paint my body memory into text. Making art creates a powerful space for people to make sense of their experience of trauma or illness; to express complex emotions that are difficult to put into words. I am interested in the idea of bringing embodied meaning into words. Using my body as both a canvas on which to paint, and as a medium to create printed images, allows me to come to accept my changed body. The meaning of my breast cancer journey gradually emerged through my art-making. From a jumble of emotions and letters a narrative, in three colours, formed to convey the healing journey of one woman's experience of breast cancer; from fear and grief to anger and passion and finally to a place of acceptance and appreciation of the joy of living.

