

2003

## Storying the Body : Women's Narratives Through the Lens of Breast Cancer

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**Storying the Body: Women's Narratives Through the  
Lens of Breast Cancer**

BY

Janet A. Griffin

A thesis submitted in partial fulfilment of the requirements for the degree of

Bachelor of Social Science Honours

Faculty of Community Services, Education and Social Sciences

Edith Cowan University

2003

## USE OF THESIS

The Use of Thesis statement is not included in this version of the thesis.

## **ABSTRACT**

What can women's narratives contribute to our understanding of breast cancer and to feminist theories of the body? This thesis explores the meanings women construct to make sense of embodied experiences of breast cancer, and the profound experience of breast loss. Rich contextual data was elicited from in depth, guided conversations with five premenopausal women who have undergone mastectomy. Adopting feminist methodology, biographic-narrative was used to place the body at the heart of inquiry. This thesis explores the personal and theoretical meanings of mastectomy, embedded in the larger story of how these five women experience their breasts, throughout their lives. Attending closely to subjective experiences, I hold these stories to the light of feminist analyses of the dominant discourses that shape {and are shaped by} these experiences. Each woman was invited to tell the situated story of her body, with emphasis on breasts and their meanings, functions and significance, across the life story. Pivotal moments in a trajectory of life events provided focal points for inductive analysis. Data was taped, transcribed and coded into themes, drawing on phenomenological and hermeneutic traditions. Moving between feminist analyses of biomedical discourses, verbatim insights from each participant, and excerpts from my research journal, my aim was to co-create a multi-layered narrative text that affirms the body as a site of knowledge, and contributes to feminist theorizing about the body. Findings indicate that short and long term impacts of chemotherapy on fertility, and associated hair loss, menopausal symptoms, and weight gain, may be more of a challenge to a woman's identity, sense of femininity and sexuality, than the removal of a breast. Each woman in this study emphasized a desire for symmetry and

balance, with or without breasts. The narrative structuring of the thesis provides gaps for analysis and reflection, and allows commonalities to be foregrounded, without abstracting and effacing individual experience. This is a collaborative project that contextualizes breast cancer and mastectomy and allows women's myriad voices to contribute to new knowledges about breasts, and breast cancer, exceeding parameters of present understandings.

## DECLARATION

I certify that this thesis does not, to the best of my knowledge and belief:

- i. incorporate without acknowledgement any material previously submitted for a degree or diploma in any institution of higher education;
- ii. contain any material previously published or written by another person except where due reference is made in the text;  
or
- iii. contain any defamatory material.

Student \_\_

Date 07/12/03

## **ACKNOWLEDGMENTS**

My sincere thanks go to the five women who share their stories, and to my supervisor Lekkie Hopkins, for finding the right balance between challenge and support. I dedicate this thesis to my mother in law Margaret, who died of breast cancer in 2002.



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# CHAPTER 1

## INTRODUCTION

Breast cancer is a gendered and culturally laden disease, occurring at the icon of the breast. For many women, breasts constitute a bodily site of contested meanings, contradictions and ambivalence. This thesis positions the experience of mastectomy within the context of a woman's lifelong interaction with the competing discourses surrounding breasts in contemporary western culture. A woman's feelings about her breasts are rarely neutral or static. While deeply personal, these feelings also reflect the social construction {and regulation} of women's bodies and femininity. The breast is an important 'marker of society's values' (Yalom, 1997, p. 278).

This thesis responds to a 'narrative turn' in social research and a call for stories with which to make sense of lived, embodied experiences (Mattingly & Garro, 2000). A story is an instrument that structures our experiences, connecting and integrating discrete elements into a coherent picture of who we are. This multi-dimensional picture incorporates actual, ideal and desired aspects of the self (Kenyon & Randall, 1997). Stories are "ways of relating individuals and events to social contexts, ways of weaving personal experiences into their social fabric" (Graham, 1984, p.119). This interweaving produces an aesthetic form of knowing. Stories make us intelligible to ourselves, and also reflect and transmit beliefs, values and customs at a cultural level.

Storying the body is a project wherein fragments of stories may be analyzed in relation to wider experiences of being female, an individual, and a self-in-relation. Women experience breast cancer on several levels, in multiple contexts of everyday life. Valorizing women's breast cancer narratives positions the disease in a political, social and cultural framework. Through storytelling, a woman may seek her own meanings and assert her individuality, whilst simultaneously reaching out to others, to find shared meanings and solidarity. Breast cancer is "a social drama, not an isolated personal tragedy" (Broom, 2001, p.265).

In Australia, a woman's lifetime risk of developing breast cancer is one in eleven and it remains the most common cancer in women (National Health and Medical Research Council, 2000). In 2000, breast cancer was the leading cause of death in women aged between twenty-five and sixty-four years. Despite a modest decline in the death rate since 1993, of approximately three per cent per year, there has been an absolute increase in the incidence of breast cancer (Australian Institute of Health and Welfare, 2000). There is an increase in breast cancer in younger women, and in diagnoses of ductal carcinoma in situ (DCIS) (Sellman, 2003).

It is well established that diagnosis and subsequent treatments have significant impacts on quality of life (NHMRC, 2000). A diagnosis of breast cancer in younger women may interrupt developmental priorities, for example childbearing and career goals. Concerns about fertility and early sudden onset of menopause as a consequence of systemic treatment pose particular challenges. Schover (1997, p. 194) asserts: "Most women over age thirty-five and many younger ones become permanently menopausal and infertile after chemotherapy", due to damage to ovarian follicles. Women are advised not to conceive for two years after chemotherapy or while on Tamoxifen, because of the risk of birth defects. The psycho-sexual impact of breast cancer may include a "perceived loss of youth", depression, anxiety, and fear of death, recurrence, abandonment, rejection, and a "loss of the sexual self" (The Cancer Council of NSW, 2002, p. 26). Younger women tend to have more aggressive cancers, a higher risk of recurrence, and higher mortality rates (Sellman, 2003). Now let us turn to five women behind the statistics, five vibrant, eloquent women who generously share stories about breasts, and mastectomy. In this way we may "add blood and tissue to the abstract bones of theoretical discourse" (Ellis, 1997, p. 117).

In presenting the stories of Susan, Ellen, Joy, Magda and Kate, I weave back and forth between analysis of the dominant discourses surrounding mastectomy, and feminist theories of embodiment and the narrative construction of self. In bringing these women to the page, I hope to illuminate the complexity and richness of a discursive rendering of experience, to glimpse how individual women negotiate their own meanings of *being* a female body, with or without breasts. These are full-bodied stories in which each woman places her own emphases on breasts across the lifestory, and interprets the significance of breasts to identity, femininity and body image, through the wide angle lens of breast cancer.

Susan is a vivacious woman of forty-six, a mother of three sons. She was diagnosed at forty-four with a DCIS and had a bilateral mastectomy (one prophylactic) with immediate reconstruction using saline filled silicone implants. Attempts to reconstruct her nipples resulted in success in only one breast. Ellen is petite and softly spoken, also forty-six, and a mother of two. She was diagnosed at forty-three with an advanced tumour and lymph node involvement. She had a mastectomy with immediate reconstruction using an implant. Ellen also underwent radiotherapy and chemotherapy. Joy is an intelligent, articulate woman, a mother of two daughters. She is forty-one and was diagnosed at thirty-nine with a four centimetre DCIS, with one malignant lymph node. She had a mastectomy with immediate reconstruction using tissue from her abdomen, plus chemotherapy. Magda is an energetic woman of forty-nine. She was diagnosed at forty-five with a large tumour, with sixteen lymph nodes involved. She had a mastectomy with immediate reconstruction using abdominal tissue, and chemotherapy. Ellen, Joy and Magda chose not to have nipple reconstruction. Kate is forty-six, a mother of two. She was diagnosed just before her forty-fifth birthday. She had a large tumour in one breast and two smaller, more aggressive tumours in the other. She underwent bilateral mastectomy and chemotherapy.

Where appropriate I have interspersed excerpts from the transcripts, to enliven the text with the words of the participants, and to deliberately foreground their insights.

Excerpts from my research journal are included to interrupt my own academic voice and reveal the multiple selves I bring to this work. Journal entries 'embody an interpretive process' and reveal the centrality of our own experience in the field (Clandinin & Connelly, 1994). They provide insights into conceptual development,

<p>"Feminist perspectives have shown us how the flesh of story embraces, disturbs, and connects more strongly than disembodied, neutralized text" (Neilsen, 1998, p. 10).</p>
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research decisions and the progression of my thoughts, feelings and intuitive reactions, as the project unfolded. I also frame theoretical insights from my readings within text boxes, to both enrich the text and trouble the narrative flow. For this technique I acknowledge and thank Leckie Hopkins (2003).

An investigation of perceptions, feelings and intimate experiences of breasts and cancer requires a qualitative-naturalistic research approach. The conceptual framework underpinning this project is a constructivist orientation towards phenomenology and

hermeneutic interpretation, infused with a feminist poststructuralist sensibility. Research narratives reveal an 'emergent and situated' version of a story (Mattingly & Garro, 2000). This thesis proceeds from an assumption that women articulate and interpret stories according to linguistic and cultural resources accessible to them, influenced by culturally specific rules and narrative conventions (Kvale, 1996). My aim is to contextualize the subjective experience of mastectomy, listening for the multiple voices that emerge in storytelling moments.

Within the vast amount of literature about breast cancer, and despite increasing attention to women's own perspectives, the master narratives still hold sway. Emerging and receding, they form the discursive backdrop against which to foreground the stories less told. Fosket (2000) highlights the neglect of embodied experience and emotionality as legitimate sources of knowledge. Her analysis exposes the conflicts between various knowledges about breast cancer, within a hierarchy in which woman-centred knowledge is subjugated. Fosket (2000, p. 19) highlights the "cultured and social contexts of biomedical knowledge production", emphasizing that biomedical knowledges, whilst privileged, are textually mediated and always contestable. To engage with breast cancer as a feminist highlights this disjuncture between dominant discourses and the lived experience of women. Drawing on Foucault's theory of the 'clinical gaze' as a material and discursive mechanism of social control, Fosket (2000, p. 24) argues that subjugated knowledges are 'sites of resistance and transformation'.

Knowledge is an activity; it is a *practice* and not a contemplative reflection. *It does things* (Grosz, 1995, p. 37).

Langellier (2001, p. 150) asserts: "narrative names a site where the social is articulated, structured, and struggled over". She stresses that storytelling is a relational act of telling and retelling the self and others, and reaching out to multiple 'ghostly' audiences, all of whom are implicated in a 'discursive struggle' over meanings (p. 151). Mattingly and Garro (2000, p. 22) emphasize: "Telling a story, enacting one, or listening to one is a constructive process, grounded in a specific cultural setting, interaction, and history. Text, context, and meaning are intertwined". Narrativization processes may resist and transgress limiting master narratives, allowing women to emerge through their stories as women in the process of becoming; visible, connected and empowered.

## **Research Journal. 22<sup>nd</sup> July 2002. Week 1**

*Feeling daunted by the prospect of 'doing research', will need to cover much ground in little time. Despite being so new to me, feminist theory and methods 'feel right'. Excited by the content and the journey – finding my voice, not to speak on behalf of but to speak (as a woman) for women, to participate in the process....phoned Mum for her birthday, didn't ask me about uni. I feel she's disappointed that I've decided to do honours rather than come home. I did promise!.... Why am I doing this – for the worst possible reason, because I'm flattered to be asked, indulging my ego? Yes, but breast cancer is very real and relevant to me, it has robbed us of my strong, beautiful mother in law and her loss is so recent and acute. I wasn't there for Mum's journey with breast cancer....*

## **Week 5. 19/08/02**

*Getting bogged down trying to do a lit review, got some 'how to' books out, making lots of notes as usual. I know what the lit review should do, its purpose in the proposal. The difficulty is determining what is relevant. It is so time consuming to read in the hope of finding something useful, and not knowing how to make the information fit. Friday – last date for withdrawal w/o HECS debt. Agonized all day but stuck with it – a failure to act rather than a conscious decision, I do really want to write the "beautiful" thesis that Lekkie expects of me, but I am worried that I'm not up to the task, not making enough progress.*

## **Week 8. 09/09/02**

*The proposal is evolving into a storying of the body...This development is exciting but also frustrating, because the message from RES5102 is to keep it narrow and focused. I'm wanting to pin the problem down, hone in, not open it up...So far I've been focused on the theory rather than contemplating the practice. I'm now trying to imagine myself actually sitting with women, talking about personal and intimate aspects of their private lives. Need to find the right vocabulary, to frame questions in positive language, to avoid being intrusive or causing discomfort.*

*OK. a passage about my breasts! This exercise is my attempt to position myself personally, biographically and politically, in the text, not a facile acknowledgement of*

*my age, class and sexual orientation but an honest disclosure of some feelings and thoughts about the topic I am immersed in.*

*I have always disliked my breasts. I remember looking forward with such impatience to finally developing breasts- the outward display of being a woman, rather than a girl or a tomboy. I was the last girl in my class, if not my year, to wear a bra. (I was also the last one to menstruate and to progress from cotton socks to nylon tights). I can recall the acute embarrassment of standing in line and having a girl run her fingers down my back, then proclaiming to my peers that I was still wearing a vest! No bra strap to twang, no exclamation from me as elastic snapped my skin. I was sixteen when I finally persuaded my Mum to buy me a training bra. She reluctantly agreed, not really seeing the need for the expense but it meant so much to me to have that strap to be twanged, even if there was not much to put into a size 32 triple A cup. I remember I would lie in the bath, a weekly event, and hope that the channel of water between my breasts would narrow as they emerged from my skinny frame...*

## CHAPTER 2

### LITERATURE REVIEW

Iris Marion Young (1990) is one of few authors to examine 'breasted experience' as a feminist problematic. Young (1990, p. 189) describes breasts as "the daily visible and tangible signifier of . . . womanliness". In terms of self-concept, identity and body image, a woman's sense of 'being in the world' with breasts is entwined with cultural notions of femininity, sexuality and desire. Young (1990, p. 203) asserts: "Phenomenologically, the chest is a center of a person's being in the world and the way she presents herself in the world". She analyzes the patriarchal construction of breasts as fetishized objects produced for a male gaze, and maintained by disciplinary practices. She argues that breasts are positioned as 'things': as commodified body parts that are judged according to phallogentric ideals of size, shape and function.

Despite our cultural fascination with the surface of women's breasts, the intricacies of breast development continue to be "a major biological puzzle" (Russo, Lynch & Russo, 2001, p. 279). After only four to six weeks of life, the embryonic breast appears as "the first of all glands derived from the ectoderm" Gyilenskold (1982, p. 296). However development into 'a functioning organ' is paradoxically late. "Breast development occurs through a [synchronous] process of ductal elongation, branching, and sprouting of ductules" (Russo, Lynch & Russo, 2001, p. 283). The breast is a modified sweat gland, consisting of adipose tissue interlaced with connective fibres, blood vessels, nerves and an intricate lymph system. Each breast contains fifteen-twenty lobes, each with its cluster of tiny lobules. Each lobe has a milk duct, converging at the fissures of the nipple. Breast development generally precedes menarche. Lobular formation begins in puberty, but full differentiation requires a full term pregnancy.

Saywell, Beattie and Henderson (2000) assert that value is ascribed to female bodies in terms of reproductive capacity and sexuality. They highlight the dichotomy between the idealized maternal breast, and its binary opposite, the eroticized breast, existing for male consumption. They argue that the 'cancerous breast' disrupts these



conceptual boundaries, perpetuating the cultural fears, taboos and stigma that frame women's experiences of breast cancer and breast loss. Yalom (1997, p. 278) suggests: "breast cancer is the catalyst that has transformed the way we conceptualize the breast". Increasing medicalization appropriates and fragments breasts as diseased, fixable or replaceable body parts (Young, 1990). This objectification of breasts frames the 'disposal' of diseased or even healthy breasts perceived as 'a site of risk' (Hallowell, 2000, p. 157). Magda: *"I can say this now, but at the time you don't think about cancer anywhere else in your body...you just think of it sticking out in front of you in your breast, you don't think about it anywhere else...well I didn't.."*.

In an 'ambiguously professional and personal' account of her own experience with breast cancer, Broom (2001) describes the disease as a 'female-specific condition' in which "gender, sexuality, sexism and morbid fears intersect" (p. 250-1). She highlights the stigma attached to breast cancer in an Anglophone culture that regards health as a 'social duty' and where death, illness and disability have become 'obscene'. Breast cancer represents 'disordered femininity' and the female body is perceived as 'inherently morbid' (p. 256). She states: "If there is a new-age stereotype of the body with cancer, perhaps it is the person whose poor self-concept, sexual or emotional repression or inner conflict have made them 'need their disease' or have allowed them to 'give themselves cancer' (Broom, 2001, p. 256). This discourse of blame presumes the self to be located in the mind, upholding the mind over body dichotomy.

The term breast cancer refers to several disease conditions wherein cells in the breast undergo molecular change and proliferation. Breast cancer may progress through several stages, from pre-invasive malignancy to a localized tumour, and ultimately to breast cancer that is disseminated to remote locations in the body (Gorman, 2002). However, each case is unique in the rate and extent of spread, and in its impact and consequences for individual women. This point is emphasized by Ellen, who now appreciates that every woman experiences breast cancer in qualitatively different ways: *"mine was quite, quite large and quite advanced and there were a few lymph nodes, quite a few lymph nodes so, that puts a different perspective on the disease as well"*.

The causes of breast cancer are still not fully understood but it seems many factors combine to effect cumulative damage to genes within the cells. Cady (2000, p. 281) describes breast cancer as a progressive disease resulting from 'multihit' genetic events. Risk factors are found to include: increasing age, exposure to ionizing radiation,

endogenous and exogenous hormones, environmental pollutants, a genetic predisposition, and lifestyle factors such as smoking. However, as Simpson (2000, p. 143) points out, currently identified risk factors account for as little as thirty per cent of breast cancer cases. Inherited mutations in breast cancer susceptibility genes may increase a woman's lifetime risk to between forty-sixty per cent, but account for as little as five-ten per cent of breast cancer cases (Potts, 2000). Breasts are understood to be "more susceptible to damage or to the effects of oestrogen and carcinogens during development and/or before pregnancy" (Simpson, 2000, p. 146). Research is needed to discover which factors or combinations of factors lead to cancer initiation and metastasis, and which factors may protect against these processes.

Historically, breast cancer has been shrouded in 'conventions of concealment', fuelling public anxieties and personal dread (Saywell, Beattie and Henderson, 2000). Treatments for breast cancer have been summarized as "the Slash/Burn/Poison trilogy" (for example, Langellier & Sullivan, 1998, p. 76). The Halsted radical mastectomy was the preferred surgical response to breast cancer for over a century. This procedure involved the removal of the breast, plus underlying pectoral muscles and lymph glands from the underarm. This debilitating procedure was later modified to retain the pectoral muscles. In the late 1970s, feminists in the Women's Health Movement were instrumental in challenging the practice of 'one-step' surgery, that is mastectomy at the time of surgical biopsy. Only in the last three decades have surgeons begun to favour breast conserving interventions, including lumpectomy plus breast irradiation (Yalom, 1997).

This change in treatment options reflected a growing concern for psychological outcomes, as women challenged the autocracy of breast cancer management, and called for more holistic responses to their complex needs. In 1990, less invasive techniques were shown by Veronesi and colleagues to be "as effective as radical mastectomy" in terms of long-term survival rates (Saltman, 1997, p. 224). Cady (2000, 282) stresses: "Since survival is almost entirely due to distant metastatic disease in vital organs, greater or lesser radicalness of local tumor removal does not govern survival". However, Meric and Hunt (2001, p. 194) caution: "breast conservation therapy is associated with a higher risk of local recurrence, including a higher risk of invasive breast cancer". If tumours are excised with clear margins, the efficacy of radiation is now controversial.

For many women, for example those with large or 'multicentric' tumours, mastectomy remains the recommended treatment option (Meric & Hunt, (2001). A review of the literature reveals the construction of mastectomy as a 'mutilating' treatment, with assumptions that breast loss *necessarily* compromises bodily integrity, with significant impacts upon a woman's sense of self, body image and sexuality. Mastectomy is conceptualized as a loss, as disfiguring, debilitating and in need of prostheses or normalization through reconstructive surgery. Saywell, Beattie and Henderson (2000, p. 43) argue that mastectomy is perceived as a 'violation' of idealized femininity, to be 'hidden' as a 'source of shame'. Young (1990, p. 204) feels that "in an important sense" a woman "is her breasts" and when this is denied "she is not allowed to be public and honest in her fear and grief". Young (1990, p. 204) is critical of prevailing attitudes that breasts are 'only decorative', that women are motivated by 'vanity', and that "a woman's major emotional problem is in relation to her husband or male lover, that she worries how he will love her body". Broom (2001, p. 259) highlights the emphasis in both medical literature and the media on women's 'adjustment' to surgery, suggesting: "that sexual availability is the criterion of recovery". She highlights a lack of attention to: "a woman's loss of a site of erotic pleasure".

Saywell, Beattie and Henderson (2000) argue that the asymmetry of an absent breast challenges cultural ideals of beauty and 'normality'. Rare media images of mastectomies are often accompanied by 'discourses of body horror', exploiting "cultural fears about violated bodies as 'leaky vessels' (where fluids break bodily boundaries-commonly associated with the anti-ideal of the feminine body) and about malformation" (Saywell, Beattie & Henderson, 2000, pp. 44-45). Yalom (1997, p. 4) asserts that breasts have always had both 'good' and 'bad' connotations, as 'life-givers' and 'life-destroyers'. McConville (1994, p. 21) identifies 'the guilty breast' signifying "shame, discomfort, failure, death". Broom (2001) highlights 'the destructive resonance of the dominant cancer metaphors' of 'battle, invasion and defence', metaphors that impact tangibly on women's experiences of breast cancer.

Lorde (1997) critiques post-mastectomy prostheses and reconstruction as forms of cosmetic 'pretence' that silence, isolate and obscure. After her mastectomy in 1979, she is unable to reconcile a pink 'lambswool form' with her warm black skin; she finds it 'inert and lifeless', with a 'grotesque dryness'. She rejects this option, asserting: "Only

false breasts are designed for appearance only, as if the only real function of women's breasts were to appear in a certain shape and size and symmetry to onlookers, or to yield to external pressure" (p. 65). She chooses to love her 'new and changed landscape', or 'remain forever alien' to herself (Lorde, 1997).

Young (1990, p. 204) also critiques post-mastectomy reconstruction as "the ultimate in breast objectification". Medical technologies are persuasive that "for a fee and through additional pain, a woman can be 'as good as new'". Young (1990) argues that women comply with the demands of a normalizing gaze primarily to protect themselves from 'the gaze of repulsion'. Dominant responses to breast loss 'give primacy to the look' and neglect the feeling, sensitivity, motility and touch of a woman's breasts. Lorde (1997) also argues that many women internalize normalizing discourses, rather than freely choose from a range of responses, including life as a one-breasted woman.

Over twenty studies have compared outcomes for women who had mastectomy and women who had breast conservation. These studies found no significant differences in measures of quality of life. Schover (1997, p. 188) reports:

"Whether women choose their own treatment or leave the decision to their surgeons, the main benefit of breast conservation is that women feel more positive about their appearance. But they are not happier, more likely to stay married, more likely to be sexually active, or more sexually satisfied than women who have mastectomy".

Schover (1997) has found that women who choose breast reconstruction are likely to be younger, more affluent women. Schover (1997, p. 189) also asserts: "women are at least as happy with the results of immediate breast reconstruction as they are when the reconstruction is delayed for months or years". Schover (1997, p. 187) suggests: "women who choose to wear a breast prosthesis are just as satisfied with their body image as women who decide to have surgical breast reconstruction". Langellier and Sullivan (1998, p. 86) indicate that prostheses may be "incorporated as breasts, visually and tactilely, into the woman's body image and her sense of self". However, they found "a decreased sense of modesty applies to prostheses, distinguishing them from breasts" (p. 87).

Breast cancer is a profound disruption to a life, arousing in women a heightened body and breast consciousness. Potts (2000, p. 116) argues that diagnosis and treatments may result in 'alienation' and a 'loss of self'. Women may experience 'split

identities' for example in becoming a patient or survivor. In narratives, new subjectivities emerge, shift and often compete. Potts (2000, p. 123) cautions that a 'woman with breast cancer' is not "an ontologically discrete category", therefore this new subject position is neither fixed nor ever complete.

## Week 8 09/09/02

*Thesis Planning Workshop = really helpful – 4 misconceptions that impede writing – yes! All apply to me. Main message: Split process of writing and editing. 'Proposals That Work': "It is easier to correct than to create". Mind mapping – very helpful technique for emptying it all out and freeing up writing. Mine far too orderly, tend to list things neatly in blocks. I write everything as though I'm to be judged on it. Or as Neilsen termed: 'self-consciously watching my feet as I danced' (1998, p. 110).*

## A View From A Body

Contemporary feminist theories of the body seek to transcend dualisms, to reconceptualize the body and its boundaries. Grosz (1994) argues that a woman's body is not a passive, inscriptive surface but is historically and culturally constituted according to *interactions with* particular discourses, signifying practices and relations of power. Gatens (1996) also emphasizes sociocultural conceptions of embodiment rather than a 'natural' body and prefers 'morphological descriptions' of the body as active, animate, and infused with potential: "the form of the body is its being, its form is its desiring" (p. 58).

Grosz (1994, p. 64) advocates: "rewriting the female body as a positivity rather than a lack". This project denies interpretations of the female body as lacking 'self-containment' {a concept that has traditionally signified deviation and disorder}, and instead embraces the possibilities of plasticity and fluidity (Grosz, 1994). According to Young (1990, p. 192-3) we subjectively 'live our breasts' as "the sproutings of a specifically female desire". She envisions a "process metaphysics...where the being of any location depends on its surrounding and where we cannot delineate clearly what is inside and outside". In her strategic, ecological view

"the body is never isolated in its activity but always already engaged with the world" (Weiss, 1999, p. 1).
--

“the breasted body becomes blurry, mushy, indefinite, multiple, and without clear identity”. She draws on Irigaray to posit an alternative ‘imagining’ of a woman-centred experience of breasts, one that embraces their ‘fleshy materiality’ and privileges the reciprocal act of touch over sight. “Touch differentiates - indeed, takes pleasure in - the subtlest difference of texture or softness, but inasmuch as the things touched also touch each other, the borders are not firm” (Young, 1990, p. 193-4).

## CHAPTER 3

### METHODOLOGY

*Kate: (clears throat) "yes, yes, in fact, I have to tell you this little bit...."*

A postmodern 're-bodied' approach to inquiry is one of 'creating a path by walking' (Neilsen, 1998, p. 175). Phenomenology seeks the essence of lived experience and consciousness. It seeks to investigate and describe rather than look for causal explanations (Minichiello, Aron, Timewell & Alexander, 1991). A feminist's use of phenomenology attends to what is observed and *how* the inquiry proceeds. From the standpoint of feminist methodology, the phenomenological research practice of bracketing is impossible in the construction of woman centred knowledge (McCarl Neilson, 1990, p.290). As Oleson (1994) points out, my perceptions and biases are essential data and become valuable resources if research practice is sufficiently reflexive.

"Inquiry is praxis that cannot be boxed up and delivered; it is a story with no ending" (Neilsen, 1998, p. 8-9).
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{ Reflexivity is a political and feminist act that enriches the narrative text through collaboration and power sharing. Feminist researchers value connectedness, immersion and personal investment in research relationships. According to Oakley (1981, p. 49), there is "no intimacy without reciprocity". Polkinghorne (1997, p. 9) conceives of research as an 'improvisatory' performance in which the researchers own "values, desires, inadequacies, skills, and personal characteristics" emerge. A research narrative accommodates "extraneous happenings and everyday distractions" and is enriched by the "exploitation of pause, interval and indecision" (Polkinghorne, 1997). I am 'biographically situated' within the text as a sexed and multi-faceted participant in the intricate textual politics of representation and legitimation (Denzin & Lincoln, 1994). Rather than find a voice or research signature, we *fashion* a multiaccentual voice through interdependent processes of auto/biography.

The storytelling impulse:  
"Auto Bio Graphy. Self. Life.  
Writing. And in the middle is  
life" (Neilsen, 1998, p. 168).

A guided conversation elicits local, perspectival knowledge, with meanings that are shifting, partial and contextualized. This method allows for a 'discursive conception of truth' embedded in a complex web of social and power relations (Kvale,

1996). As Denzin (1994, p. 505) reminds us: "Truth is a textual production". Narrative is not merely referential but an 'enhancement of an experience' (Langellier, 2001). In our hearing and reading of a story, we need to 'situationally' analyze the material and discursive conditions of its telling (Fosket, 2000, p. 21). Some of the unruliness inherent in raw experience may be lost in the construction of a smooth and coherent text (Mattingly & Garro, 2000, p. 267). In our knotty entanglement "the story marks out the territory in which intrusion is tolerated" (Graham, 1984, p.107). Stories may reveal and conceal, highlight and obscure, and unintended consequences may flow from their telling.

The view beyond the  
master narratives  
contains: "kaleidoscopic  
montages of theoretical  
moments, shifting and  
slipping in elusive  
patterns" (Neilsen, 1998,  
p. 97).

The sampling strategy for this project was non-probability purposive sampling. The participants were all 'friends of friends' and the ease of locating so many younger women with breast cancer within my circle of acquaintances is a sobering reminder of how many lives are touched by this disease. Our taped conversations were at least one hour in length. Rather than an interview schedule, a list of topic areas was used to guide the conversations towards the research aims. Topic areas

followed a trajectory of life events centred on breasts. Data was coded into themes by grouping and prioritizing the responses according to how they related to the constructs in my readings. Throughout this process I sought plausibility and conceptual coherence. In this way, instead of being fragmented and compartmentalized, the responses are theoretically framed and enriched. This search for interpretive links and patterns allows for both internal consistency, and for 'recursiveness' and 'intuitive leaps which defy audit' (Neilsen, 1998, p. 275). In attempting to act as a prism, I aimed not for a spotlight, but for diffuse illumination of the texture of the stories.

The constant comparative method was used to develop and organize emerging concepts and themes. On-going analysis of each conversation informed the next,



privileging certain topic areas, generating alternative questions, and refining and strengthening the data (Janesick, 1994, p. 214). Through these iterative tactics, I attempted to stay close to the data, to be open to the nuances of each story, and to be attentive to the 'latent content': that is the symbolic message implicit in the spaces 'between the lines' (Minichiello et al., 1991, p.290). As women reflect, their ambiguities, contradictions and omissions all provide material for inductive analysis and ideographic interpretation.

Detailed memos were used to record ideas as the conversations proceeded. I promptly wrote descriptive field notes, 'margin notes' {detailing sensations, feelings and hunches}, 'reflective passages', and summaries to condense the data (Huberman & Miles, 1994). I attempted to jot down the intensity of feelings that accompanied various statements, and my own strong reactions or ideas as they arose during each conversation. These techniques clarify thought processes, document the processes of knowledge production, and provide an audit trail. I placed cut portions of the transcripts into separate files labelled under topic headings, {some passages fitted into more than one file} and as analysis proceeded, the findings were subject to constant refinement. I felt an increasing desire to foreground the words of my participants and I looked for opportunities to illuminate constructs with pertinent phrases from each. This is a collaborative effort to co-create a text that is honest and meaningful to women. Entering the liminal space of narrative entails walking on shifting ground, finding ourselves in stories that "bring us to our senses" (Neilsen, 1998).

*Magda: "...a lot of the questions you've asked me, I'm imagining now if I didn't have a partner and I would be, have totally different answers..."*

#### **Research Journal: Week 11 07/10/02**

*I can do my proposal next semester! So relieved, as I do not feel in any way prepared to present what I have so far. In another way, though this is bad for me, I am such a procrastinator. Must use this extra time to get on top of this. Must find a balance- ground the project in the academic conventions that grad school expects and my own desire to participate in freer, more creative experimental forms of inquiry, as espoused by Lebbie and Lori Neilsen. Don't know if I'm up to this, it's all so new, trying to be the 'good student' but scared of disappointing.*

**Wednesday 20/11/02**

*Attended seminar: Knowing, Fiction & Liminality- inspiring stuff- yes, I'm on the right track. This all fits so well with the way the proposal is tending-conceptually at least. Still struggling with its physical incarnation! Storying the body: I want to give an impression of reflecting on embodied events from a changed perspective= shifts in perspective impact upon lived experience, creating possibilities for change.*

### **Research Journal: Approaching Semester 2**

*As usual, my good intentions have come to naught. I have not reached the goals I set, lots of reading and note-taking so I can console myself that yes I have worked on the overall thesis, but the proposal is no nearer completion than at the end of term. The thesis doesn't scare me {as much!}, the proposal has become the obstacle!...Panic, Week 1 and I still do not have anything I'm happy to show Lekkier. The proposal is 4,500 words and all over the place! I don't know how to polish it into a concise, rational, well constructed and argued proposal.*

*Phoned Lekkier on the Friday of the second week. Decided to just be honest and own up to my difficulties. She reassured me that most students get to just such a point and that it is all part of the process and that I should bring in the draft, however fragmented, for constructive feedback. I feel so relieved. This has been a lonely process so far and I feel silly that I have been so reluctant to ask for help. It's all about wanting to appear competent and not wanting to be judged.*

**March 8<sup>th</sup>**

*Just back from my proposal seminar. It was great! After the dread of this day arriving, I really enjoyed the whole experience. I was so relieved that so few turned up, but now I regret that there were not more people there, as the feedback was so useful and, as*

*Lekkier would say, nourishing. It went so much better than I thought it would, my confidence built and I could feel myself physically relax into the presentation. There was a friendly atmosphere, not at all how I imagined...I feel quite swept up with excitement. As Lekkier says after nine months gestation, this project is well and truly ready to be born, and I am eager now to get on and interact with my women.*

<p><i>"To write, I must wade into a textual ocean and disappear in order to appear. I come to embody words" (Neilsen, 1998, p. 181).</i></p>
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## CHAPTER 4

### THE STORIES

#### **Acquiring the '*trappings of womanhood*' (Latteier, 1998).**

Latteier (1998, p. 15) suggests that breast development signals 'the advent of body consciousness' when we emerge from "the me of childhood - that bundle of amorphous pleasures and pains" into an often acute awareness of our bodies as 'equipment' and 'display'. In adolescence, girls must learn to manage this evaluating gaze. They may transform this attention into newfound sexual power, or shield their new contours behind loose clothing or stooped posture. Latteier (1998) argues that early maturity in girls has come to signify promiscuity. Women with large breasts are commonly perceived as 'incompetent, immoral' and 'immodest'. McConville (1994, p. 16) explains the "lusty busty" myth as a product of dichotomized thinking: "the more female you are - that is the bigger your breasts - the more biologically driven and sexual you are".

Susan's earliest memories of breasts begin as a twelve-thirteen year old and are conflated with menarche, and her first bra. For Susan, the experience of developing breasts was "a slow process and one to sort of feel more distressed about than look forward to". She identified "such an emphasis on girls having breasts", attributing this emphasis to other girls rather than boys. Susan also felt that her 'being skinny' was more a focus of attention than her breasts. She does not recall any boys "ever saying anything about breast size...but mind you uniforms sort of hid it", apart from "a few little references when you wore a t-shirt or a revealing v-neck". In comparing herself with friends, Susan expresses 'disappointment' in her breast size: "I'm *only* small". She responds by creating the illusion of bigger breasts, by 'tucking tissues' into her bra: "everybody did no matter how big you were". Breasts were important to Susan's adolescent self-image: "I wanted them because other girls had big breasts and I loved the cleavage look, I love that volumptuous [sic] look". Susan remembers "lying in bed saying: "please God, can I have bigger, bigger breasts". In response to hearing Susan's plea, her mother bought her "a bigger padded bra". However, Susan also "wanted to be

fatter", "wanted to be bigger full stop" that is, in proportion. By the time Susan started dating boys she was: "well into the padded bra and who would know". "Thank God" she says, for the Wonder bra! The emphasis seems to be on the specular image of breasts, on measuring up to an externally imposed ideal of size and shape.

From her first sexual experience at seventeen, men have generally reacted positively to Susan's breasts and large nipples. She asserts she "never ever had a problem attracting boys". Her desire was "to be sexy because sex has been, or my sexual image has been my main consideration and that I continue to be a sexually active person". Susan feels that breasts make a woman desirable 'to her mind', but in her experience 'most men' told her: "I like small breasts...I hate big loads of fat hanging off women's chests". In her late teens, she says: "I would never wear a bra, just little tight t-shirts and I did have small breasts but they were tight and, and I used to like them".

In analyzing the pleasure women take in our engagement with fashion, Young (1990, p. 186) asserts "There are ways of looking at oneself in the mirror that do not appraise oneself before the objectifying gaze, but rather desubstantialize oneself, turn oneself into a picture, an image, an unreal identity". Yalom (1997, p. 160) embraces the notion that "our choices correspond to an inner aesthetic ideal (however socially constructed!) which contributes to a general sense of well-being, and to the admittedly pleasurable sense of feeling sexy".

### **Research Journal Extract: 25/05/03**

#### **Interview 1: Susan**

*Met with Susan....After a few pleasantries she surprised me by asking if I would like to see 'what we're dealing with'...and she lifted up her soft, close fitting jumper, displaying her reconstructed breasts. She seemed quite proud of them and started to explain the procedures of incisions, placement of the implants and further surgeries to reconstruct nipples, although one nipple had 'failed'. She then asked if I would like to touch her breast and when I responded that I had cold hands she replied: "don't worry, I can't feel them". I genuinely admired the look of her breasts, their firmness and the neatness and faintness of the scars. The surgical skill involved was very impressive...I had arrived prepared to offer some anecdotes to establish our conversation as an exchange, but from the start Susan seemed to talk freely and openly....*

For Ellen, an awareness of breast development is not prominent in her memory: "I think, what's probably relevant is because I am small breasted...what stands out most is the growing up and the, er *publicity* and er, what's the word-*expectations* of women to be big breasted". Ellen recalls her friends being "more developed", and would have liked bigger breasts but says: "I never did anything about it....just a bit bigger would have been nice, not huge".

We must "continue to see ourselves seeing and to see how others see our seeing" (Weiss, 1999, p. 43).

In adolescence, Ellen did not have "a positive body image". She explains: "I think everybody likes to be something they're not unless you're perfect...people who are perfect still find something wrong. Although she "never had a negative body image" she would have liked "to have been a bit better" than she was: "like most girls,

teenagers do". As we talked, Ellen recalled an incident on the last day of high school: "we had er white collars on our uniforms and one boy wrote on mine 'oh, I'm not worried, one day my tits will grow' {both laugh} and...I thought 'oh well' you know, now you just reminded me, I hadn't thought about that, so they must have been pretty small, well they were, they still are {laughs}".

Joy remembers being taken shopping by her mother to buy a 'training bra' and learning what seemed like 'womanly things', such as "how to put a bra on properly, leaning over forward into it and all those sorts of things". She recalls delight in trying on her older sister's "proper grown up" bras as a twelve or thirteen year old. Joy recalls the appearance of stretch marks on her breasts at eleven or twelve years of age. She remembers "being self conscious in bathers...but that was more...the really typical teenage thing of always wanting to be, in those days five pounds lighter you know, erm but never, I, I didn't get into, you know fanatical dieting or fanatical anything...I never had the energy {laughs} so I would say I had a reasonable body image but not fantastic".

Joy remembers her breast development being noticed by her father: "but in a.... cheeky, playful positive way". She recalls him saying: "your boobs won't be as big as your mum's'...and me saying 'oh you know, I've got a few years yet' {laughs}. Joy recalls her sister's boyfriend joking that 'more than a mouthful's a waste', indicating that "size wasn't that important". Joy "arrived at high school with boobs" and they "never got any bigger". She says: "I think for a while I was thought of, you know early

in high school as having big boobs but...I always thought of them as completely average", within her frame of reference. In high school, Joy realized that 'everybody's different'. She acknowledged the subtle guiding influence of her mother in finding her own 'individualism'.

Magda's first memories of her breasts are: "I can only think of maybe when I needed a bra". She describes her development as 'just average' at around thirteen or fourteen years. Kate's earliest memories also involved first bras: "...we all had to have bras by primary, in primary school"....if you didn't have a pair of bras you were lag-sort of dropping behind a bit". In school, girls would "deliberately let their flag fly" by letting a piece of the strap show: "and we used to say 'your flags flying' and you'd have to tuck it back in...it was like a bit of a status symbol like you know 'I've got bras'".

Kate muses: "...I don't know that I had early feelings or expectations about my breasts. I think it was just a part of life". She explains that her mother was 'quite modest' and there was limited conversation about such topics. Kate considers her physical development to be: "fairly average...I seemed to be quite in step with my friends. I...don't recall ever being any different to anyone else". She stresses: "I really don't have any great recollection of kind of being that tuned into my breasts developing or it being an issue or, but then I'm, I've never been a person to be terribly tuned into my body". Her pragmatic voice resurfaces: "...honestly I can't give you any great story about any emotional reactions...I don't have emotional reactions I don't think {laughs lightly}").

Susan described living in a "very conservative household". Her father was 'half-Lebanese' and disapproved of immodest dress. Susan never saw her mother naked until later in life when, due to illness, her mother became 'disinhibited' and Susan took on a caring role: "that's when shock of all horrors I actually saw her naked for the first time". Susan's reaction was: "it was my mum and that was her body, *as a whole thing*". She remembers watching her grandmother wiping under her large breasts in the bathroom but stresses: "it never occurred to me that it was *'a breast'*...it was a part of her body".

**Menstruation:** "it remains a kind of excretion, the liquefaction of abjection" (Greer, 1999, p. 37).

For many women, menarche is a sudden, dramatic event, more prominent in our memories. Joy referred to "the classic phrase: 'it means you're a woman now'", alluding to the construction of menarche as a symbolic event, a rite of passage into womanhood. For Joy, early physical development and menarche, at eleven years: "was something that I... was aware of erm and felt that it sort of set me apart a little bit from my peers but it was erm more, it, it wasn't, wasn't a great thing, you know it wasn't something to be proud of...it wasn't handled necessarily in the way it's handled and understood these days, or how I would have or have handled it with my daughters". Joy feels that she was not well prepared for menarche. There was "minimal contact around that stuff" with her mother and it was dealt with "quickly". She described herself as a "bright, independent and mature kid" who gleaned her own information and discussed it with friends. She acknowledges that, despite enjoying a close relationship, her mother had a "difficulty" with such topics and events. In taking the initiative to deal with menarche by herself, Joy identified a "bit of a theme of erm looking after others emotionally there".

Ellen's first menstruation occurred at around eleven or twelve years of age. She felt she was ill prepared for the changes of menarche: "it wasn't explained at, at home, just sort of, you know, brushed off and so I didn't really know what was happening". Ellen began to experience 'monthly pain' resulting eventually in her taking the contraceptive pill from age fifteen.

Kate recalls being 'a tad traumatized' by menarche at around twelve or thirteen: "I think I remember waking up one morning and going 'oh my God' and my Mum was in bed and she said 'don't worry about it, you've just got your period'.... and I mean I obviously was aware that it was going to happen and it happened, and then it was all over with". Although Kate asserts that she was "definitely prepared for it" the event was "a bit of a surprise when it finally happened".

Magda remembers 'the very day' of her first menstruation, at twelve, as a significant event in her life. Her mother rang Magda's grandmother to announce the arrival: "like it was a big, like I'm a woman sort of thing like 'guess what, Magda's got her period' {laughs} well, wouldn't have said period then, menstruating was the word".

Magda spoke affectionately of how, the year before, her mother had taught her about periods and how to wear 'Modesse pads'.

For Magda, being invited to talk about her breasts seemed to shed light on certain aspects of past bodily existence. Magda recalled "a bit of pain" and breast tenderness associated with the menstrual cycle: "but I never found that out till a lot later, see, I was not that aware probably. You know you talk to me about my breasts and that so I reckon I was never, I was never aware of...PMT". She explains: "like I never really cottoned on....I went through my whole life not knowing if I ever had PMT or not". She does not feel that she was in tune with her body for much of her life as a single person or in heterosexual relationships. Now living in a lesbian relationship, Magda feels: "I've learned a lot more about my body since I've been with a woman".

The contours of our bodies, and our feelings about them, are forever changing, dramatically at adolescence, and more subtly through the cycles and phases of our lives. Joy acknowledged breast swelling as a consequence of her menstrual cycle, and her experience of premenstrual tension. For her, breast tenderness was the first sign of pregnancy. Both Susan and Ellen enjoyed the increased size of their breasts during pregnancy. Susan thought: "wow, I've got a cleavage". Her nipples "became darker and more volumptuous [sic], just like big cherries, they were just wonderful". Ellen laments that the increase "didn't last long and I think they actually got smaller when I had another child...but now that I'm putting on weight, one side is actually bigger than it ever was, well I think now, that would have been nice a few years {laughs}, all round the wrong way". Kate ruefully described the changes of time and experience on breasts, marking a transition from "quite pert and then you get pregnant and they get big... and then you breastfeed and they get saggy, and then you don't just hold pencils anymore you hold the pencil case {laughs}". She adopts a philosophical tone: "my boobs were very droopy, rested on my stomach {laughs} erm....but you know it's, it's <sup>life</sup> life". Kate adds sardonically: "...I got rid of mine before they got too bad {laughs}...they weren't very picturesque...and {laughs} I don't miss them".



## Our milk-giving breasts

Breasts are indeterminate zones of libidinal intensity 'overcoded with the resonances of motherhood' (Grosz, 1994, p. 205). In 1752, the term 'mammalia' entered scientific discourses, creating a "new nomenclature for the class of animals previously called quadrupeds" (Yalom, 1997, p. 109). The choice of *mammæ* ('milk-secreting organs') to denote mammals upheld essentialist notions of a maternal instinct, and relegated women to the private sphere of reproduction and domesticity (Yalom, 1997). Breasts are deliberately desexualized during lactation. This practice is regulated within a male-oriented (hetero)sexual hierarchy in which breasts are required to meet the needs of both babies and male partners. Young (1990, p. 199) asserts "Nipples are taboo because they are quite literally, physically, functionally *undecidable* in the split between motherhood and sexuality". Rich in nerve endings, nipples are active, erogenous, and redolent with tactile sensuality. Young (1990, p. 200) urges women to 'shatter the border' of this dichotomy that suppresses the psychosexual experience of breastfeeding, and "insist that nurturers need, that love is partly selfish, and that a woman deserves her own irreducible pleasures" (p. 200).

Susan's grandmother was of Scottish descent and "you always breastfed your bairns". Susan felt blessed by her parents' positive attitude towards breastfeeding. Her father "always said it's a woman's right and it's a graceful, wonderful thing to do". However, she points out: "it wasn't the done thing to breastfeed in the fifties....it was dirty, particularly for an extended period of time". Her mother "lied to the clinic nurse" to avoid a perceived emphasis on bottle-feeding with formula milk.

Susan breastfed her three sons for eighteen, fifteen, and fourteen months respectively. She found breastfeeding to be "a wonderful experience" and "a positive part of the marriage". This was despite "quite a bit of mastitis" with her first child. She recalls: "it was the only time I had some antibiotics....I don't take stuff like that". She had subsequent problems whilst breastfeeding the other two boys, but not "as painful". She only discontinued feeding her first child when her mother in law caused her embarrassment "saying 'it wasn't right' and 'it was about time I got that child off my breast'". She also felt her husband "probably felt neglected because of a focus on children". Susan describes an abundance of milk: "pumping out....squirt out....it was constantly sticky and sweaty and sweet smelling". She was advised to lie down to feed

because “the force was so strong”. Susan felt that breastfeeding helped her to ‘bond’ with her sons, a process she feels is particularly important for boys.

Ellen was not breastfed. Her mother “tried to in the beginning er but it never lasted she said, I don’t know why but she just couldn’t”. Ellen’s youngest sibling was breastfed: “there was a six year gap between the second last and the last and then we were all off at school, and she was able to be quiet and rest and, and we were all older then...but maybe that was a later time too when they were talking more about breastfeeding”.

Ellen enjoyed breastfeeding: “it was great because I could sit down and I’d read a book...to my daughter”. The baby cried a lot in the first few months and Ellen would frequently breastfeed her, just to soothe her when nothing else worked. Ellen reports “no problem with milk and I know that’s another expectation, people think if you’re not very big you haven’t got a very big milk supply, but obviously there was no problem”.

Joy identifies a ‘naturalism’; an “earth-motherly sort of theme” that “was not necessarily talked about explicitly” but runs through her understanding of breasts. For Joy: “breasts have always been associated with mothering”. Joy and her three siblings were all breastfed and she notes: “that was unusual in her era”. Joy recalls a Year nine class debate in which she argued that ‘breast was best’. From an early age she “was very much into the functionalism of, you know that breasts are you know biologically for feeding babies, that’s their *purpose*” and aware of how “that idea had been er removed and that, that in a sense bottles were....probably I saw them as almost a, in an indignant way of er almost obscene that this was something that had been taken away from...women”.

Joy was strongly motivated to breastfeed. She remembers feeding initially being ‘painful’ due to ‘chafed and cracked nipples’. She had one episode of mastitis with her first daughter but went on to feed her for sixteen months. Her second daughter had jaundice and was consequently “so sleepy... getting a suck going was really hard work”. Joy conceded to bottle feeding her expressed breast milk in the hospital. She recalls being told to expect difficulties in resuming breastfeeding but, determined and confident in her ability, she went on to achieve “a very long and satisfying breastfeeding relationship”.

Magda was breastfed, but did not have the opportunity to breastfeed her son before his adoption. Kate was not breastfed. She enjoyed breastfeeding her two children and describes the experience as totally positive. She did experience “engorged breasts in hospital in agony” and, like Susan and Joy, had mastitis whilst breastfeeding her first child. She was offered “the old hot sock treatment” and “cabbage leaves” as a remedy. With her second child, Kate explains: “she was a little bit of a tricky feeder”. Kate “dealt with it for a while” until “the voice of reason kicked in” and she substituted the occasional feed with bottled milk. She described how her daughter would “suck, suck pull” causing Kate some discomfort. Kate reasons: “I think if it had of been a first child I probably would have been a little bit more traumatized about it and you know ‘I’m failing’ and ‘what have I done wrong’”. Despite the difficulties, Kate fed her for a number of months: “long enough for it not to be a big drama”.

With her two daughters, Joy is conscious of the language used to denote and discuss breasts: “with my own children breasts have always been breasts”. She recalls men and boys using the term ‘tits’. Susan finds this word to be particularly “rude, crass and disrespectful”. Her present language includes the terms ‘cahoonas’, ‘bazookas’ and ‘hooters’. All five women use the term “boobs” to discuss their breasts, and all associate words such as ‘bosom’ or ‘chest’ with an older generation. Magda feels that she has now changed her terminology: “I’ve only said breasts probably since my breast cancer”. She now describes ‘breast’ as “a warm feeling term” and a “feminine” term.

## **Femininity**

Asked if she attached any importance to breasts in terms of a woman’s sense of femininity, Ellen responded that there was a definite importance, that breasts gave “a feminine look”. Kate indicated that her breasts had always been peripheral to her sense of femininity. She reveals: “funnily enough I always used to say if ever I had... cancer and I had to have a breast removal I’d just tell them to take them both cause I didn’t like them anyway {laughs lightly}”. She elaborates: “if I’m thinking about femininity I look more at whether I’ve got frumpy looking clothes on or, or nice clothes or whether I’ve put some make up on or whether I haven’t or whether my hair’s looking daggy or whether it isn’t. I can’t say it’s ever been anything to do with my breasts {laughs lightly}...not really something that I would think about and now that I don’t have any it’s still not an issue... really”. However, she feels: “as far as self-image goes that’s

probably a little different, but it's not really to do with femininity I don't think...might have to contradict myself there, I'll see how it goes {laughs}”.

Kate reveals: “I don't think I was ever one to want to flash my boobs. I never wanted to be seen...naked really...erm I have always been fairly self-conscious of my breasts in, since I've been with a partner because I have very big areolas...I have a girlfriend that has actually got the same issue and we've talked about it and kind of gone, you know 'maybe we could go and get them cut off' or 'maybe we could have an operation' {laughs lightly} but I've never really been that self conscious to the point where I would do that”.

Magda chose to highlight the functional importance of breasts. She responds: “no, not really...all your breasts are for, originally, were for feeding children”. She does, however, acknowledge sexual feelings in her breasts. Joy associates breasts with ‘being womanly’ but ‘not necessarily’ with femininity. For Joy, femininity signifies ‘a softness’. She experiences the impacts of surgery and “the aspects around the chemotherapy, around erm the possibility of chemically induced menopause and Tamoxifen for five years and the effect of those things on erm my fertility” as “more confronting around femininity or, or what it was to be a woman, than the breast”.

### **Research Journal Extract: Thursday 05/06/03**

#### **Interview 3: Joy**

*Arrived early, waited in the corridor while she made some calls. Joy had been off sick and was taking Sudafed as we sat down. I felt so grateful for her time and thought this must be the last thing she feels like doing with a backlog of work and blocked sinuses! I felt slightly anxious because the dynamic in this encounter was different. With the other two women it seemed they perceived me as 'knowledgeable student' and Ellen particularly seemed eager to give me the information she thought I wanted. I'm not sure how Joy perceived me. After I'd commiserated with her sinusitis she immediately put me on the spot and asked me how I thought my research was going to help women with breast cancer. This is a question I've struggled with from the beginning and I don't know how my response came across, but I described how the project has evolved quite spontaneously, and that in all honesty this project will primarily benefit me! in getting an honours degree!...Whilst Joy went for some water I looked around the room and the dynamic was definitely influenced by the rows of texts on psychotherapy! I found it a little*

*daunting to engage with Joy the counsellor but before the inferiority complex could muscle in I tried to see her as a woman who has lived the profound experience of breast cancer and mastectomy....*

### **Familiarity with our breasts**

Susan did not routinely self examine her breasts. She has a history of gynaecological problems and her doctor physically examined her breasts yearly. Ellen also did not routinely self examine: "I kept thinking I know I've got to do this but I just kept thinking I had plenty of time. I thought ten years I've got, I don't know why, and it wasn't until actually the day I came out of hospital after having the mastectomy that I was actually, there was an article in the newspaper, that they were saying erm...at forty you should have your check at forty...whereas before I went in, the week before it was still the fifty, erm and now they're saying forty".

Magda also responds: "no never, oh when I thought about it once every couple of years, maybe, very naughty, very naughty". After being told "that there was something different" with her left breast, Magda was still unable to "feel much happening there". She says: "it was hard to feel, hard to tell but then that's probably because I never did regularly feel my breasts, if I had of...then you'll know if there's a difference...and I know that, I know that". Asked if she now self examines, Magda responds: "oh no...still not, still not, neither does my partner, to be truthful, even though we talked about it...I've gone just back to my normal ways of not checking myself". In response to my comment: "OK, that's interesting", Magda says: "mm isn't it? isn't it bad? I'm telling you the truth, it is isn't it? that's what you need to know".

Kate reveals: "I didn't make a conscious effort to go right on the third of every month I'm going to do this...but I think like most women I mean I think I did used to kind of, but obviously I wasn't diligent enough". Joy, in contrast, "always did, always, always did". She protested to her surgeon: "*I'm a good person*, I, you know, self examined and I will tell other women to self examine". His response was: "your cancer was very deep, you wouldn't have been able to feel it, there's nothing that you could have done...with the types, different types of tumours you know you might have had this tumour for ten years...and not known about it and, you can't beat yourself up about it, you know that's just the way it is". Joy concludes that in "balancing responsibility and control with life...you can only do what you can do".

## Stories of Detection.

Stories of detection often begin with a woman's embodied knowledge that something feels wrong: an intuitive knowing (Fosket, 2000, p. 21). Susan found the lump herself and *instinctively knew* it was breast cancer. Ellen 'accidentally bumped it' and thought: "hell what's that". By this time, she explains: "it was quite deep and I probably wouldn't have been able to feel it in the very early stages obviously but if I'd been looking for it I would have felt it a lot earlier". Ellen was sitting with her family but didn't disclose her discovery until after diagnosis "so nobody would be worrying unnecessarily". She waited 'for the right time' to inform her children, a week before going into hospital. Like Susan, Ellen "just knew that it had to be". She explains: "it was no shock. I was expecting it to be erm malignant. I don't know why, probably because of my mother who had it just a couple of years before so...I was sort of resigned to the fact...and it probably just gave me time to think....to myself without anyone else knowing, saying anything".

Joy had been advised by her doctor to have a mammogram at age thirty-six but decided to wait until she turned forty. She was diagnosed at thirty-nine years with a four centimetre DCIS. Joy recalls: "I was probably aware for a couple of weeks of a tenderness in my left breast...my breast felt fuller...like I, I had a very mild mastitis". Thinking it might be related to her menstrual cycle, she decided to wait a month. Then, realizing "this was something more important" she visited her doctor, telling her: "there's possibly an area of thickening, a quadrant of the breast that felt thicker erm and my breasts had always been very dense". Referred to a radiologist, Joy 'knew' she wanted a prompt appointment, although she stresses: "I wasn't particularly concerned about any of this, I didn't think this was a, a big deal I'd had tests you know for other things before, I come from a health professional background...."

Realization came quickly for Joy: "immediately we started I knew that she was concentrating...I knew something was going on. There was no emotional reaction, I was in sort of automatic pilot, I was in analytical mode". After the ultrasound she felt a growing sense of urgency and wanted mammography to be immediate. Joy had several mammograms: "so then and there I knew what was going on. I was still in automatic pilot, still absolutely on analytical scientific mode". In the space of a working week Joy met with her surgeon.

Magda requested a mammogram from her doctor: "I was forty-five, and I said 'I just want to have a mammogram because, just to see that everything's alright with my breasts'. I knew everything was alright, I knew that for sure because I'm a strong healthy person, but I still felt that why do you have to wait for fifty...why not do it now". Upon this suggestion, Magda's doctor performed a physical examination, which she stresses: "no doctor in my whole life has ever done".

### Stories of Diagnosis

Magda remembers that her doctor "started... beating about the bush...and I said 'look, just tell me what's wrong with me, don't...fart around sort of thing...and she said 'yes well, you've got breast cancer' and I said 'oh, can't be true, can't be true' and er, and I just sort of stood up, looked out the window and I'm thinking 'why me?' and I thought 'oh well, that's alright, they'll cut the lump out and it'll be right, it'll just be a lump still' ...and she said 'no it's not as easy as that, we've got to take, remove the breast' and I said 'oh well that's OK *but you can keep the nipple can't you...* and she said 'no' so it just got worse by the minute". Magda recalls: "it had to be done within a period of time...not saying why, you know you've got to work that out for yourself why... so then I got scared about that, thinking in a couple of weeks that must mean it's pretty serious".

Kate discovered her breast lump while lying in bed, thinking about a close friend, whose mother was in hospital and not expected to live through the night: "it was three o'clock in the morning and I'm lying there on my back and I had my hands on my chest and I was actually really worried...and then I went {demonstrates feeling the lump} 'oh shit' {laughs} and of course you know in the middle of the night things are always worse". In the morning, Kate searched the phone book, without telling anybody of her discovery. She found she needed a referral for a mammogram and made an appointment to see her doctor that morning: "that started this roller coaster ride {laughs lightly}". She had a biopsy on the same day and by late afternoon she knew. A locum doctor gave her the news. Kate commented on how 'distraught' and 'devastated' the doctor was, whilst she describes her own immediate reaction as stoic and composed: "shit happens you know, you have to deal with it I suppose... and I ended up ringing him and saying 'look, it's OK'".

Kate recalls: "it did kick in over the weekend and I kind of went 'oh...this is terrible' {laughs}". She elaborates: "we went away actually, we were away with some other people...I was fine most of the time but every now and again it sort of like all of a sudden hit me, thinking 'God, I could die, I might die' you know {laughs} 'I won't see my kids grow up' and of course once you start to think about your kids you know that's the end of it you know, the bladder sort of comes into operation behind your eyes {laughs}". I am touched by how often Kate uses humour to defuse the emotion in her accounts.

Kate's pragmatic voice resurfaces as she 'dealt with' what was happening. She "got into the doctor thing and sort of sorted it out". Six days after the initial diagnosis tests revealed two smaller, but more aggressive tumours in her other breast. This is how Kate recalls the scene in her surgeon's room: "he said 'really you don't have an option, you have to have a double mastectomy' you know either that or you know... forget about it, and he said 'so I do surgery on Fridays, you can have tomorrow or next Friday' {laughs lightly} yeah, and I said 'well tomorrow, I don't want to have to think about it for another week, just deal with it'...so the next day, off they came".

On the morning of the surgery, Kate said goodbye to her breasts after her shower: "I stood there and looked at them and thought 'well this is it guys' [she laughs lightly at this memory] 'it's all over'". After the operation, Kate remembers: "I came out of the anaesthetic about three hours later, and I haven't actually had a sad moment since really".

### **Perceptions of Risk**

Simpson (2000, p. 132) argues for a 'pluralistic approach' to discourses of risk and prevention. She analyzes a three level hierarchy of discourse: the level of personal responsibility, the level of science and research, and the societal level. She highlights an overemphasis on women and our behaviour, acknowledges the powerful interests of the cancer industry, and advocates a longer term, broader perspective and a heightened sense of *social* responsibility.

Susan has no family history of breast cancer. She felt that she was not 'at risk', identifying her history of breastfeeding as a perceived protective factor. She emphasizes stress and the contraceptive pill as risk factors. Susan remembers "I used to have menstrual flow to die for and...my mother sent me off...to have a contraceptive



because I was seventeen but also to stop the flow...and it was a large, large, large dose of estrogen". She identified several sources of stress in her life: "lots of things, just I think, it's not one stressful incident but it's a continuation of stressful situations and the carrying over of a high level of stress for a long period of time". Susan felt that in the months before discovery and diagnosis, she was "precancerous". Her doctor diagnosed Susan as stressed. On diagnosis of breast cancer, Susan protested: "how could this happen, it's impossible, *I'm not in the group*". Her surgeon responded: "which group Susan, which one...we just don't know". This gave Susan some relief: "that actually made me feel better. I can't, I couldn't blame anything".

Stress has been shown to depress the immune system by altering the body's complex network of nervous, endocrine and immune systems. The role of stress in breast cancer remains unresolved. Many women express the belief that stress is a causal factor in breast cancer. The hypothesis of a cancer prone 'type C' personality, marked by repressed anger and anti-emotionality, is only weakly supported (Butow, Hiller & Thackway, 1997). Studies in links between breast cancer and depression, stressful life events and optimism, are contradictory in their findings (Cooper & Watson, 1991, p. 9). Butow et al. (1997) note a lack of research in Australia to support hypotheses concerning psychosocial factors and risk.

Ellen's mother was diagnosed with breast cancer at sixty-three. Ellen's impression was that: "you would look at being checked up when you were ten years younger than they were when they were first diagnosed". Ellen was diagnosed at forty-three. She says: "I thought I had plenty of time and foolishly I didn't do anything about it....I always felt that being small breasted I would notice any lumps, and I wasn't really looking for them either which was foolish too but erm, I just thought I would have known, would have been able to feel it". She reiterates: "I thought I was too young".

Joy points to her early menarche: "from the literature that's a common er, or seen as a risk factor...just basically having too much estrogen in your body for too long". Magda has no family history of breast cancer. She identifies stress as a risk factor but says: "I never really think to myself well why did I, what did I do wrong, or what did I eat...". Magda was a smoker, and took the contraceptive pill from age seventeen "off and on" until "maybe thirty-five". Kate's mother and maternal aunt have had breast cancer but were diagnosed at older ages. She explains: "so it hadn't actually occurred to

me that it could possibly happen to me soon, but I am being a bit of a pain in the neck with my daughter”.

The single known cause of breast cancer is radiation, especially if exposed before the age of nineteen (Russo, Lynch & Russo, 2001, p. 279). Advice to women tends to be instrumental and focuses on our reproductive behaviours and our genes. An emphasis on genetic and hereditary factors results in a relative neglect of primary prevention. Simpson (2000, p. 147) argues for greater research attention to the role of manufactured oestrogen-mimicking chemicals that continue to accumulate in post-industrial societies. As Fosket (2000, p. 30) reminds us, early detection should not be conflated with prevention.

Simpson (2000, p. 144) analyses the medicalization of risk and prevention, and the politics of intervention at the level of risk. Technology is harnessed to *alter the individual* through surgical or pharmaceutical prophylaxis, in order to lower a woman's risk profile. Hormonal manipulation may extend to the use of contraceptives that reduce the number of ovulations, “inducing false pregnancies... in teenagers/young women to allow them to benefit from the protective effects of pregnancy” (Simpson, 2000, p. 146). Drugs are prescribed to *healthy* women, drugs with side effects and their own risks to health. She argues that these are strategies with which many women feel they *should* comply. Media framing of risk and personal responsibility discourses reinforce public alarm and personal dread. Younger women may develop a distorted view of their individual risk, overestimating their risk of breast cancer, and deflecting attention from other, potentially more urgent health concerns.

### **Stories of treatments**

From the outset, Susan felt strongly that she wanted a skin sparing mastectomy. She initially agreed to a lumpectomy but refused radiotherapy: “seven weeks of erm radiation I was to have and because it was right over my heart I said ‘I can’t have that, I don’t want to do that’”. The initial lumpectomy was performed under “a twilight”. Susan comments: “so I was talking to him while he did it and, because I’m a control freak”. Susan identified a ‘pathway’ that she feels doctors have to follow because women demand that they keep their breasts: “I know this was the pathway he had to take. I know because *women make him*, and I’m saying: “no, take it off” and he said: “no, I can’t”.

After the lumpectomy, Susan felt: "by this time, because I only had small breasts, the amount that was taken out, it looked hideous, it was horrible, the nipple came pointing down...and 'oh, my God'". Susan urged her surgeon to perform a mastectomy. She asserts: "I know I could have argued and gone in for the radiation and kept my breast, and I said [emphatically] "just get rid of it, I don't want it".

After a period of research, Susan felt that there was an elevated risk of occurrence in her other breast and chose a prophylactic mastectomy. The surgeon had assured her of a "very minimal" risk, explaining: "when you do get it you'll be around seventy". Susan responded: "you didn't say if, you said when, and when I'm seventy, there is no way I can go through this, you do it now, I want both gone". The right breast was removed and pathology tests found evidence of "fibrotic breast disease". Susan now feels justified in her decision. She acknowledges that the surgeon "has an obligation to take the lesser option" but stresses that "*women make him do that*, because it's them that say: 'I want my breast, I want to keep my breast'".

Joy lists the impact of her surgery and its aftermath: "coming to in the hospital, erm realizing you know I didn't have a nipple, erm physically probably feeling more vulnerable than I've ever felt in my life erm, how major the surgery was, erm recovering from the surgery...and it was the scar on the abdomen which made it hard for me to stand up and do all those sorts of things, recovering from the surgery...". Microsurgery surgery using a woman's tissue typically entails a six-eight weeks recovery period, and up to six months without lifting, pulling pushing, to avoid abdominal strain (Meric & Hunt, 2001).

Magda stresses the impact of chemotherapy in her breast cancer experience: "the first day of me having chemo, I'm telling you now fair dinkum was worse than them telling me I had breast cancer". Because of her preconceptions about chemotherapy, Magda felt "so paranoid about the chemo", and especially the prospect of hair loss. She explains: "what are people going to look at - think, you've got no hair, what are they going to think. Reconstructed breasts can be concealed "so people don't know that I'm different now...but then as soon as you have your chemo you're going to lose your hair so then people do know". Magda did experience hair loss and describes this as: "the worst thing in my whole life". Hair loss for Magda marks her as '*different now*' in the public realm.

Kate describes her six months of chemotherapy as: “absolutely crap and disgusting”. She also asserts: “*I was more traumatized about losing my hair than my breasts*”. She stresses the ‘debilitating’ side effects of her chemotherapy, which for her resulted in various complications, and menopausal symptoms. Kate was prescribed an alternative to Tamoxifen to be taken for five years: “and the down side is that it’s not on the national health...and I do truly feel sorry for people who can’t afford it...cause they’re, they’re dicing with death {laughs lightly} taking the other one”.

Cady (2000, p. 283) highlights the inadequacy of the current “shot-gun” approach in oncology. He argues that adjuvant therapy results in toxicity for all, while only a few women benefit:

“A proportional thirty per cent mortality reduction of a breast cancer that carries a fifteen percent absolute risk of death means that ninety-five per cent of patients (fifteen per cent reduced to ten per cent) receive no ultimate benefit, yet pay the toxicity price”.

He advocates that the medical world should move beyond ‘halfway technologies’ (including screening) to develop ‘high technology’ solutions such as targeted drugs, genetic engineering to alter defective cells, and immunization.

In 1992, the Breast Cancer Prevention Trial (BCPT) was undertaken for five years to test whether Tamoxifen can prevent onset in healthy women assessed as being at high risk for breast cancer. Despite results indicating “a forty-five per cent reduction in incidence” the BCPT was discontinued fourteen months early, when Tamoxifen was shown to increase the risks of endometrial cancer, pulmonary embolism, deep vein thrombosis and cataracts (Meric & Hunt, 2001, p. 139). The trial concluded that given these risks “the decision to take tamoxifen will need to be a personal/individual one” (p. 140). Women’s uncertainty about medical advice is compounded by a lack of consensus at the ‘scientific/medical’ level. Results of the BCPT cannot be generalized, particularly to different ethnicities who were under-represented. However, the media continues the discourse of optimism and the often debilitating side effects of Tamoxifen are down played (Simpson, 2000).

Susan describes herself as peri menopausal. She feels unable to take hormones ‘for the rest of [her] life’. “I know in my heart I can’t, because I believe it fertilizes, and that’s what will make it blow again, I just know”. Susan’s gynaecologist prescribed “five days of hormones to bring on a menstrual cycle” and Susan recalls her vehement

reaction: "I thought how misinformed are people, I'm saying to you I can't take them, you're saying it's only for five days, it won't hurt, and I'm just not taking these little bombs, I'm just not doing it".

Joy reports: "after about three months my crm periods stopped and then...I was having hot flushes and all that sort of stuff, along with all the chemotherapy side effects, having the sweats and flushes and so on was like 'oh my God' {laughs}". However, in retrospect, she asserts: "that was something that I thought was going to be really difficult for me and, and it hasn't really".

Magda's exuberance stilled as she said: "I have to tell you what was a terrible thing for me...". Magda, at forty-five was still considering having a baby. She had a son when she was seventeen but he was given up for adoption. She was told that chemotherapy would probably result in infertility: "sterile they said - sterile, and that was a horrible thing to hear". Magda now feels that chemically induced menopause has robbed her of the chance to experience motherhood: "I had no choice, I had five years taken away...when I could have had a baby, you know, natural...naturally".

Magda stresses the impact of menopausal symptoms: "menopause hits you full on". She tells of the 'horrible' impact of 'hot sweats': a "hot sort of creepy feeling all over your body". Magda believes that Tamoxifen contributed to her weight gain, telling her doctor: "I really don't want to have it anymore...I hate it, it makes me fat, it makes me have hot sweats...". Her doctor advised her to continue taking Tamoxifen saying: "if you were my sister I would insist on you still having it, you cannot go off it. Magda: "that's how much she believed in it....so I believed her and kept having it". After three years, Magda stopped taking Tamoxifen.

On being told of the possibility of chemically induced menopause Kate responded: 'oh fantastic {laughs} isn't that great'. Her first course of treatment was followed by a 'terrible' menstrual period but Kate has not menstruated since. She remarks: "my God do I have the hot flushes, oh man they're debilitating". She is unable to take any medication to relieve her menopausal symptoms: "so I have to put up with them and they're a nuisance...awful, they're the worst".

## Prosthesis

Kate asserts: “not having any [breasts] I, I’m not, it doesn’t concern me, I’m not upset about it, and half the time I don’t wear a prosthesis because I can’t be bothered”. However, recently Kate did buy prostheses but explains: “I guess that is to do with self image but it’s nothing to do with femininity... I think it’s just to do with my general body shape because I look at myself and I think I look a little bit lop-sided, a bit crooked-you know not crooked, a bit kind of caved in at the top and fat at the bottom cause I am overweight {laughs lightly} which doesn’t help”. She stresses this is an issue of *balance*, not femininity. Kate also feels that she ‘compensates’ by stooping “to kind of make my clothes a bit looser on the front so that it’s not blatantly obvious that I don’t have breasts”. She explains this as a response to: “other people kind of looking at you a bit, like I mean I don’t think they do look at me a bit weird but I think they might {laughs lightly}”. Because of this, Kate now tends to wear the prosthesis more that she thought she would. On a recent overseas trip, Kate did not take her prostheses: “a couple of times I kind of thought...I mean it didn’t, it doesn’t upset me or phase me terribly but a couple of times...I went out and I thought oh it would have been easier if I had them because...people wouldn’t notice anything whereas I think they do notice if you haven’t got any breasts, but it doesn’t, doesn’t kind of, it hasn’t scarred me or anything {laughs}”. Kate sometimes does not wear them because they cause her discomfort against her scars.

## Reconstruction: *“How am I going to feel when I wake up”.*

Here I examine the tension between a desire to ‘look the same’ and a desire for symmetry and balance. Achieving symmetry does not require the curves of breasts, a point emphasized by both Magda and Kate. If she had been advised to have a double mastectomy, Magda suggests: “I wouldn’t have bothered having anything put there in place of them, if, if my body was even and balanced”.

Large breasted women may require reduction of her other breast to achieve symmetry, while smaller breasted women may be advised to undergo augmentation. The latissimus dorsi flap may be used as filler for larger tumours. Implants are a cheaper option but requires additional surgery over the long term. Nipples can be fashioned from the tissue and an areola later tattooed (Robb, 2001).

Ellen underwent the latissimus dorsi flap procedure and found: "that was probably more of a problem than the actual implant area, getting, because that was very sensitive on the back". Radiation may compromise symmetry in women with reconstructions using their own tissue and may cause capsule problems in women with implants. Robb (2001) cautions that 'skin and fat necrosis', scarring and reduced blood flow as a consequence of radiation may result in the breast being firmer or 'distorted'. Ellen has experienced implant contracture as a result of radiation.

Susan chose teardrop shaped implants to enhance her breast size from a "10A" to a "12B" bra size. Initially, she considered enhancement of the 'healthy' breast, before choosing a prophylactic mastectomy, but her partner stressed: "I just want you to be alive, why do that, why, what's the point, and then you can have both of them the same and you'll feel more subtle". Her brother also factored into her decision making, urging: "no, both off, both the same, reconstruct properly". Susan reveals: "the money was...not a big issue but, it was under Medicare if I had them both at the same time, or the prosthesis was covered". However, Susan's main concern was her perception of elevated risk: "it's a twenty three per cent chance to get it in the other breast at some stage and that's just too high for me". She was given one week to consider her decision to remove the right breast. Susan describes being shown: "two diagrams, one to augment and one to remove and I said: 'no, I, I'm more positive than ever, I want, I don't want it, I can't live with this, I just don't want it...take it". She offers a glimpse of the procedures: "so he drew all over me, I think that was the most upsetting time was having blue markers all over me, and photos and stuff, it was awful".

Susan had tissue expanders inserted to avoid extra surgery. The surgeon "slowly inflated them over a six month period so I actually grew into my clothing, which was weird". She now feels: "it would have been nice to have been bigger". At the time, she tells: "the plastics guy said 'I'll put these in and you'll say I wished I had chosen the bigger ones' and I said 'no, no, they're big enough'". Choosing her implants, she remembers that the surgeon "pulled them out of his drawer and [her partner] said "God, I wish I had drawers like you, you've got all these breasts in your drawers" and he said "it's pretty cool isn't it?" Susan stresses that they "always made light of it".

Decision making for Ellen encompassed several factors. She reasoned: "cause I'm not very big I thought what's the point, and my age you know, it would be different if I was thirty or hadn't had children or single, you know they are all big factors, but at my

stage of my life I thought, it would have been a very big issue had I been a big breasted woman". She considered having a mastectomy without reconstruction: "because it's so easy...you're not sick...there's no recovery, but having a reconstruction's a lot harder". Ellen was not so much concerned about being flat-chested on one side but worried that she may have been concaved. She explains: "the more I thought about it I thought how am I going to feel when I wake up, what do I actually want". Her husband 'was very supportive', telling her: "you do what you want and what's important to you". However, Ellen feels: "he really was happy that I did a reconstruction... he never said it but I got the impression he was...probably just so I'd look normal".

Ellen had never had an operation so she "wanted to have it done straight away, once, all together and not have to go back and do it again". She was initially worried about "publicity about implants and what can go wrong with leakage" and she "felt better knowing...the implant is in a casing the same as erm a pacemaker".

When Ellen first saw her surgeon, she relates: "she was a very big breasted woman and she suggested doing, I could get them both done, to enhance *both breasts*...and I said 'ooh that's a good idea, I, I wouldn't mind doing that', and then when I saw the plastic surgeon a week later I jokingly said the same thing to him, 'oh I could get them both done' and he said 'no let's just do one thing at a time'". Ellen feels that "he was more conservative in thinking this is my life we have to think about, not what I'm looking like at this stage {laughs}". At that time, just as Ellen had decided to have the implant, she told her neighbour: "she is a big breasted woman too and she said to me 'what's the point, why are you bothering?' meaning there's not much there to worry about...and erm that shocked me". Ellen was "quite hurt by that...she was implying that I had no breasts so I didn't need to have an implant". As a consequence, Ellen felt: "maybe I should keep this opinion to myself you know not tell people what I'm doing".

Ellen still has a 'port' where the saline was injected. She explains: "they used to take them out straight away but I don't want to go back and have another operation". Initially, Ellen asked her plastic surgeon for a little more saline but he cautioned that she would look asymmetrical. Ellen feels that now she is experiencing weight gain, her healthy breast is larger: "I notice it more now, we didn't at the time but now I do". However, Ellen stresses: "I don't want to tempt fate, everything's fine at the moment, I don't want to muck anything up, that's just a psychological thing... leave well enough alone....it's not that important". Ellen discussed the option of nipple reconstruction but



again stressed that she did not want further surgery. She suggests: "it would be different maybe if I was younger, you now twenties or thirties, maybe, I don't know I'm only guessing...maybe it wouldn't make any difference then either but now I certainly can't be bothered doing that".

Joy was 'initially somewhat surprised' when her surgeon recommended an immediate reconstruction. He felt she was a 'perfect candidate', due to her age and {"otherwise, ironically"} good health. This was described to her as a straightforward procedure, requiring only one operation. Joy explains: "it's classed as a skin graft erm so the level, the intensity of the nursing and the, the time that you're in hospital is much longer". Her surgeon recommended this option, telling her: "it's the best thing to do and in terms of body image and so on it's, it's more positive".

After having two children and with excess abdominal tissue, Joy welcomed the additional cosmetic benefit. Joy recalls a discussion with her surgeon about nipple reconstruction. He seemed to think that this would be important to Joy in the sense that "they could make a great nipple and then everything would be fine". However, Joy feels that "pretending or making a pretend nipple would be er pretending it didn't happen, or, or covering it up in some way".

Magda was shown a video with depicting women who have had mastectomy, with and without reconstruction. Magda says: "I don't know if those women talked or not, I don't, d'you know I just can't remember, but I knew even before I saw that video...as soon as she told, gave me the choice that I could have part of my body put there, and my tummy, because I had a bit of a tummy anyway...I thought 'yes' {laughs}, then I started getting happy again...I was going to have my tummy there and skin, and, and part of me there that's going to look like a breast well then I thought 'oh well it can't be all that bad' you know". However, Magda says: "when the bandages came off, my right breast's hanging down there and this one's just sticking out like that, they were so *lopsided*". After almost five years, Magda feels her reconstructed breast 'is nearly level' with her other breast. She explains: "like it's drooped, it's fallen...if I haven't got any clothes on you can see my right breast is lower...same with a t-shirt but I don't worry about it". Although Magda enjoys not wearing a bra at home "cause it's nice just to be free", in public Magda says: "I put on a bra no one would ever know, with bathers, everything, would never know I've had a...you would never know". In choosing reconstruction, Magda was concerned about not appearing 'lopsided'. For her, looking

'normal' entails two-breasted symmetry in order to: "look and feel normal when you've got clothes on". However, she stresses that this is not an issue of femininity but a desire to look "like everybody else".

Magda chose to have the mastectomy and reconstruction in a single operation: "so I'd come out looking, feeling a bit still, *the same?*" After her reconstruction, Magda found: "there was more skin on the left side, it's still there...but I've gotten used to it". She says: "when I stand up it sort of sticks out here, it's just more rounded here that's all, and I could notice this feeling there all the time and it used to, I'd get upset about it...cause I wasn't, I wasn't normal, like the right one". Consequently, Magda considered a further operation to remove the extra skin, construct a nipple, and reposition her other breast. Twice, Magda arranged for this operation but reveals: "I kept thinking 'I don't know if I want them, want them to touch my right one at all'...I kept thinking 'no' and I actually chickened out, twice I chickened out...I said 'I think I'll just leave everything as is', bugger it you know, so now whatever, however it looks I'm used to it...but it does feel, I constantly feel it, I'm so aware of it, it's a different, there is a feeling there now all the time, a feeling". Magda was told to expect five years to 'heal properly' and she muses: "it's still not five years so maybe that's why".

For Kate, reconstructive surgery has not been an option to this point. Kate feels that her surgeon was concerned to remove her tumours urgently, wanting 'to deal with this and get it done'. She felt a lack of time for a thorough consideration of the procedures and consequences of reconstruction. She reflects: "so we didn't talk about it, and even if we had of I probably would have said no, at that stage...I probably would of just said 'no look just get 'em off, I'll think about that later' {laughs lightly}...one thing at a time, I mean I was thinking more of *health* than, than what I looked like or whatever, that wasn't an issue at that stage".

Kate feels that she has endured enough operations, time spent in hospital and side effects of medications, that she is reluctant to undergo further surgery at this stage in her healing process. She says: "I'm still completely numb, my arms are still numb". Kate stresses: "you feel like a pin cushion you know...you just get so sick that you just think 'oh I just don't want to put myself through being sick for anything'". However, she reserves the possibility of future reconstructive surgery. She says: "but like I say 'never say never', you never know in twelve months time I might think 'damn, I'll go and get rid of some of my stomach'".

## Feeling

In terms of feeling and sensitivity, Ellen stresses: "it's definitely, it's not the same...it's just not that softness". Ellen feels this difference is reinforced because she does not have a nipple. She was advised that it may be a year before feeling returned "because all the nerves are cut". After almost four years, she reports: "there's still some numbness, a numb area, but it's not something I really think about a lot". Joy feels she has "quite good sensation... compared to, to a lot of people" but lacks 'deep sensation'. Although improved, she still experiences numbness but describes herself as "pretty much a erm good advertisement" for the procedure.

Magda reveals: "well it's, it's different, it's my tummy tissue, so the feeling is different to my other breast...it's actually can be numb". She says: "I've got to be careful with my left breast that I don't bang into things". Magda's response to the loss of her [reconstructed] breast as a site of sexual pleasure, is to inform intimate partners: "I don't have any feelings there, you can kiss it, you can love it, you can touch it but this is the one that's got the feelings, if you want me to have the feeling you'll be doing this more to this one, for instance I would say that...you can make a bit of a joke about it you know". Later, when Magda imagines meeting a new intimate partner, she admits that she would feel "totally embarrassed". She says: "knowing that I've, what I look like under my clothes". She concludes: "I would have to tell the person first". Magda stresses that for her, breast loss in a sexual partner: "wouldn't make any difference". She explains: "you don't love the body, it's not the parts of their body you love, it's them, the whole person".

Magda relates a story of having her first massage after her reconstruction. She recalls: "even though these people are probably quite used to touching, or looking at different shape bodies and things I still felt quite nervous going there knowing, that I looked a bit different". She prepared the two female masseurs in advance and says: "I felt quite good talking about it to them...and showing them, they could see it erm, they then had a better understanding about how women are with breast cancer too, probably helped them a little bit".

## Quality of Care

All five women praised highly the standard of care they received in hospital. Joy described her care as 'absolutely fantastic', 'immediate', and 'very responsive' to her needs. She stresses: "it's really technical, I mean absolutely miraculous". Joy spoke warmly about her reconstructive surgeon, describing him as a 'wonderful man'. She elaborates: "I've talked to a woman whose currently a client of his and what she said about him was erm, the strength of his care was, how good he was, was that he touched you so *unambiguously*, so intimately but unambiguously...he was very human and very humane and very erm erm respectful of you as a person, and as a woman".

Magda felt: "very well cared for, very well looked after, it was er really, really, I had a really good time in the hospital {laughs}". She felt fortunate that her female partner was able to stay with her during the diagnostic procedures. Magda found it "very sad for the men" that male partners were, she felt, excluded from this part of the process. She praised the expertise of the surgeons: "it was just amazing, unbelievable".

Ellen stressed that 'caring and thoughtful' nursing staff made 'a big difference' to her recovery: "a big issue for me is who's looking after you at the time". However, Ellen described feeling uncomfortable and "a bit exposed, a bit self-conscious" in her plastic surgeon's rooms, when required to sit topless for examination. She reflects: "I think now maybe that's something I should tell him so they can be aware, you know, I think it would be better if you had a gown that you could put on".

## Surveillance

Women are exhorted to reinforce personal vigilance with technological surveillance. We must negotiate our way through a quagmire of complex and often contradictory information, and our uncertainties may have 'very real consequences' (Fosket, 2000, p. 28). She highlights an element of randomness in breast cancer incidence, and the 'seeming hiddenness' of cancer, due to an "absence of pain and other embodied markers". Magda expressed this emphatically: "I honestly can't explain that feeling but I wasn't sick...you don't feel anything with cancer, it's not a pain". This contrasts with Susan's experience who, in the months before diagnosis reported: "I had intermittent diarrhoea, I had loss of sleep...I was more needy, I wanted more touching, more comfort".

Hallowell (2000, p. 154) argues: "mammography is less effective in detecting cancers in younger women because of the density of the breast tissue". Furthermore, breast screening carries its own risks and the anxiety of 'false positives'. Gorman (2002) asserts that mammography fails to detect ten per cent of breast cancers and, in its reliance on human expertise, is "as much an art as a science".

Susan says of her mammogram: "I'm sure it squashed the lump and spread it when I had it. I'm almost positive that, you know it compresses so hard, and after I had the mammogram I couldn't find the lump, I'm sure it dispersed...and it sort of pushed it down the line a little more". I asked her if she discussed this with her doctor. Susan laughed, saying: "yeah, they sort of look at you and go 'dunno', they're not going to get into that...no point really, not an argument".

#### **Research Journal Extract: December 5<sup>th</sup>**

##### **Mammogram 10.45 am.**

*My mum has often encouraged me to have a mammogram; she was diagnosed in 1994 and had a lumpectomy plus radiation. This 'family history' resides in the back of my mind but I have so far had a feeling of being too young to worry yet. I was partly motivated to have a mammogram by my involvement in writing this thesis. I wanted to empathically feel what it's like to be screened for breast cancer, to know the discomfort and the anticipation of results. An academic exercise then, I wasn't prepared for the ordeal I found it to be.*

*One elderly woman was leaving as I arrived. I sat alone for a few minutes, filled in a form, went through to a cubicle. Efficient staff, polite smiles, strip topless, put on the gown...wait. My anxiety built slowly. I found it exquisitely embarrassing {my personal hang-up} to bare my breasts to this young woman, pleasant and professional as she was. My body tensed as I squirmed and self-consciously hugged myself. Yes, having small breasts squashed between cold plates caused physical discomfort, not quite pain, but that wasn't it. Asked why I'd decided to come, I feel an unexpected welling of grief. Margaret. I mumble: "because my mother in law recently died..." and here is my eligibility claim: "...family history".*

*Back in the cubicle for the ten-minute wait, I realize how the course of my life lies in invisible hands. I wonder how many women have emerged from this small space into the world of breast cancer diagnosis. Rationally, I know that I'm not likely to be among that number, but emotionally, I feel... the tears are streaming down my face. Polite concern: "Are you alright"? "I'm fine". She watches me leave. I cry all the way home. Breast cancer has touched my life and taken from me. I've seen what it can do. This disease scares me.*

Susan's doctor promised her a ninety-nine per cent "cure". He cautioned Susan to be vigilant and that this may be more difficult because of the implant: "you must be in tune with your body and you will know". Susan spoke philosophically about her sense of mortality: "my estrogen levels are really high at the moment...I don't know what's wrong with me, so I just wait, and those things are a worry, you never know what's going off inside your body, that's one thing when you've had cancer every bone that aches you're sure it's a secondary....I get a twinge in my ovary and I think 'that's it, I'm gone', but I go and get it checked out, OK, so the doctor's pretty used to me now". Ellen now sees either the oncologist or the surgeon at six monthly intervals. The radiologist wanted to monitor Ellen but she decided not to visit her radiologist at the hospital because Ellen is employed at the hospital, and wants to maintain her privacy in the workplace.

Joy relates: "I don't like to think about the possibility of it coming back so I think *I've had* breast cancer....I treat my body to help...that it doesn't return". Joy stresses: "I have to take a responsibility for that". She finds the level of follow up care as "very reassuring". She says: "the procedure of [the doctor] actually feeling your lymph nodes, down your neck, across your clavicle you know, across your chest is almost a healing experience in itself, the, in an age of machines and so on to have a doctor do the hands on thing...is very human....and that's about feeling that you're being looked after, that you're being considered and thought about and monitored". Joy believes: "the healing aspects of that are probably as significant to our reduced rate of death from...breast cancer as just the mammogram screening...I think there's a very important psychological component to those things". Magda reveals: "I felt quite privileged because I was being very, I was being monitored so well by doctors after

then and I still am, much more than anyone else who hasn't had breast cancer...so I'm being looked at, so I feel quite special".

Kate sees her surgeon every six months: "I go to the surgeon and he says you know 'take your shirt off, oh gee I did a good job of that didn't I?' {laughs}. I don't even know what they're looking for, I just rock up, they look at your scars, I'm not really sure why, I must ask him actually why I go back, I don't know what they, I mean how, what, you can't tell if I've got cancer from prodding my scars surely {laughs}". Kate goes on to say: "I'm terrible, I don't ask a million questions, I only find out what I need to know, which is really frustrating for other people {laughs} but I'm quite comfortable with it". She describes her surveillance regime and concludes: "I really don't think there's much more you can do, apart from get on with it". Kate acknowledges the possibility of recurrence, saying: "I guess you just sort of hope that it doesn't". She says: "I put myself in the hands of the doctors...I'm not a person to dwell or to sit and think about things, I, I don't think it's a case of being tuned into my body, I think it's just how could you ever know, how can you ever predict you know"?

## **Counselling**

Susan spoke with some emphasis about her negative experience with female counsellors. She recalls: "when I was looking for answers, asking about DCIS I kept getting the 'well take one day at a time', 'make your plans' and 'yes well see how it goes' and I thought this is so, you're almost telling me that it's over and I'm not ready to do this". Before her surgery, Susan reveals: "I said goodbye to them [her breasts] in the mirror, the whole thing you're supposed to do and I thought that was pretty stupid, what did I do that for...I wished I hadn't done it".

Susan reacted negatively to the information brochures and booklets on reconstruction: "The pictures were horror stories, I flipped out when I saw them and I...remember throwing them across the lounge room floor and saying to {partner's name}: "I can't do this, I'm going to die, this is horrible" and he had a look and he said: 'burn it, this is not what's going to happen to you, burn it, these are old ladies' and one breast was up and the other one was hanging down....". She remembers: "there was also a video which fortunately my friend said: 'don't watch the video', there were women crying and sobbing about the loss of their breasts". This friend discouraged her from

attending a support group, saying: "don't, they continue to talk about their breasts as though it's something dead in the garden, in a coffin, all of its own".

Susan says: "yes they, they did talk to me about how sad it was, how did I feel, they put me in touch with a psychologist who was going to talk about erm planning and things and I thought 'I'm not going to die', but they were all, everybody, all the women around me were talking about 'Oh my God, you're going to lose your breast'. No-one said to me 'oh my God, you've got cancer', their focus was on my bit of fatty tissue slapped to my chest that was diseased, not about me, that there was this thing that was growing in me that could blow my life away within twelve months. A woman from a support group told her: "I would never have silicone in my body" and said: "I cried for three weeks when I lost my breast". Susan's response to this was: "oh my God, I must be weird, I'm actually happy about this, I'm looking forward to new breasts, to a new life, to a new image".

In contrast, Susan found her male manager in work to be less focused on her breast loss: "he never spoke about my breast image at all...I was ill, that was all, and all the men without any omissions were like that". She found most women reacted with shock and mortification: "whether if, they thought it might happen to them or they just couldn't believe I lost a breast and why was I still smiling, how dare you kind of thing". Susan recalls: "one woman that did call me a couple of times from the Cancer Foundation who had had both breasts removed, but hers was ten years ago and she hadn't had reconstruction straight away so it really wasn't the same". Magda also did not relate to the counsellor in the hospital, explaining: "she did not have the same thing that happened to me which was silly, she did not understand my true feelings, when I'd ask her stuff she didn't know the answers because she hasn't experienced it".

At the time of her diagnosis, Ellen worked for the Cancer Foundation. She expressed embarrassment, saying: "that's why it's hard because I should have known, I should have done a lot more earlier than I did". Ellen drew upon her own work experience and also enjoyed a close friendship with a woman closely aligned with the cancer support service. She therefore felt: "it's a great service, but I personally didn't feel I needed that". She felt that she had enough support and information.

Kate also feels that she receives enough support from family and friends and therefore did not access counselling services. Kate asserts: "I don't seem to need to kind of pour my heart out to other people". She emphatically rejected the idea of



joining a support group: "oh God no, couldn't stand it". She perceives such meetings as a "lot of people sitting there telling you all these stories, no, I hate that". She adds: "I'm a bit cautious of sort of listening to what other people say...because it might not ever happen...I don't like to give myself ideas...so I'm reasonably self-sufficient".

Asked if she accessed counselling services, Joy responded: "no I didn't...it actually all seemed very straight forward to me, and because in some ways, in yeah, in lots of ways *in terms of the cancer journey the breast was such a small part of it*".

### **"A slightly re-arranged self"**

Susan points out that her reconstructed breasts are different from each other: "to me it's a great difference. I can see great differences in my breasts but I could when I had real ones as well, and women often have really different breasts". Susan describes her present self-image as "great, it's wonderful, yeah, from when I woke up". She feels "very fortunate" to "have small breasts to begin with", a point also made by Ellen.

Since her breast cancer, Susan feels in many ways "a different person". She is 'less likely to take nonsense' and is "not as much of a control freak". She feels more able to 'let go' of stressful issues and is generally happier and inclined to construct her experience as "an opportunity". She feels that she continues to be in tune with her body, and paradoxically feels: "much more in *control* than ever before".

Joy's recovery from surgery suggests an element of 'boundary work' (Hallowell, 2000, p. 169). For Joy, "it was about having a slightly re-arranged self...there were no implants, there was nothing artificial there". In the immediate aftermath of surgery, Joy recalls: "there was so much going on, there was so much that needed to happen, to take everything into account that actually you know, I had a breast and *it was a part of me* and that was fine, it was enough". Joy asserts: "my reconstructed breast isn't the same as my....other breast, but it's fine". She initially wondered about the impact on her children: "I thought for them seeing their mother with no nipple would be....but it's like we're all used to it now". Joy's primary concern throughout was for her children "so that they knew what was going on, so that they knew how I was, erm er and so there was room for their emotional reactions to it as well and that, that they had the space to tell me what was going on for them as well as erm, so I think that helped an awful lot".

Kate describes her first sight of the changed contours of her body after mastectomy: "actually I was quite surprised, all I had was a piece of sticky tape that went from armpit to armpit, there was no stitches, there was nothing, it was just like a little line {laughs lightly} amazing, incredible". Asked to describe her condition now, Kate firmly responds: I don't, I haven't got a condition now {laughs lightly}...I'm well".

Ellen describes her present body image as "probably worse now than it was then, not because erm of my mastectomy, because of now with medication I'm putting on weight, and I never had the weight problem...and now that annoys me more...I find that more difficult now than, than I would have at any other time". Ellen reflects: "I'm definitely glad I had it done, I'm, looking back now, I'm, I made the right choice because erm, to think what it could have been like, and because you look at yourself every day". Magda's body image has also been compromised by medication related weight gain. She stresses that her present body image has: "nothing to do with [her] breast". What seems more important to her is weight gain in the abdominal area.

Kate considers the impact of her breast loss on her sexuality: "I think the sexuality thing is to do with how secure you are in your relationship and... where you're at in your life...after you know, twenty something years of marriage and...the same person I mean, I think personally for us I think we're probably best of friends more than anything and I don't think {husband's name} would ever.. it's not an issue for him, he doesn't think about it, he never mentions it...I think he's just happy that I'm alive {laughs}...so sexuality you know, for me it's not an issue but I can imagine for some people it would be...especially if you're starting out in a relationship or you know you're at a different point in your life but for me it's not an issue".

In her concluding statements, Susan reveals: "I only said to {partner's name} a few days ago 'can you tell me do you still find me attractive and sexy with rubber slapped on my chest' and he said 'even more so, cause they're great, they look wonderful, they were good before, they're great now, they're just wonderful, and they look so good and you look good in clothes', and I think it's cool and I can wear little strappy numbers, I feel good, it's a reward for a bad - for a really awful horrible situation. The only connection to my breasts is that I fed my children with them. I'm sad my nipple had to go but sometimes you've got to let go of things to grow and I had to let go of it so I could get on to the next phase of my life and this is a reward, it was given to me to do that. Absolutely, no doubt".

Broom (2001, 262) discusses the multiple effects of speaking about breast cancer experiences, and the pitfalls in our quest for 'authentic' voices. She suggests: "Perhaps the price of support is a potential infringement of autonomy". Ellen describes her resolve to maintain her privacy: "I find it's *easier for other people* if they don't know....and they don't have to worry about what they say". Ellen tells of wanting to support a woman in work with breast cancer, but without self-disclosure. She says: "how I got around that was, because I'd worked at the Cancer Foundation, I sort of used my knowledge of what I've been through as, as if it was just because I'd worked there".

In closing, Joy widens the terms of the discourse from breast cancer to all cancers and from survival to quality of life issues: "I'm really interested in talking about the effects of treatment on *other* aspects of, of your life, particularly...the effects of chemotherapy on *other* fertility and those, those things". She queries: "once you get past the survival thing *other* and now that you've survived, how is your life actually much different to the way you thought it was going to be?"

"crystallization provides us with a deepened, complex, thoroughly partial, understanding of the topic" (Richardson, 1994, p. 522).

## CHAPTER 5

### CONCLUSION

The process of storying the body allows individual women's experiences to be differentiated and affirmed but also celebrates the connective power of narrative in pooling women's words and insights into a body of knowledge with which all women may articulate. When richly evocative, narratives have the communicative power to stir our emotions, and generate ideas, associations and insights. These women's stories reveal awareness in each participant both of dominant discourses, and of current narrative conventions.

These guided conversations yielded a wealth of data, highlighting the function and power of women's narratives as a necessary corrective to male bias in positivist research paradigms. Storying counteracts the tendency of traditional social science methodologies to inscribe, abstract and dichotomize experience, thereby erasing or distorting women's subjectivities. Feminist research challenges the authority of objectified knowledge, creating spaces for women's own active voices, and amplifying women's own understandings, in celebration of the fullness, depth and complexity of women's lives. Presenting a sampler of stories reveals an intricate design in which each thread may be seen as distinct and contiguous.

Breasts are always responded to according to the prevailing ideals of a particular time and place. This thesis explored how each woman manages the gaze and negotiates with disciplinary practices that produce and maintain the idealized 'feminine' body. Individual women adopt different styles of material embodiment. Situating a woman's experience of breast cancer and mastectomy within a lifeworld of 'breasted experience' (Young, 1990), places the emphasis on *being* not *having* bodies, and breasts. However, these accounts are not merely breast-centred. This research project celebrates the importance of the materiality of bodies, without resorting to essentialist notions about what is 'natural' or knowable. Too close a focus on the functionalism and medicalization of breasts obscures other woman-centred embodied meanings.

Susan and Ellen both acknowledge that their experiences of breast cancer would be qualitatively different if they had larger breasts. I am reminded of Susan's delight in her own breasts and her tender respect for the bodies of her mother and grandmother, perceived wholistically. Susan's confidence in her attractiveness, and her use of sensual language { voluptuous, big cherries } is contrasted with Kate's self-conscious modesty and dislike of her large areolas. Taboos of menstruation were touched upon. For four of these women menarche was dealt with 'quickly' or 'brushed off', but was celebrated by the women in Magda's family. I was moved by Magda's increasing awareness as we talked, and she disclosed insights from sharing her body with another woman.

All participants acknowledged dominant cultural norms of femininity, but each woman resisted this discourse, with varying degrees of emphasis. Joy chose to emphasize a 'softness' to signify femininity, and identified themes of 'looking after others emotionally', naturalism, functionalism, and mothering. Breastfeeding was constructed as 'dirty' in the 1950s, but Susan remembers the warmth of her mother's breasts and took sensual enjoyment in the sticky, sweaty, sweet smelling abundance of her own milk. The feeling, touch, sensitivity motility and changeability of breasts were emphasized at various points, to varying degrees.

Four of the participants engaged with the transformative potential of medical technology. Susan constructed her double mastectomy as an opportunity, however cruelly won, to enhance her breast size. Ellen's ambivalent desire for bigger breasts was thwarted by the attitude of her surgeon who discouraged her from having an enhancement of the other breast, or to have more saline in her implant. She now feels asymmetrical but is loathe to endure further operations. All women privileged balance and symmetry over narrow heteronormative definitions of a feminine 'look'. Joy and Magda, as larger breasted women, were concerned to avoid being 'lopsided'. We need to foster social conditions in which women who choose to avail themselves of these technologies, do so from a wider range of choices, including a capacity to love her changed contours and claim her own embodied meanings.

These accounts stress the impact of therapeutic and reconstructive surgeries and their aftermaths. The four women who underwent chemotherapy stressed the short term debilitating effects of menopausal symptoms, caused by medication, and the longer-term impacts of Tamoxifen. It seems that hair loss and weight gain are more of a challenge to femininity for these women than breast loss. These visible bodily effects

of breast cancer project a woman's experience into the public arena for scrutiny and judgement.

All of these women felt a lack of relevance in available counselling services. In their rejection of formal counselling options, all drew support from established social networks, or moved into new and intimate supportive spaces. This perception of counselling services as irrelevant or ineffectual provides a rich site for future research.

As Hopkins (2003) reminds us, women *choose* narratives from the particular suite at their disposal, and stories tend to emerge from, and linger in the cerebral realm,

“...bringing history into our present, we are always just beginning” (Neilsen, 1998, p. 175).

making it difficult to glimpse the raw emotion, the grittiness of experience. How much of the stories here are revisionist renderings of past experiences to make them more bearable, to the self, to me as researcher, and to absent audiences? I am reminded that all five women displayed concern *for me*, and adopted strategies to protect

*me* from the ‘raw life’ of their experiences. In their choice of language, use of euphemism, in the omission of certain words, and in their use of humour, they all attempted to smooth their experiences, to make it more palatable, perhaps to themselves but certainly for me. They were each concerned about meeting what they perceived my needs to be. These aspects of performativity in research relationships demonstrate that we exist in and through our personal and social texts, and are each subject to perpetual re-vision. Here lives the potential for hermeneutic ‘truth’ and transformative knowledge. Through the processes of narrativization, each story is invested with its own authority and the power to move the reader on its own terms.

All five women in this study refused to define themselves as *having* breast cancer. Magda feels she is “the same”. Asked to describe her condition now, Kate stresses: “I don’t - I haven’t got a condition now...I’m well”. In a summing up of how each woman feels she has changed through her experiences, we risk imposing textual coherence by marking a narrative end point, and miss an opportunity to fully enter the emotional context of memory and desire. I am reminded of Kate’s poignant assertion “I don’t have emotional reactions” in a conversation saturated with emotion and wry humour. I found her stoic resilience and determination to just ‘deal with’ whatever comes her way deeply moving. There is no real sense of closure for these women: we do not know how their stories will continue to unfold, or end.

Magda's change in terminology to include breasts as a warm feeling term, reminds us to be respectful in our use of language, attending to not just what is told, but *how* we tell the story of our bodies and bodily experiences. These stories invite a full-bodied reading, and there is space here for hope, triumph and personal growth, but also for a sombre recognition of the anguish, fear, and the harsh realities that women face in their everyday active engagement with this life-threatening, body-altering condition.

This thesis opens up narrative spaces, outside of dominant discourses, in which five women who have experienced mastectomy speak themselves into the foreground. These women offer stories that differ from culturally preferred stories in several ways. For example, the findings complicate discourses that valorise reconstruction and promote prostheses in order to re-normalise women's bodies after mastectomy. These contextualised stories of breasts and breast cancer highlight a need for narrative research into unanticipated short and long term effects of other breast cancer treatments, particularly chemotherapy, to elicit a plurality of understandings about these issues and their implications for women's decision making.

What I've learned from this research journey and these encounters, will impact tangibly on the way I live my life from this point. A narrative construction of these women's experiences allows outrage and fear to co-exist with optimism and courage, mortality with hope and resilience, conveying the full complexity of a life with breast cancer. These five women have privileged us with their remarkable stories and they instil in me, above all, a joyful affirmation of life.

## BIBLIOGRAPHY

- Australian Institute of Health and Welfare. (2000). *Australia's Health 2000* [on-line]. Available: [www.aihw.gov.au/publications/aus/ah02/ah02.c02.pdf](http://www.aihw.gov.au/publications/aus/ah02/ah02.c02.pdf).
- Broom, D. (2001). Reading breast cancer: Reflections on a dangerous intersection. *Health*, 5 (2), 249-268.
- Butow, P., Hiller, J., & Thackway, S. (1997). *Psychosocial factors and the risk of developing breast cancer* [on-line]. Available: [www.nbcc.org.au/pages/info/resource/nbccpubs/psychrisk/contents.htm](http://www.nbcc.org.au/pages/info/resource/nbccpubs/psychrisk/contents.htm) [28/07/02].
- Cancer Council of NSW. (2002). *Talking about sexuality: Body image and cancer: A teaching resource for health professionals*. (Available from The Cancer Council).
- Cady, B. (2000). Breast cancer in the third millennium. *The Breast Journal*, 4 (5), 280-287.
- Clandinin, D. J., & Connelly, F. M. (1994). Personal experience methods. In N. K. Denzin & Y. S. Lincoln (Eds.), *Handbook of qualitative research* (pp. 413-427). London: Sage Publications.
- Cooper, C. L., & Watson, M. (1991). *Cancer and stress: Psychological, biological and coping studies*. Chichester: John Wiley & Sons.
- Denzin, N. K. (1994). The art and politics of interpretation. In N. K. Denzin & Y. S. Lincoln (Eds.), *Handbook of qualitative research* (pp. 500-515). London: Sage Publications.
- Denzin, N. K., & Lincoln, Y. S. (1994). *Handbook of qualitative research*. London: Sage Publications.
- Ellis, C. (1997). In W. G. Tierney & Y. S. Lincoln (Eds.), *Representation and the text: Reframing the narrative voice* (pp.3-21). New York: State University of New York Press.
- Fosket, J. (2000). Problematizing biomedicine: Women's constructions of breast cancer knowledge. In L. K. Potts (Ed.), *Ideologies of breast cancer: Feminist perspectives* (pp. 15-36). London: Macmillan Press Ltd.
- Gatens, M. (1996). *Imaginary bodies: Ethics, power and corporeality*. London: Routledge.
- Gorman, C. (2002, February 18). Rethinking breast cancer. *Time* 6, 42-50.
- Graham, H. (1984). Surveying through stories. In C. Bell & H. Roberts (Eds.), *Social researching: Politics, problems, practice* (pp. 104-124). Melbourne: Routledge & Kegan Paul.



- Greer, G. (1999). *The whole woman*. London: Transworld Publishers.
- Grosz, E. (1994). *Volatile bodies: Toward a corporeal feminism*. NSW: Allen & Unwin.
- Gyllenskold, K. (1982). *Breast cancer: The psychological effects of the disease and its treatment*. New York: Taristock Publications.
- Hallowell, N. (2000). Reconstructing the body or reconstructing the woman? Perceptions of prophylactic mastectomy for hereditary breast cancer risk. L. K. Potts (Ed.), *Ideologies of breast cancer: Feminist perspectives* (pp. 153-180). London: Macmillan Press Ltd.
- Hopkins, L. (2003). Bad news: A narrative account of the subjective experience of mastectomy. *Health Sociology Review*, 12 (2).
- Huberman, A. M., & Miles, M. B. (1994). Data management and analysis methods. In N. K. Denzin & Y. S. Lincoln (Eds.), *Handbook of qualitative research* (pp. 428-444). London: Sage Publications.
- Janesick, V. J. (1994). The dance of qualitative research design. In N. K. Denzin & Y. S. Lincoln (Eds.), *Handbook of qualitative research* (pp. 209- 219). London: Sage Publications.
- Kenyon, G. M., & Randall, W. L. (1997). *Restorying our lives: Personal growth through autobiographical reflection*. London: Praeger Publishers.
- Kvale, S. (1996). *Interviews: An introduction to qualitative research interviewing*. California: Sage Publications.
- Langellier, K. M. (2001). "You're marked": Breast cancer, tattoo, and the narrative performance of identity. In J. Brockmeier & D. Carbaugh (Eds.), *Narrative and identity: Studies in autobiography, self and culture*. (pp. 145- 184). Philadelphia: John Benjamins Publishing Company.
- Langellier, K. M., & Sullivan, C. F. (1998). Breast talk in breast cancer narratives. *Qualitative Health Research*, 8 (1), 76-94.
- Latteier, C. (1998). *Breasts: The woman's perspective on an American obsession*. New York: The Hawthorn Press.
- Lorde, A. (1997). *The cancer journals: Special edition*. San Francisco: Aunt Lute Books.
- Mattingly, C., & Garro, L. C. (2000). *Narrative and the cultural construction of illness and healing*. London: University of California Press.
- McCarl Neilsen, J. (1990). *Feminist research methods*. Colorado: Westview Press Inc.
- McConville, B. (1994). *Mixed messages: Our breasts in our lives*. London: Penguin Books.

- Meric, F., & Hunt, K. K. (2001). Surgical options for breast cancer. In K. K. Hunt, G. L. Robb, E. A. Strom & N. T. Ueno (Eds.), Breast Cancer (pp. 188-222). New York: Springer-Verlag.
- Minichiello, V., Aroni, R., Timewell, E., & Alexander, L. (1991). *In-depth interviewing: Researching people*. Melbourne: Longman Cheshire.
- National Health and Medical Research Council. (2000). *Psychosocial clinical practice guidelines: Providing information, support and counselling for women with breast cancer*. Canberra: Commonwealth of Australia.
- Neilsen, L. (1998). *Knowing her place: Research literacies and feminist occasions*. San Francisco: Caddo Gap Press.
- Oakley, A. (1981). Interviewing women: A contradiction in terms. In H. Roberts (Ed.), Doing feminist research (pp. 30-61). London: Routledge.
- Oleson, V. (1994). Feminisms and models of qualitative research. In N. K. Denzin & Y. S. Lincoln (Eds.), Handbook of qualitative research (pp. 158-174). London: Sage Publications.
- Polkinghorne, D. E. (1997). Reporting qualitative research as practice. In W. G. Tierney & Y. S. Lincoln (Eds.), Representation and the text: Reframing the narrative voice (pp. 3-21). New York: State University of New York Press.
- Potts, L. K. (2000). Publishing the personal: Autobiographical narratives of breast cancer and the self. In L. K. Potts (Ed.), Ideologies of breast cancer: Feminist perspectives (pp. 98-127). London: Macmillan Press Ltd.
- Reinharz, S. (1992). *Feminist methods in social research*. New York: Oxford University Press.
- Robb, G. L. (2001). In K. K. Hunt, G. L. Robb, E. A. Strom & N. T. Ueno (Eds.), Breast Cancer (pp. 188-222). New York: Springer-Verlag.
- Roberts, B. (2002). *Biographical research*. Philadelphia: Open University Press.
- Russo, J., Lynch, H., & Russo, I. H. (2001). Mammary gland architecture as a determining factor in the susceptibility of the human breast to cancer. The Breast Journal, 7 (5), 278-291.
- Saltman, D. C. (1997). Feminism and the health care movement. In K. Pritchard Hughes (Ed.), Contemporary Australian feminism (pp. 216-241). Melbourne: Addison Wesley Longman.
- Saywell, C., Beattie, L., & Henderson, L. (2000). Sexualized illness: The newsworthy body in media representations of breast cancer. In L. K. Potts (Ed.), Ideologies of breast cancer: Feminist perspectives (pp. 37-62). London: Macmillan Press Ltd.
- Schover, L. R. (1997). *Sexuality and fertility after cancer*. Brisbane: John Wiley & Sons.

- Sellman, S. *Mothers prevent your daughters from getting breast cancer*. (2003). Tulsa: Getwell International.
- Simpson, C. (2000). Controversies in breast cancer prevention: The discourse of risk. In L. K. Potts (Ed.), Ideologies of breast cancer: Feminist perspectives (pp. 131-152). London: Macmillan Press Ltd.
- Weiss, G. (1999). *Body images: Embodiment as intercorporeality*. New York: Routledge.
- Yalom, M. (1997). *A history of the breast*. New York: Alfred A. Knopf.
- Young, I. M. (1990). *Throwing like a girl and other essays in feminist philosophy and social theory*. Indianapolis: Indiana University Press.