

1-1-1997

What is the intimate experience of couples following the woman's cancer-related breast surgery?

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**WHAT IS THE INTIMATE EXPERIENCE OF COUPLES
FOLLOWING THE WOMAN'S CANCER-RELATED
BREAST SURGERY ?**

VOLUME ONE

by
Lynne Amor (Bachelor of Arts)

A Thesis
Submitted in Partial Fulfillment of the Requirements for the Award of

Master of Nursing

at the
School of Nursing,
Edith Cowan University

Date of Submission: February 18th, 1997

USE OF THESIS

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

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Abstract

The purpose of this phenomenological study is to describe and interpret the experience of couples following the woman's surgery for breast cancer, in order to gain an in depth understanding of how this mutilating surgery affects their everyday lives. Breast cancer is the most prevalent form of cancer in Australian women, and in most industrialised nations. Women in Australia have a one in fourteen lifetime risk of developing the disease.

Little is known concerning what meanings this surgery brings to the intimacy experienced between partners. It is important to seek knowledge of the phenomenon of intimacy, how the couples understand it, and how breast surgery has affected it, if at all. Literature to date has focused on the psychological and physiological effects of mastectomy on women, with little attention given to the plight of partners.

A phenomenological approach was chosen for the study, and a purposive sample of seven couples was selected for the interviews. Primary data was obtained from audio taped interviews and from participant observation. Data analysis followed the protocol outlined by Colaizzi (1978), and seeks to describe, interpret and extrapolate common themes and meanings from the data.

Six key findings relating to women were gleaned from the data, and five from the men. Anger concerning the professional guidance received was a theme in both men's and women's findings. Common themes to emerge from the interviews with women were: 1) Existential plight concerning cancer diagnosis; 2) concern about their husbands reaction to mastectomy; 3) a sense of loss in relation to body-image; 4) feelings of somatic strangeness; 5) their awareness of husbands support; and 6) their feelings about fertility and early menarche. Common themes to emerge from the interviews with men were: 1) Uncertainty and a loss of control following mates cancer diagnosis; 2) sexual affects of mastectomy; 3) feelings of grief and loss since

mastectomy; 4) Denial; and 5) awareness of role changes. Anger directed at professional care givers was a theme which emerged from both men and women.

The findings suggest that it is important for health professionals to be cognisant of the potential for emotional and physical effects in the relationships between couples who experience this surgery. By understanding these relationships, health professionals may offer appropriate support. The seven couples stories highlighted that even while individuals (and couples) denied they were affected by the mastectomy experience, their narratives indicated otherwise. This finding infers that couples affected by mastectomy at the very least need a sympathetic ear and the luxury of time in which to articulate barely recognised but nonetheless substantial shifts in their relationships. This study will add to the knowledge base on how mastectomy affects couples, and contribute recommendations for further research to improve the way in which health care providers care for couples affected by mastectomy.

Declaration

I certify that this thesis does not incorporate without acknowledgment any material previously submitted for a degree or diploma in any institution of higher education. To the best of my knowledge and belief it does not contain any material previously published or written by another person except where due reference is made in the text.

Signature:

Date:

30th April, 1978

Acknowledgments

Firstly would like to thank three nurses who I was fortunate enough to have as colleagues and mentors - Dr. Mary Jo Bulbrook of the U.S.A., and two Canadian nurses - Professor Anne McMurray and Janet Reinbold. These knowledgeable and generous women were major influences in channelling my interest towards qualitative research.

Secondly, my warmest thanks for all the personal and professional patience, kindness, support and, not least, wisdom I have received from my supervisors in this study. I thank Judith Davis, whose invaluable presence I lost at the data collection stage of the research undertaking, and Dr. Nancy Hudson-Rodd, and Lebbie Hopkins, who were always available to offer advice when necessary. Without their guidance I would not have accomplished this task

Thirdly, my warm regards and thanks are extended to the men and women who so generously gave up their time to sit and share such personal aspects of their lives with me, a relative stranger. Without their participation, this study would not have been possible.

Fourthly, I extend my thanks to the stalwart trio of friends - Rosemary Allen, Anne Crawford and Wendy Stradwick who assisted me in the onerous task of converting what could formerly only be 'data as listened to,' into twenty- one, lengthy, 'hard copied' transcripts.

Lastly, I say thanks to my family, for their love and forbearance over this last year: to my mother, who cared and cooked for Annoushka on the many evenings I spent researching, to my husband John, who in his support of me has probably absorbed more phenomenology than he ever intended to, and to my children Natasha and Annoushka, whose faith in me never flagged.

VOLUME ONE

Introduction, Literature Review and Methodology

CHAPTER ONE

Introduction to the Study

This study describes couples' feelings, experiences and perceptions of intimacy following the woman's diagnosis of breast cancer and mastectomy. There have been no studies undertaking an in-depth knowledge of this phenomenon from the unique standpoint of the couples.

Structure of the Thesis

This thesis has been divided into two sections. Section one comprises Chapters one through to chapter four. Chapter one introduces the research topic, outlines the background, significance and purpose of the study and defines the terms used within the document. Chapter two is comprised of a literature review broadly delineating different types of foci undertaken on the subject of mastectomy over the last four decades. This review also examines theories and definitions of the body, body-image and the concept of intimacy. The third chapter describes the research method undertaken in the study. This section discusses the research paradigm appropriate for the study, and the particular methodological approach used to undertake it. This includes a description of the research design, sample, data collection and data analysis. The limitations of the study, validity, and ethical considerations are also addressed within this chapter.

Section Two (chapters five to twelve) comprises the findings discussion and recommendations. This section is introduced by a participant profile and the participants' definitions or experience of intimacy. A conceptual framework for intimacy is used in order for the reader to be able to make sense of the exhaustive descriptions that touch upon the complex phenomena of intimacy. Chapters six

through to nine are separate discussions linked within loosely analogous gendered themes (described in the chapter titles). Chapter ten includes a discussion of common themes related to fertility which only the women shared, while chapter eleven, which concerned anger directed at medical personnel, was unique insofar as it shared by women males and females. Chapter twelve outlines recommendations and suggestions for further research.

Background to the Study

My personal impetus towards undertaking this study

As a Registered Nurse of twenty-nine years experience, including my more recent work as a clinical educator, I have nursed many women who have undergone mastectomy. Since the time I began my nursing career in 1967, the surgical and nursing management strategies have been streamlined to the extent that in the 1990s, women usually spend only a few days in hospital, whereas in the 1970s they would have spent from 7-10 days as in-patients. As I worked with these women, it seemed that in many instances their partners were not encouraged to be with them at important times during the 'rites of passage' of the woman experiencing this surgery. By this I mean in the lead up to/entry to the operating room, the immediate post-operative period and the time of the first (wound exposing) dressing. Some of my peers were (I thought) trying to 'normalise' the procedure for the woman, and would not overtly suggest the man's presence may be an extremely significant part of her rehabilitation. It seemed clear to me that women were receiving the very best of physical care, but that their emotional needs were largely unknown.

As an Australian hospital based nurse and as a clinical teacher in an undergraduate nursing program, I was exposed to American literature about the enormous emotional impact mastectomy had on women. I was always curious to know how the women and their partners fared once they went home. I sensed the operation itself could be the 'tip of the iceberg,' under which could be unplumbed depths of feeling, and I suspected that these feelings may not necessarily have been limited to the woman. As I have 'travelled' a clinical career path, I have been drawn increasingly to the essential person embedded in language rather than action, and this has drawn me

away from viewing physical care as the goal most necessary for health. This 'departure' has led me into a more philosophical inquiry about the nature of illness, and the meanings/feelings of illness as experienced by people. One of the things I enjoy most about clinical practice, is the sense that people honour themselves and their listener by their openness.

Secondly, I have had a long-standing interest in breast cancer, as a woman, and as a nurse. As a woman, my risk for developing breast cancer increases with age, and, as a nurse, I may possibly be more aware (than women who are not nurses) of the high level of epidemiological significance it holds for my sex. As a forty-seven year old who has a life partner, a grown-up child and a growing child, my own experience of life as a woman, partner, mother and nurse is a significant, if somewhat subsidiary element in the background of this study.

Many women who research mastectomy or breast cancer had experience of it themselves, however I do not belong to this group. Ironically, at the time I was about to commence my conversations with the participants in this study, I detected a breast lump. Fortuitously, this lump was only a benign cyst, which simply required decompression (of fluid) at the time of the needle biopsy. The pre-diagnostic period was a worrying time for my partner and myself, and I was aware of living on the cusp of the potential for a radical change. While there were negligible and positive physical changes as a result of the biopsy, I felt it was a somewhat salutary experience on the emotional level, which I believed in a small way helped me to be more sensitive to the experience of the couples participating in my study.

Thirdly, I have made a conscious decision not to depersonalise the essentially, exquisitely personal nature of this research by writing in the third person, (ostensibly) objective narrative style. The phenomenological researcher does not attempt to maintain a pretence of objectivity, preferring to delineate clearly existing biases and assumptions, bracket all presuppositions, and acknowledge that researcher and participant interaction effect the data. I believe that the omniscient, disembodied voice would alter the tone of thesis as process as well as content. Therefore, I am in the thesis as well as entitled upon the cover sheet. From this perspective then, the only person who remains omniscient is you, my reader. It is perhaps a misfortune of our

world-as-limited -dimension, that you (and other readers) cannot be personally involved. I defend my right to use this style as a legitimate form of academic thesis discourse. I have occasionally departed from the first person narrative in those areas of the thesis in which I discuss the work of others, most particularly in the Literature Review.

Fourthly, I am drawn to the interpretive paradigm of research, which involves a humanistic perspective of human behaviour, because it allows for expression of the poetry, pathos and gnosis of human existence. So, while my own perceptions of humanism are much less elegantly conceived than others, I have accreted deep beliefs concerning the essential integrity of human beings gleaned from my own life experience. Since girlhood, my intellectual and imaginative life has been invigorated by maintaining an eclectic diet of literary fiction, and it was no after thought that my first degree was in literature. This lifelong background of personal and professional interest in human experience has good fit with the phenomenological, interpretivist paradigm which was chosen for this study.

Incidence

All women are at risk of developing breast cancer. Breast cancer is the most common female malignancy in the Western World and is the leading cause of death from cancer. Approximately 7000 Australian women are diagnosed with breast cancer annually, and in 1991 more than 2500 women died from breast cancer. This amounts to six women dying each day in Australia from breast cancer. In Western Australia in 1992, 650 women were diagnosed with this condition, and a further 200 women died with this disease (Health Commission of Western Australia, 1993). Australian women have a 1:14 lifetime risk (to age 74) of contracting breast cancer, which accounts for 27% of all cancer in women (Health Commission of Western Australia, 1993), and the most cancers for any site in any sex (Cancer Foundation of Western Australia, 1994). Breast cancer is the second most frequent cause of death from cancer with a lifetime risk of death from breast cancer of 1 in 47 for women (Cancer Foundation of Western Australia, 1994). The death rate from breast cancer is much lower than the incidence, with two out of every three women surviving the disease, and women whose cancer is diagnosed at an early stage are more likely to survive

than women whose cancer is more advanced at diagnosis. The incidence of breast cancer may be increasing in Australia, but it is believed that some of this increase reflects the improved diagnostic technology of mammographic screening (Giles, Farrugia, Thursfield & Staples, 1993).

Prevention

The current understanding of breast cancer makes it impossible to predict, with any degree of accuracy, those women who are likely to develop breast cancer.

Consequently, there are two approaches to prevention of breast cancer, which involve primary prevention: reducing exposure to known risk factors, or active prevention by chemo-prophylaxis (Tamoxifen therapy) in high-risk women (The Australian Cancer Network, 1994). Non-modifiable risk factors are:

- Being women
- Getting older
- Family history of breast cancer

While modifiable, likely risk factors are:

- High fat content diet
- Not breast-feeding
- Having children later in life
- High intake of alcohol

(The Australian Cancer Network, 1994)

Secondary prevention surrounds the early detection of any thickening, lump or discharge from the breast, via breast examination, mammography or ultrasound. This is followed by more exact diagnostic technologies, most frequently needle biopsy and histological evaluation to determine the presence of cancer. If cancer is diagnosed early, the chances of long term survival improve. Effective treatment is surgical removal of the lump, with dissection of a margin of healthy, (histologically clear) surrounding tissue (NH&MRC, 1995). If the lump is too large, multifocal, or clear margins cannot be isolated, mastectomy is the appropriate treatment. Breast conserving treatment of lumpectomy or segmental resections are currently favoured for such clearly differentiated tumours, because research has shown that there is no

difference in the long-term survival rate of women who have mastectomy, than those who opt for breast conserving surgery. Local (surgical) treatment is often followed by radiological (local treatment), as well as systemic chemotherapeutic treatments to arrest the growth of tumour cells which may have metastesised in the body. Even while breast conserving treatment is available to many women, some still elect for mastectomy, because of their fear of cancer recurrence.

Significance of the Study

While there have been large studies conducted in the United Kingdom as long ago as 1893, in more recent times, the scholarly writing relating to mastectomy began in earnest in the decade following the Second World War. This interest began as a trickle of information, which swelled to a stream of information until the late seventies. During this time, there was an upsurge in clinical interest in the psychological effect of the disease and surgery, whereas in more recent times the trend has been towards the social dimension of mastectomy and how it affects women's social relationships. Since the eighties, there has been increased focus on the influence that social support has on the woman's recovery from mastectomy. Excluding one much earlier study, the nineties have seen the emergence of awareness that the sexual partner may feel the psychological insult of his partner's mastectomy almost as much as she does.

While previous research has been conducted in North America or the United Kingdom, and since the preponderance of the focus has been on women, it seems pertinent in the late 1990s to examine the intimate experience of Australian couples following mastectomy. In spite of the increasing numbers of women who are affected by breast cancer, there has been little research done in this country concerning the emotional and sexual impact that this breast surgery has on women, and a paucity of research which focuses on the experience of the partner or the couple.

It is particularly relevant to understand the experience of couples in this position, as, knowing their perspective will enable health care providers to facilitate sensitive guidance and counselling to couples, particularly to men, who do not appear to believe they need emotional support.

Purpose of the Study

The purpose of this study was to describe and interpret the everyday meanings which couples ascribe to their experience of intimacy following cancer-related breast surgery. If more is known about how couples experience intimacy following breast surgery, this information could form the basis of further research, and provide for a more informed conceptual base for clinical practice with individuals or couples. If utilised, this research therefore has the potential to improve the quality of life of couples following surgery.

The Research Question

What is the intimate experience of couples following the woman's cancer-related breast surgery?

Definition of terms

- Intimacy: this term will be defined by the couples.
- Breast Surgery: breast surgery performed for the purpose of eradicating cancer - either by the removal of the woman's whole breast (that is mastectomy), or by means of a lumpectomy.

CHAPTER TWO

Literature Review

Introduction

This chapter provides a selective critical review of the literature pertaining to mastectomy and the impact it has on intimacy between partners. Currently, there is a paucity of research that examines the realm of intimacy between couples as a specifically identified phenomenon following cancer-related breast surgery. Therefore, this review includes studies in which one or more of the possible component characteristics of intimacy was studied or could be inferred from the title. Firstly, as the preponderance of literature falls understandably within the study of the female 'mastectomate', the studies involving the psychological effects of mastectomy on the woman will be reviewed first, and then, research pertaining to couples or the sexual partners' perspectives will be scrutinised. Thirdly, mastectomy surgery involves prolonging women's lives at the expense of removing an external organ (an external organ which is invested with somewhat momentous symbolic significance by both men and women). It has therefore been relevant to analyse the literature related to body-image, in order to gain a wider understanding of the complex associations ascribed to the female breast, and how its absence may significantly impact on the intimate lives of couples. Finally, as the research question involves the rather slippery term "intimacy," I also examine theories and research studies conducted on this subject, prior to scrutinising the participants' own experiences and definitions of the concept in the research findings. I was careful to avoid performing a literature search on intimacy and body-image outside of the area of mastectomy *prior* to my data collection, as I wanted to remain as free as possible from any pre-conceived ideas that may have tainted my questioning. While I found no overt references to intimacy, in my initial literature search, there were numerous titles involving body-image and

mastectomy, and 'psycho-sexuality' following mastectomy which inferred that broadly, concepts of intimacy were involved within these studies. However, it is a word rarely used in the medical or nursing literature, which is the discipline most dominant in mastectomy studies.

Research Concerning Women

Research conducted with women recovering from breast surgery has highlighted several areas of concern for women, but a dearth of information on the affect that this has on their partners. Foremost amongst womens concerns was psychological stress (Ervin, 1973; Wellisch Jamison, & Pasnau, 1978; Quint, 1963; Stein, 1993) while other variables identified were physical pain, altered sensation and body image difficulties (Masters & Johnson and Kolodny, 1979), curtailment or cessation of coital activity (Frank, Dorbush & Webster, 1978; Silberfarb, Maurer & Crouthamel, 1977), and lack of psychological support from professional carers, both doctors and nurses (Northouse, 1981).

Psychoanalytical Studies

In the 1950s, research seemed to reflect the post-war preoccupation with psychoanalytic interpretations of disease. Researchers were puzzled -then as now - as to why cells changed from orderly growth to chaotic mutations, and about whether certain people were at risk. In 1952, Bacon, Rennecker and Cutler interviewed forty women at a breast tumour institute, and found that 65% of them had avoided early (medical) detection, even though they had been exposed to education regarding the urgent implications of better prognosis with early detection of disease. Major behavioural characteristics of the forty participants were found to be: (1) masochism; (2) sexual inhibition; (3) inhibited mothering; (4) inability to ventilate anger, covered by a veneer of pleasantness; and (5), unresolved hostile conflicts with the mother. Some of the questions asked of the women in this study reflect patriarchal attitudes of early psychotherapeutic approaches and this era, but the "psychobiological hypothesis" the researchers raised are nonetheless interesting. That is, is it possible for emotional states to act as biological triggers to cellular mutation?

Another more rigorous comparative study by Reznikoff (1955), examined personality trends in fifty women attending a breast clinic. All the women were interviewed prior to diagnosis, twenty-five of whom were subsequently diagnosed with malignant breast tumours and required major surgery. The questionnaire focused on the patients' maternal and heterosexual relations, which were assumed to have the primary psychological meaning to women. Women diagnosed with malignancies were reported to have had a greater number of sibling deaths at birth or infancy, and had greater responsibility (as children), particularly associated with caring for younger children. They also evinced more negative feelings towards birth and pregnancy and feminine identification.

These findings are of historical but doubtful scientific interest, as it was a very small study, and to my knowledge, further studies involving breast tumours in this psychosomatic hypothesis of the genesis of cancer have not been published.

A Swedish study by Gyllenskold (published in English in 1981) was of major importance to me, as it published large tracts of the researcher's interviews. Unfortunately, this study was unavailable to me until after I had completed my interviews. This researcher conducted open-ended interviews with 21 women using a psychoanalytical model as a conceptual framework. She interviewed the women at the point of diagnosis and at intervals for two years during their recovery after mastectomy. In all, she conducted 142 interviews, which generated 5,000 pages of transcript. Gyllenskold's conclusions were (1) That women who were able to mourn their breast loss in an adequate way were better able to negotiate the crisis of breast cancer surgery; (2) that most of the women in her study were still moving through an as yet unresolved crisis at the two year post-surgical mark; (3) all the women in her study reported existential concerns, and all spoke directly of their own death with the author; and (4) 6 out of the 21 women in her study had phantom breast phenomena. Gyllenskold (1981) recommended that women were in need of greater sensitivity to their psychological welfare regarding somatic care, and more openness from medical personnel regarding information giving concerning potentially distressing treatments. The richness of the interviews are evident in much of Gyllenskold's transcriptions and are a vindication of the unstructured interview method.

This psychoanalytic notion of malignancy being causally linked to emotional or certain life events is a familiar motif in popular culture, and these assumptions have a negative impact/consequence leading people to believe they 'deserve' the disease, or that it is inevitable. The very word cancer has few modern parallels in its capacity to strike people with feelings of fear. The notion of psychological, or personality 'types' has had popular social, artistic and literary traditions which predated psychoanalysis. The Romantic era was a pivotal influence in 'elevating' tuberculosis into a disease associated with sensitive, cultured, or artistic people, thought too be 'too fine' to survive the industrial age, perceived as mechanistic and cruel. The artistic lives, disease and early deaths of Keats, Byron, the Bronte sisters, and Chopin were possibly seminal influences in this social transformation of disease.

Theory of Cancer as a Metaphor of Invasion

The power of disease as symbol has been trenchantly analysed by the essayist Sontag (1979) in her treatise "Illness as metaphor". Sontag examines the centuries long human tradition of transforming incurable diseases into powerful political and militaristic metaphors. The disease is seen as a symbol for the rapid growth of industrialised society and not merely a biological reality. It becomes a symbol of corruption within the body politic, and the corporeal body. These militaristic metaphors are so commonplace in scientific and medical literature (as well as popular culture), that they are rarely questioned. Nonetheless, the social ascriptions given to the disease have the effect of externalising the internal biological disease process as a foreign, invasive 'enemy', to be 'fought', rather than internalised as a disease process. This is not to undervalue the very real feelings of fear people experience when diagnosed with "curable/treatable"/incurable cancer, but simply to emphasise the social mythology that surrounds it surely enhances this dread.

Descriptive Studies

Quint's (1963) pioneering descriptive study focused on the impact of mastectomy from the woman's viewpoint. This longitudinal study was based on interviews and participant observation of 21 women one year following mastectomy. Quint found that women had little opportunity to ventilate their concerns, and the time of physical healing was much longer than anticipated. Also, Quint revealed the deep psychological tasks of adaptation to disfigurement and the possibility of death required longer periods of adjustment as well as more chances to speak about sensitive feelings. One of the most frequent surgical techniques then used for mastectomy was the Halsted procedure, the woman's breast and underlying muscle was frequently excised, (causing a severely mutilating, indeed concave dimension to the chest wall). This procedure often required a skin graft, as the wide excision of breast tissue was unable to be approximated for the primary closure (stitching) of the two or more skin surfaces. Of course, skin grafting meant that another body wound was involved, with all the concomitant risks of pain, immobility and infection. In the thirty years since Quint's findings, the use of the radical Halsted procedure has been largely outdated by research, which has proven that lumpectomy and radiotherapy and /or adjuvant therapy is as effective for long-term survival as radical procedures. As a result of this research, and the sociological changes which have come in the wake of women's insistence on a more active role in decision making, mastectomies have become less radical, and theoretically at least, are less painful than before. They are less painful because less tissue is dissected, and pain control therapies in most hospitals are more adept at meeting the analgesic needs of patients.

Ervin's (1973) research also suggested that the emotional difficulties of women following mastectomy may be long standing. Ervin had 25 years of practice as a surgeon, and he became interested in the emotional effects of mastectomy when three of his patients committed suicide. This descriptive study was undertaken by interviewing twelve disease-free women who had breast surgery five to ten years previously. Even though this sample was very small, and there was no comparison group, all but one of these women reported that the post mastectomy experience

remained negative for many years, even though the threat of death was diminished. Of the three women who committed suicide, two had lost the support of their partners.

Weisman and Worden (1976) conducted a study called "Existential Plight in Cancer: Significance of the first 100 days". Those surveyed were 120 cancer patients newly admitted to medical and surgical services. Of these patients, 37 (females) had breast cancer. Data was collected via semi-structured interviews, two psychological testing scales and a general coping behaviours/resolutions chart. Patients were followed up at ten days post-diagnosis, and at three, six weekly intervals. Existential stress, concerning the uncertainty of life was universally observed across all the participants, overriding all the other treatment or psychosocial concerns, but peaked at different times for different cancer diagnoses. Of the five different cancers, women with breast cancer had the second highest vulnerability peak at the six and twelve week assessment, and this was partly attributed to a period in which radiation or adjuvant therapy was current. These findings were even more pronounced with those people who voiced pessimism, past concerns, marital problems, and poor support systems. This means that health care workers should be able to detect persons identified who may require some support, and provide counselling, particularly where it is identified as lacking.

This deep seated existential emotional distress was also found to be a common experience among women following breast surgery in a later study undertaken by Stein (1993). Thirty-two percent of women in Stein's research revealed that mental stress and fear concerning death and cancer recurrence was the most difficult part of recovery. Thus, the incidence of stress and fear of death reported by Stein implies that a significant group of women have areas of need which require further investigation. It is probable that this stress has an impact on women's self esteem and subsequently, affects their intimate relationships with partners.

Wellisch et al. (1978) identified relatively positive results in their non-comparative correlational study involving 41 middle-class women. Disturbingly however, almost a quarter of their cohort identified suicidal ideation for reasons they associated with mastectomy. These authors also found that age is significant in post-mastectomy adjustment, with younger women reporting significantly poorer adaptation, as well as

mastectomy impacting negatively on their sexual relationships. This latter finding was corroborated in the overall data analysis from the partners, which identified that 36% of the respondents rated the impact of the surgery as negative, and 20% of these men had not seen their partners naked during the first year following surgery.

While I found no overt references to intimacy, in my initial search of the mastectomy and cancer-related research, there were numerous studies involving body-image and mastectomy, and ‘psycho-sexuality’ following mastectomy which inferred that intimacy may have been involved as a topic, but it is a word rarely used in the medical literature, which is the discipline most dominant in mastectomy studies.

Research Concerning the Partner or Partnership

While the impact and aftermath of mastectomy have been extensively studied since the early 1950s, there has been relatively few studies which examine the phenomenon of mastectomy as experienced by the sexual partner. By the mid to late 1970s, researchers began to study the nature of stress experienced by husband following the wife’s mastectomy. One of the first to examine men's responses to cancer-related breast surgery was an American study by Jamison, Wellisch and Pasnua (1978), who investigated 31 women who had mastectomies, and 31 of their partners. Their purpose was to address the adjustment of men following their spouses’ surgery. Results revealed a ‘sizeable proportion’ of this sample coped well with the surgery, and denied psychological stresses. It was also plain that a subgroup was “... distressed, remained distressed, and reported a downward spiralling in the quality of their relationship” (p. 545). Sleep disturbances and nightmares were reported in 40% of this sample, while others reported loss of appetite. Forty-two per cent of participants indicated that their ability to work was temporarily affected by easy distractibility. Generally, the men indicated that that sexuality and intimacy were severely stressed following surgery. Sexual satisfaction decreased, both in relation to the men’s feelings and in regard to their perceptions of their wives’ feelings. Those respondents who ranked themselves highly in their pre-mastectomy sexual relationship indicated little change in post-mastectomy sexual satisfaction. The opposite trend was true of those reporting low pre-mastectomy sexual satisfaction. Men who most highly valued their

relationship were highly involved in the decision making process prior to the surgery, and those men who failed to visit their wives, or limited visiting in the hospitalisation period were most likely to experience emotional disturbance. This small study concluded that "... the man is anything but a detached observer, even if he takes a seemingly distant, uninvolved stance" (Wellisch Jamison & Pasnua, 1978, p. 546).

In the more recent Australian study by Sturestep and Darroch (1987), couples were sent detailed questionnaires to determine husbands' responses to their wives' mastectomies. The authors noted that "Sexual behaviour was severely affected during the first year but reportedly improved thereafter, however it did not return to the pre-mastectomy level"(page 21). Prior to surgery, the couples were considered to be well adjusted, from which I infer that if there are noteworthy sexual changes in well adjusted couples, then there is likely to be more sexual and emotional disturbance in the poorly adjusted couples. However, Sturestep's and Darroch's (1987) study found that the attribution of sexual and emotional stress in couples does not necessarily mean a lack of love or support, but rather women commonly reported the husbands as being supportive, encouraging and loving. "Also mentioned frequently were: consideration, caring and understanding, and a stronger bond than before"(page 25). Similarly, the responses of the men to the question concerning their comments re the mastectomy evoked in general a feeling of love and concern for the wife. These findings are similar to Wellisch et al (1978) who revealed that while women had emotional distress, they also gave strong indications of positive coping mechanisms. This was expressed as women perceiving their partners to be understanding.

This Australian study also highlighted the fact that 82% of men had a need to talk to someone about the surgery, and 14 out of the 34 men had to initiate the talk themselves. Respondent's rated the helpfulness of people spoken to thus: (1) mastectomees and husbands (highest); (2) doctors/surgeons (second), with (3) family and friends having the lowest average rating. Sturestep and Darroch's findings were not disimilar to the earlier study by Wellisch et al.

Baider and Kaplan de Noir's (1984) study of 20 couples found that spouses had as many adjustment problems following surgery as did their wives and there was a significant correlation between husbands and patients adjustment scores. These

researchers were the first to examine the adjustment of both the patients and spouses using the same instruments in order to compare their reactions.

In 1987, Northouse and Swain conducted a larger quantitative study of the adjustment of couples to the initial impact of breast cancer which involved 50 couples. Subject's psychosocial adjustment was assessed during the time previous research had identified as crucial to the broad process of adjustment (in women). Adjustment was viewed as a multidimensional construct, and included: (1) the absence of extreme psychic distress; (2) the ability to function in work, familial and social settings, and; (3) a positive balance of mood. Northouse and Swain found that husbands and wives experienced considerable distress during the hospitalisation period. Husbands reported difficulty in balancing their conflicting domestic and work responsibilities, while visiting wives and offering support. They felt marked alterations in their moods, and increased levels of distress, and comparison of the couples psychosocial adjustment 30 days following surgery revealed they did not differ in terms of overall mood states. From the hospital assessment until the 30 day assessment, patients and spouses reported dramatic improvements in their mood scales, and they were still bothered by almost the same number of distressing symptoms like somatic disturbance, depression and hostility.

Northouse (1988), used the same sample to examine the relationship between social support and adjustment to mastectomy, and found that husbands perceived significantly less support from professionals than their wives throughout the illness phase, but, did not differ significantly in the amount of support received from patients and families. This study indicated a strong sense of reciprocity in the support systems of the sexual dyad. Among the women, patients with higher levels of support had higher levels of adjustment than those who had lower levels of support, and this adjustment was not affected by disease staging, type of surgery performed, type of adjuvant therapy or number of breasts removed.

Interested in the medium term adjustment of men following their wife's mastectomy, Northouse (1990) conducted a longitudinal study, again using the same instruments, to measure psychosocial adjustment. This study involved 41 men eighteen months following their wives mastectomies, and, overall, the mean scores registered mild

levels of distress, although 24% of the sample reported moderate to severe distress. These distress levels did not differ significantly from distress registered at 3 and 30 days post-operative to their wives' surgery. Northouse hypothesised that her quantitative findings may have been caused by the men's fear of their partner's cancer recurrence. However, it is possible that this stress may have been caused by factors unrelated to the cancer diagnosis or breast surgery.

Like Northouse (1990), Zuhlis and Shands, (1991) explored the experience of partner adjustment to mastectomy, and found an even higher level of negative impact (27%) as long as 18 months post-operatively. In their qualitative study, 67 men were interviewed at 4 monthly intervals, and questioned about the day-to-day impact of their wives' breast cancer. Thirty of the participants were identified as meeting the study criteria, and of these, the majority of their wives (50%) had had lumpectomies, while 40% had a modified radical mastectomy, and 10% radical mastectomy. Men who denied that their wives' breast cancer had had any impact on their lives were dropped from the study, however, 24% (8) of the remaining men described some distress. The distress that men revealed was related to concerns about disease recurrence, and marital concerns related to the breast cancer. Fears were expressed when a wife's lump returned, while another man's thoughts returned to the spectre of cancer at check-up times; and one man simply said "It's still on our minds ... all the time. You're just not gonna drop [it] ... I don't think it'll ever diminish" (Zuhlis and Shands, 1991, p. 85). The marital concerns related to intimacy concerns, and were of a sexual or communication nature. One couple had separated during the illness and the husband attributed the separation to the cancer. Even though he said the disease appeared to be in remission, he said the psychological effects were 'devastating' on the whole family - he said his wife had said "It [is] too much to have cancer and be married at the same time (Zuhlis and Shands, 1991, p. 85)".

The immediacy of these people's voices strike richer, more humanistic interpretations than that given by data drawn by quantitative research methods. It is the human essence (of the phenomenon under study) that I seek describe in detail via this phenomenological study. The above study was the only descriptive study of this kind *concerning partners* isolated in the literature, and indicates that the qualitative study of intimacy within couples effected by mastectomy is a productive field of inquiry.

Phenomenology is the chosen research method, for this method is able to put flesh and human experiential meaning onto the bare bones of quantitative research

Research to date points to the listing or naming of the symptoms of the impact of the surgery, rather than attempting to define the Gestalt of the experience as it affects the intimate lives of couples. Johnson (1987) is one writer whose personal account following cancer-related breast surgery achieves the experiential clarity of mastectomy and intimacy, which this study will hope to capture. Johnson reveals her own reactions and feelings following surgery, and also interviews others who have suffered the effects of cancer, which reveals a strong focus on the intimate lives of women and their partners

From 1975, with the publication of Kushner's *Breast cancer: A personal history and an investigative report*, there has been an increasing trickle of self-help books written to inform women more about the disease of breast cancer. Johnson (1987), is yet another writer whose personal account following cancer-related breast surgery reveals her own reactions and feelings following surgery, and also interviews others who have suffered the effects of cancer which reveals a strong focus on the intimate life of women and their partners. Two nurse academics have contributed to this 'popular' literature. Elizabeth Gee began a diary at the time of her diagnosis in 1987 and this was published posthumously under the title *The light around the dark*, in 1992. Moch (1995), published a volume of themes which emerged from 20 women she interviewed who had breast cancer. These books are potent experiential accounts, which, as well as the studies by Gyllenskold (1981) & Zahlis & Shands (1991) (study of men) achieves the first-person narrative clarity that participants in this phenomenological study captured.

Summary

In summary, the literature has revealed that many women do suffer emotionally following cancer-related breast surgery, and that aspects of the sexual and emotional relationship are affected. What has not been researched is the intimate experience of couples who have experienced cancer-related breast surgery. There is a gap in the published literature which indicates a need to describe this phenomenon as it is

experienced in the everyday life of men and women, in order to gain a deeper understanding of the nature or meanings couples attribute to it.

Literature Relating to Intimacy

While the medical literature was almost devoid of direct references to the phenomenon of intimacy, it holds a special place within the framework of popular literature, personality theory, psychotherapy, and social psychology. It was the latter area which provided the richest source of information, and even in this field, it has been acknowledged that there is a relative paucity of material relating to intimacy. This is further compounded by the fact that theories, constructs or descriptive studies all define intimacy in very different ways. Sykes (1976, p. 567) defines intimacy as, close in acquaintance, familiar, having sexual intercourse with, close or closely personal, and promoting close personal relationships. It derives from the Latin root, "... intus meaning within, and is related to intimare, which means to make known" (Weingarten 1991, p. 287). Thus, this definition implies notions of interiority or privacy, and disclosure. I will return to these meanings later in this discussion. Weingarten (1991, p.285) emphasises the 'slipperiness' of this human construct, arguing that

Both one's experience and ideas about it - connotes a vast area of thought and feeling. Like so many other aspects of life, the maps one uses to understand, explore, and guide one through the territory of intimacy are changing. Whereas the dictionary can give a definition of intimacy, one's associations to its meanings are much more complex. One's associations, attunement to the word "intimacy" vary with the kinds of meaning - written, spoken, gestural, and symbolic, that one shares.

Writers acknowledge that a major problem in advancing knowledge concerning intimacy has been in circumscribing it as a phenomenon (Register & Henley, 1992). As I formulated my research question, I had an intuition that it would be a difficult term to define. It is the goal of this study to seek the everyday meanings which

couples who've undergone mastectomy attach to the concept, towards advancing knowledge in the field of intimacy and mastectomy research.

Historical Perspectives of Intimacy

We live in an epoch in which intimacy is increasingly valued as a cultural norm within sexual relationships. However Wynne and Wynne (1986, p.384) note that our current historical emphasis on intimacy “ stands in stark contrast to the rarity with which intimacy has been regarded as important in other settings and times.” Amato’s (1986, p. 156) essay, *A world without intimacy, a time before we were intimate individuals and lovers.*, put the subject of intimacy within a materialist, historical framework, arguing that this concept is a comparatively new human phenomenon. Of pre-industrial European peasant society in his essay, he opines-

..privacy - possessed by neither king nor queen nor court nor urban dweller - was as rare as the belief in a personal life of fulfilment. Health, cleanliness and beautification, aids to intimacy in all forms, were scarce. Security, warmth, space, excess calories, and leisure - essential elements for the intimate life - were missing. A full belly was the ever essential and the always temporary condition of having a warm heart.

Amato also observes that right up until the time of the mid nineteenth century, living conditions of three quarters of European peasants comprised of one or two roomed dwellings, which were small, uncomfortable, low, dark and unhealthy. If people had a second room, it was frequently used for stores and/or animals. Unfortunately, Amato doesn't define what is meant by intimacy, but frequently mentions it in relation to privacy, human kindness, and individualism. From this materialist, historical perspective, intimacy has taken a long time to find a place in the popular imagination because even western industrialised nations have only transcended the combined vicissitudes of pandemics, hunger, famine and poor living standards in relatively recent times.

Historians have tended to ignore the experience of intimacy, as history until recently reflects an interest in the power relations between tribes or nations. Historically, these

accounts have frequently been written by historians in politically ascendant or victorious nations, who wrote accounts of and for male populations (see Clark's (1968) *History of Australia* for a case in point). There are few historical accounts of women, or what men or women's *feelings* were. Crawford's (1983) feminist historical research has uncovered documentary evidence from women who lived in pre-industrial England. She found that:

Some women were very happily married, as their letters and comments reveal. They praise their husbands as ' an honest and kind husband,' or a ' prudent, religious, and a loving husband'. Women mourned the deaths of their husbands in moving language. Lady Russell wrote of lacking the dear companion, the sharer of all my joys and sorrows,' lamenting ' I want him to talk with, to walk with, to eat and sleep with [p. 73].

Notwithstanding the persuasiveness of Amato's analysis, it ignores the rich literary sources of concepts of intimacy which sprang out of an educated, more materially comfortable, leisured class. Fiction began as an oral tradition, and it should be remembered that even if people were unable to read, the retelling of tales, fables and biblical stories must have helped shape society, regardless of class. Poetry and fiction is a treasure trove of the tradition of romantic love which began as an oral, sung phenomenon, with the 'romans' of courtly love originating in the sung poetry of the travelling troubadours (Lewis, 1936). Guillaume de Lorris (C. 1240) wrote 4, 058 lines of an allegorical romance in his *Roman de la Rose* , to expound the 'whole art of love.' Chaucer (Prob. 1344-1400) also wrote a version of *The Romaunt of the Rose* , and *The Boke of the Duchess*, in which the art of courtly love is extolled (Harvey, 1967).

In English literature alone, since Sir Thomas Mallory's (d, 1471) enduring triad of King Arthur, Gueneveire and Lancelot in *Le Mort Darthur* through to Shakespeare's well known lovers, *Romeo and Juliet*, Miranda and Ferdinand, (*The Tempest*) Othello and Desdemona, (*Othello*) fiction has opened windows of light on the intimate lives of heterosexual men and women in emotional and sexual partnerships. With the advent of the Romantic Movement in the late eighteenth to nineteenth century, the poetry of Keats, Shelley, and Byron, and the novels of Jane Austin,

George Sand and the Bronte sisters, the exploration of romantic intimacy and passion was extended. For many of these artists, romantic passion lay at the epicentre of their work. Considering Emily Bronte's Heathcliff and Cathy in *Wuthering Heights*, one is hard pressed to imagine a more passionately romantic evocation of intimacy. It stands as perhaps the most intimate fictional relationship of all time. Thomas Hardy (1975) continued this romantic tradition with his tragic novels of sexual passion; Bathsheba Everdene, Sergeant Troy, and Gabriel Oak in *Far from the Madding Crowd*. [first published 1874]; Eustacea Vye and Clym Yeobright in *The Return of the Native* [first published 1878]; Tess and Angel Clare, in *Tess of the D'Urbervilles* [first published 1891]; and, Jude Fawley and Sue Bridehead, from *Jude the Obscure*, [first published 1895]. Hardy revealed human sexuality in myriad permutations, from the romantic to the profane. Early this century, D. H. Lawrence wrote eroticised accounts of heterosexual intimacy, in sensitive (though essentially masculine) accounts of psychic and sexual relationships.

Humanistic Concepts of Intimacy

Erikson (1963) viewed the attainment of intimacy as a developmental goal in early adulthood. He viewed the person as striving to resolve a conflict between intimacy and isolation. People who cannot commit themselves to a loving relationship, because they fear being hurt or are unable to share, risk being isolated. Studies indicate that an intimate relationship with a supportive partner contributes significantly to a person's emotional well being and health. People who have someone to share their ideas, feelings and problems with are happier and healthier than those who do not (Truapmann & Hatfeild, 1981).

While Erikson's concept of adult relationships infers an either/or paradigm, Orlofsky, Marcia and Lesser (1973), postulated that people could be classified into intimacy status groups, relating to how they coped with their intimacy crisis, and that such statuses would reflect this person's ability to be intimate. This 'staged' framework is a more workable, flexible model to describe intimate human relations. Depth, commitment and autonomy which characterise a person's closest relationships were used as criteria for individuals within these groups. These groups were: (1) Intimate; committed deeply to a relationship, and having autonomy..(2): Pseudo-intimate -

committed to a relationship/but lacking in depth; (3) Pre-intimate - one or more relationships having depth/autonomy but are lacking in commitment; (4) Merger - committed and deep relationship without equal autonomy; Stereotyped - the person has numerous relationships without commitment depth or autonomy; and Isolated - the person is socially withdrawn, with no close relationships.

The psychological literature has focused on the value of self-disclosure as an important step towards building intimacy with others (Waring & Chelune, 1983), and this is also evident in popular literature. Howell and Conway (1989) cite research related to self-disclosure suggested that positive emotional disclosures are considered more appropriate, are more likely to be made and are reciprocated to more often, than negative emotional disclosures. This suggests that intimacy rests with positive rather than negative interactions. Howell and Conway studied 30 male psychology undergraduates (who were blind to the research hypothesis) in order to test two hypotheses, (1) that negative self-disclosures are perceived as more intimate; and (2) that if intense, both positive and negative disclosures are viewed as more intimate. The results of this research upheld the hypothesis. Their single sex survey was an acknowledged limitation. For this small male sample then, negative disclosure is viewed by some as a necessary part of intimate experience.

Weiss (1987) however, posits that the research concerning the efficacy of personal disclosure as a means to attain intimacy, infers that interpersonal privacy is an obstacle to intimacy. He views the two concepts as interdependent (“a part and apart”) rather than oppositional. He introduced the notion that intimacy is necessarily circumscribed by personal boundaries and privacy, and that mutual respect, value and intimacy come from respecting these boundaries. In support of this stance, Weiss (1987, p.123) cites Brown (1979), who wrote of intimacy “as a courtship dance” which waxes and wanes in relationships thus -

The prerequisite for “letting someone in” is the certain knowledge that one can “keep them out” and - if need be - throw them out if they prove ungracious. Thus, the best playgrounds have fences and a secure gate, which one can open and close at will and lock if necessary.

Weiss' argument appears to elaborate Erikson's theory. Erikson's ideas incorporated elements of privacy within the concept of isolation, but his developmental theory involves dichotomous, rather than co-dependent concepts.

Notions of closeness and distance were a frequently recurring theme in the literature search. Ridley (1993 p. 251) picks up on this human tension between what marital and family therapists call 'distance regulation' around the need for and fear of intimacy, maintaining that there may also be a need for and fear of separateness within couple relationships. Ridley (1993, p. 251), posited that there were four areas of closeness and distance men and women could pursue in the quest for intimacy. These are; sexual closeness; physical and non-verbal closeness; emotional empathy and operational closeness (sharing of tasks), but cautions that operational closeness is mediated by the complex interplay between the need for separation and independence and the need for closeness. Academic awareness has grown in relation to this need for and fear of separateness and intimacy, and more recently feminist authors have contributed theories on gender differences between intimacy perceptions.

Feminist Interpretations of Intimacy

More recently, Dowrick (1992), has suggested that the concepts of intimacy and solitude are interlocked, for, in sharing intimacy with someone and in sharing solitude, one needs the ability to 'let go,' to feel the personal freedom and confidence to be assured in one's sense of self, and paradoxically 'the other,' we become when we form relationships with others. In this sense, 'our other within' is our reflected appraisal of the beloved.

Translating your perception of intimacy from something which is happening between two people while you remain shut out, to something which is within you and which can embrace other people, will not be achieved by a simple act of will. But a simple act of will - of goodwill - can begin the process (p. 244).

Dowrick believes that people who strive for intimacy should be open to intimate moments and encounters, recognise the unexpected faces that intimacy may reveal, and forego preconceived ideas about what intimacy should or could be. This position

is similar to that taken by Weingarten (1991) , who eschewed sexual prescriptions as the hallmark of intimacy, and urged that therapists highlight behaviours which evoke feelings of intimacy in their clients.

Feminist theory has provided insight into gender differences in separateness and connectedness in relation to others. From her analysis of psychoanalytic literature Chodorow (1978, p. 69) argues that men and women have a different psychology. Explaining this, she states-

From the retention of pre-oedipal attachments to their mother, growing girls come to define themselves as continuous with others, their experience of self contains more flexible or permeable ego boundaries. Boys come to define themselves as more separate and distinct, with a greater sense of rigid ego boundaries and differentiation. The basic feminine sense of self is connected to the world, the basic masculine sense of self is separate. This points to boys' preparation for participation in non-relational spheres and to girls' greater potential for participation in relational spheres. It also points to different relational needs and fears in men.

Gilligan (1982), accepting this theory of gender difference, uses Marxist theory to illustrate that post-industrial society conditions men and women into respective positions of alienated worker and child carer. She contends that it is the near universality of the female childcaring role that is responsible for personality differences. She also holds that these differences have implications for morality, positing that while women's sense of connectedness results in a morality of responsibility, men's sense of separateness results in a morality of rights.

Tannen (1990) notes from her research that women and men have different communication styles, and, when faced with emotionally distressing situations men tend to want to solve problems, whereas women will try to listen to the person's feelings without attempting to find a solution. Women, she said, are more prone to private, domestic 'rapport talk', while men are comfortable with public, 'meeting talk.' Tannen's research showed that women tended to tentatively ask questions, while men seek to present themselves as knowing the answer.

Ridley (1993), gives a good example of these different gendered approaches to emotional crises by citing a couple's interaction relating to mastectomy. The woman tries to tell her husband how upset she is about her mastectomy, whereas he tries to solve the problem by suggesting reconstructive surgery. This increases her distress, as he has suggested more surgery, while he feels worried that he has been unable to help. This particular example is one which suggests that a gendered perspective of intimacy would reflect quite negatively on a couple undergoing the crisis of mastectomy, and this study may cast light on this hypothesis.

The Brain Sex Theory

Moir and Jessel (1991), posit that behavioural sexual differences relate to hormonal influences from embryonic development, and that as a result of these influences, there are distinct physiological differences between female and male brains, and that these differences are complementary. However, this 'complementarity' seems lacking with regard to their view of how men and women approach sexuality, as Moir and Jessel argue that men want sex and women want relationships. If sharing on a sexual level is part of the intimate experience of couples, then this gender difference in sexual attitude would imply that men intuit intimacy as sex, whereas women use sex to access relational intimacy. While it is certain that hormones play a role in the sexual dynamics of a relationship, it is less certain how pervasive their psychological influence is.

Register and Henly (1992), conducted a qualitative study into the phenomenology of intimacy to discover what ordinary people meant by and experienced as intimacy. They recruited nine females and eleven males into the study. All were white middle class tertiary students, and unlike this research, were not romantically/sexually linked individuals. The themes evinced from the twenty individuals were: (1) non-verbal communication; (2) presence or spirit of other(s); (3) a keen sense of the temporality; (4) partial/complete removal of personal boundaries; (5) a sense of bodily awareness; (6) a sense of destiny and surprise about the intimacy, and (7) a sense of transformation/merging. This was the only phenomenological study of intimacy which I am aware of, and I found it a refreshing change from the stereotypical view of intimacy which prevails within the literature. For example, intimacy was not always

described within romantic/sexual dyads, one was a foster mother's perception of her first encounter with a premature, sick infant, and another related to a veterinarian assistant's experience with a pained, wounded dog. Register and Henly (1992) criticise the modern misconceptions and type-casting of the intimacy experience, as well as the belief that intimacy exclusively relates to people spending lots of time together.

Summary

This review has indicated that there are many possible theoretical frameworks and definitions through which to evaluate the construct of intimacy. These frameworks will be beneficial as a comparative tool in the analysis of the participants own experiences of intimacy.

Theories Concerning the Body

According to the literature, any surgery, accidental injury or disease which affects the integrity of persons' skin, appearance, or bodily dimension can have profound effects on the individual's view of themselves. Since half of the research participants in my study have undergone a surgical amputation, which has a physically mutilating effect, it follows that the women in this study may have had, or may currently have an image disturbance.

While there is much literature related to body-image, apart from Carroll (1981) there is little interest purely devoted to the impact that mastectomy has on this phenomenon, although it is frequently addressed within the umbrella term 'of the psychological adjustment/ impact' of this surgery. Thus, while researchers are always aware that there is the strongest possibility of a disturbance in body-image following mastectomy, they rarely define it, implying that it is a simple, easy-to-understand concept. I would suggest that while the concept of body-image has been somewhat simplified in the literature pertaining to mastectomy, like many abstractions, it is a far from simple concept. It is hoped then, that this study will describe this phenomenon from the perspective of the women who have, or are experiencing a body-image adjustment.

Price (1990, p. 3, citing Schilder) provides a simple definition of body image as “ The picture of our body which we form in our mind, that is to say the way in which our body appears to ourselves.” This is the type of commonsense interpretation which many authors cite in their work. However, Price describes body image as a dynamic construct involving a triad of concepts, these being: i) the person’s feelings of bodily reality; ii) the person’s ideal body; and iii) the person’s bodily presentation. This second construct of an ideal body means that whether the body is damaged or not, it may have significant impact on how the person feels about her body, and her feelings may not relate to her (so called) objective bodily presentation.

Historical Perspectives of the Body

Historically, the body has been assigned different metaphors, and these have been determined by the popular and philosophical thought about embodied being. E. Schilder (1989, p. 30-31) citing Duden (1986) stated that “almost everything ever written can be understood as an embodiment of its time and related to body perception.” The ‘prison-house’ is a Platonic metaphor, and is a result of the belief that the body restricts pure rational consciousness. The body, according to Plato, lures us towards pleasure and desire, away from higher consciousness. The ascetics subscribe to this idea, that the carnal, physical body is the root of restlessness, illness and decay .

While Platonic ascetic thought influenced Christian concepts of the body, conversely the “temple” metaphor (1 Corinthians, 6:19) described the body as a holy vessel, a potentially sacred entity enshrining a divine spirit. The body as a spirited being sprang from the divine (Deutsch, 1993).

The machine metaphor has pervaded Western thought since the seventeenth century, with perhaps its most enduring and tragic literary image being Mary Shelley’s characterisation of the monster in *Frankenstein*. The mechanistic view is the precursor to the modern scientific ‘systems theory’ which seeks to reduce the body to a part of nature. Within the machine is consciousness, via which, according to the mechanistic view, the mind transcends the physical. This transcendence is not viewed religiously,

rather it is something that has been given to us by virtue of being human (Deutsch, 1993).

Closely resembling the machine metaphor, is the “instrument” metaphor, which postulates that human beings have independent wills and ‘use’ their bodies much as they would use a tool or implement to fulfill their purposes. Currently, the cult of the body (as instrument) seems to have achieved an unprecedented ascendancy and diversity in Western civilisation. Examples of this may be seen in athletes pushing their bodies to the limit of endurance, the epidemic of anorexia nervosa/bulimia, and the popularity of plastic surgery. Deutsch (1993, p. 96-97), believes that these latter -

.. dominant, controlling metaphors, in addition to being dualistic in character, are conceptually “static;” they presuppose that the meaning ‘ of the body’ can be spelled out in principle in purely descriptive terms, ‘the body’ referring to an objective given of nature or of experience. This static character is quite typical of the logic of many of our most basic concepts.

As already suggested, concepts of the body are not easy to describe, indeed the further one delves into the literature, the more complex it becomes.

Phenomenological Perspectives of the Body

I would like to explore this complexity somewhat by referring to the etymology of the term body-image and also discuss the scientific and ontological meanings that various theorists have ascribed to it. Moss (1978), contended that the scientific literature of psychology and neurology have developed a group of ‘clumsy and convoluted’ terms to describe the inner awareness the person has of her/his own body and self. Of these terms, body-concept, body cathexis, body-schema, body-ego, and somatognosis are just a few, all of which refer to things relating to the body, as well as things relating to the mind. He also argues that they rather unsuccessfully attempt to unite the apparently dual domains of body and mind into a lived entity.

Moss dissects the view of body-image from past misconceptions which would have us align it with the ‘common sense’ viewpoint of daily life. That is, we suppose that our

view of our bodies is the same (and as disinterested) as an objective onlooker who may gaze upon any object in the natural world. This view pre-supposes that the very sophisticated and specialised intellectual skill of 'objectivity' is the primary basis of all perception and knowledge. Moss says that this skill is the relatively late achievement of the mature adult.

According to this misconception, we start out [in early life] with an objective, disinterested visual picture of the body, and then subjective meanings are stuck on later to produce the body-image. The findings of 70 years of neurological, physiological, and psychological research have long ago undermined this view. Nevertheless, this view has powerful roots in the common everyday view of life - and in the natural scientific world view. It has therefore continued to haunt scientific research long after every trace of evidence for such a theory has vanished [Moss, 1978, p. 75]

The human perception of a reflected, mirror image of oneself or the sight another human being puts the natural scientific view, dominated by empirical, behaviour/response - cause effect analysis into disarray. Indeed, we see an image in the mirror 'reflected from reality,' but very much take from it, or interpret from it what we want to, including our present expectations and our awareness about what others think about our visage. Our selection of details concerning our bodies then, is subject to much more than simply what is so-called "objective evidence" as seen in a mirror.

Rather, Moss (1978, p.77), says that:

The picture we have of our own body then, is not based on a passive visual perception of "what is there". Rather, the picture is built up around those parts of our body which have a special relation to the world of things and of other people.

Moss (1978), purports that we make quite radical distinctions between my own, and all other bodies, and that my body is not able to present itself as an object completely accessible to my perception. However, my body is nonetheless the thing which never leaves me, but which I will never see before me.

My body is also, unlike other objects, something I live and only secondarily know. I act through it, exist through it, perceive the world and others through it, without explicitly reflecting on the body. Thus my body as I live it inhabits the pre reflective realm of the human life-world, and not the objective world which exists for scientific knowledge. We make a strict distinction here, between the objective body as the object external observation and of laboratory scrutiny, and my own body as I experience it, animate it and live it. It is my own body which existential-phenomenological psychology calls the lived-body. It is a body integrated into human life and expressive of character; it is the living envelope of our actions. [Moss 1978, page 77 citing Merleau-Ponty 1963]

Thus, the phenomenological view of the body involves interiority, but as it also involves our peripheral 'envelope', or sensations, this means the body both impacts upon the world, and is impacted upon by the world.

The phenomenological-existential concept of body image posited by Merleau-Ponty then, stands in counterpoint to the received view that the widespread doctrine of natural science research has left us with. This view is so pervasive that it is perceived as common-sense; that all human behaviour can be reduced to stimulus/response, cause and effect. Merleau-Ponty rejects this theory as to how the person perceives his /her body, for he asserts that we don't 'know the body' because of objective learning at all. Rather, he believes we become familiar with our selves /our bodies prior to reflection. So, prior to our 'thinking about our bodies, or knowing our bodies and what the body is/ or is going to do, we exist within our bodies pre-reflectively, and live in a world in which we always have a capacity for action (Moss, 1978).

This pre-reflective familiarity within a body with an innate capacity for action Merleau-Ponty refers to as the lived-body, and the body image is partly the perceived body picture and what he refers to as the body-schema, or the bodies propensity for action. This capacity for animation equates to what the existential phenomenologists call lived-space, a pre reflective, quite different space than the reflective space of physics (Schilder, 1933).

The phenomenologists' view body image (indeed the phenomena of being alive and sensate) as a dynamic concept of being which involves the pre-reflective interiority

of the self, the exteriority of other 'selves' or objects and the disposition for human action within space and time. In this way then, phenomenological perspectives of the body should have good theoretical fit with an analysis of physical disfigurement and how couples' intimacy is affected by it.

Nursing Perspectives of the Body

Many nursing practitioners who work within a philosophy of holistic delivery of care recognise the importance of treating the person rather than the disease. However, there has been comparatively little written of a philosophical nature which examines the different perspective of the body held by the patient and the health care worker. Writers who have successfully done so include, Sally Gadow (1980), Josephine Lawler (1994), and Erna Schilder (1989).

Josephine Lawler (1991, p.2), in her seminal qualitative study of the way in which nurses deal 'with the problem of the body', posits that the body has become 'problematic' on account of - firstly, the fact that it has been interpreted and re-interpreted by the 'organisation of knowledges; "... and secondly by a way of life which has rendered the body private and silent." She asserts that:

The emphasis on empiricism, abstract knowledge and increasing specialisation in the sciences ... have resulted in a theoretical and epistemological fragmentaion of our corporeal and embodied existence. 'The problem of the body' means, therefore, that, although a social and human body is integral to our existence, no discipline has yet accommodated it, except in pieces. The body has been subjected to reduction, and so too has our knowledge and experience of the body in social life. The body has been subjected to reduction[via studies in medicine, pathology, physiology, biochemistry] and so too has our knowledge and experience of the body in social life [via via studies in sociology, psychiatry, anthropology, and neurology]. Our understanding of the body has been constructed in terms of the seperate body and mind, and not one entity of body and mind (Lawler, 1991,p.2).

While Lawler opines that the nursing literature tends to subsume and privatise the body, she says the opposite is true of nursing practice, in which the body and mind are

acknowledged, but that nurses intimate work with patients' bodies presents them with real social difficulties in practice and in life, as a result of the privatisation of the body, and the relegation of nursing as women's 'dirty work.'

Erna Schilder (1989, p. 30-31) is also critical of 'Systems Theory' of the body, and argues, citing Duden (1986), who uses the metaphor of a layer-cake to describe the physical science approach to the body:

Each profession extracts the layer defining their turf and reads it like a sheet of music as if it constitutes the totality of human experience. ...

The assumption that the lived embodied experience is a mental representation that can be expressed and put into words, is creating a conceptual framework which closes off the access to 'nameless' sensations. A whole industry has sprung up to serve the idealised cultural image of the body... This visual mental model of a person is of rather recent vintage. Duden [1986] stated that almost everything ever written can be understood as an embodiment *of its time and related to body perception. On the other hand, reflections that concentrate directly on the 'Gestalt' of the human body in a given epoch are rather scarce.* [My italics].

However, Sally Gadow (1980) wanted to raise nurses' awareness of the patients 'Gestalt' although she didn't use this psychological metaphor. She contributes to the philosophical debate concerning the corporeal and the existential body in the clinical setting. She examines the difficulties nurse clinicians have in ameliorating the differences between what is felt by the patient (about the patient), and what is perceived by the nurse/doctor (concerning the patient). Her work has come close to theoretically unravelling the 'existential puzzle,' or what Lawler (1991) called 'the problem of the body' contained within this difference. That is, how does the person standing outside another, understand herself as a unique, 'interiorly-lived' person as well as an objectively realised human being. Gadow is sensitive to the alienating effects health consumers face when they seek help, and she highlights the different philosophical perspectives that patients versus professionals hold in regard to the body.

Gadow expands on the difference between the phenomenological concepts of the lived body and the object body. The object body is familiar to all clinicians, who, when examining the human body (as opposed to the essential person) categorise physical phenomena and assign medical 'labels' to signs and symptoms. According to Gadow (1980 p.94-95);

The immediacy of the lived body is only partly mediated by illness, injury, or pain. With the appearance of incapacity, one experiences the body as something which opposes his purposes, a weighted mass, a thing-like other.

Gadow contends that the lived body is mediated by injury or pain into feelings of otherness. She also says that incapacity 'shatters the lived body.' This suggests an evanescent, unmeasurable component of human vitality and health than that arrived at via systems theories.

Gadow purports that the lived body is overtaken by the object body in the practice of modern Western medicine. The lived body is 'partly mediated' by pain or injury, but once symptoms and scientific tests have been interpreted, then:

The clinical view presents the patient with a body that is not his or her own, [but] a disease process of which the patient has no direct perception. But, the new reality is objectively discernible to others. "Others have informed me of it, others can diagnose it; it is present for others even though I am not conscious of it"

This then, is the discrepancy between lived and object body, generated for the patient, first by the experience of incapacity and second, by the experience of science (Gadow 1980, page 95)

While Gadow's arguments provide a theoretical basis for much of the psychological unease or distress people face when they seek medical help, given a background on which the predominant focus is the physical treatment of the disease, it is perhaps more likely that the patient will be unwilling to share any 'trifling' physical or emotional concerns with others. Interestingly, Gadow believes that (with special

nursing care) the insult to the body can allow for a more integrated person in whom the lived body is enriched by the object body, and the object body is enlivened by the lived body. "The person 'recovers his/her objectified body at a new level which is neither pure immediacy nor pure otherness, but an otherness-made-one's-own, a lived objectness'" (Gadow 1980, p.96). There are obvious implications for nurses and all health care professionals in this. Gadow implies that if not treated holistically, patients may be left with feelings of being 'thing-like, and alien' and fail to integrate their experience into a sense of wholeness.

Since the work of Merleau-Ponty, feminist philosophers outside the field of nursing have also contributed to a fresh perspective to the debate on the body (Grosz 1995, and Young,1985). Many feminist writers espouse the phenomenological approach, and find Merleau- Ponty's work groundbreaking. However, they are critical of what he and his predecessors wrote in relation to human experience and bodies; that is, they wrote in universal terms, which assumed that men and women experienced the world in the same way as men.

Feminist Concepts of the Body

Deutsch, (1993); Gadow ,(1980); Merleau-Ponty, (1964); Plugge (1970) and Spicker (1976) all speak of the body in existential/phenomenological terms of the 'lived body', and 'the object body.' There is a paradox in these terms, as Young (1985) points out, for these same existential phenomenological terms refer obliquely to an attachment to idealist forms of 'mind-body' duality that existential phenomenology purports to succeed. Gadow referred to the body as 'object' only when it was vitiated by pain or dis-ease. Implicit in this notion of the lived-body then, is the idea that it is 'body-transcendent.' Young objects to these terms as having a gender bias as they purport to account for human experience universally. She believes that:

The experience of pregnancy and motherhood challenges the way Western philosophy has typically described the relationship of self and other as opposition and confrontation. In pregnancy the relationship of self and other is experienced not as negation, but as continuity in difference. The diary of a woman quoted by Rich expresses this sense of I-other

continuity. "I was one and the other at once. Could I control its movements with my will? Sometimes I thought I could, at other times I realised it was beyond my control" (Young, 1985, p. 29).

Young suggests that the lived experience of the pregnant body challenges Western philosophical attitudes to the body because the woman is both a source and a participant in a creative embodied process. There is a splitting of the 'self' (in pregnancy) because self involves 'other', ' but the 'other' is me, or, part of my body.

In pregnancy, Kristeva suggests, the multiple character of all subjectivity enters experience itself. "Pregnancy seems to be experienced as the radical ordeal of the splitting of of the subject: redoubling up of the body, separation and coexistence of the self and an other, of nature and consciousness, of physiology and speech (Young 1985, p. 28, citing Kristeva 1980).

The notion of the body as a mere instrument of my projects falls apart in pregnant subjectivity, for the body is on its own journey in time, and, over time, its very shape, weight, movements and feelings change. Young synthesizes Kristeva's psychoanalytic theory of pregnancy, coupled with the spirit of phenomenological research in analysing diaries and literature concerning pregnant subjectivity. She theorised that the lived pregnant body -

.. reveals a mode of body existence in which the borders between self and other, subject and object transcending action and attention to self, come into question and dissolve (Young, 1985, p. 28).

While it may seem that Young's philosophical musings concerning the body are not a little abstruse, they are nonetheless intellectually exhilarating, and, her argument resolves the inherent conflict of subject/object duality which the phenomenologists of the body espouse. Furthermore, she articulates the differences in experience that arise from different bodies, namely male and female bodies.

Grosz (1994), believes that 'psychic investment' in our bodies or various parts of our bodies is a result of learned socio-cultural values, shared familial experiences and

fantasies concerning bodies. Although her thesis concerns a philosophical study of the 'corporeality' of bodies, her ideas I have paraphrased could have referred exclusively to the female breast, for it has become a pre-eminent symbol of femininity in the Western world. Viewed objectively, this could be seen as surprising, given the lack of status attributed to child rearing and the horror with which public breast-feeding is quite frequently seen. In Western culture, breasts have become revered not so much as functional organs which play an enormously important role in the sustenance and comfort of babies, but rather as sexually charged organs, made for the pleasure of adults.

While it may seem too obvious to mention, the human body is invested with different abstract meanings, and these meanings are objectified in our hygiene practices and social taboos, our clothes, our hair, and our behaviour. Those body parts which play a central role in our lives may become a major focus of our individual body-image, such as our eyes or hands, or, physical attributes which infer social attractiveness, such as a man's physique or woman's figure or hair may also become a central part of the personal body-image (Grotz 1994) A body deformity has the effect of stigmatising the person as different than the social group, which may have the effect of her rejecting the affected area from her body-image, or giving it a central place in the self-image beyond its visibility for others. It is not difficult to understand just how problematic the adjustment of body-image could be for the women in this study who undertook such radical surgery.

Ussher (1991, p. 23) comments on the media bombardment of images of the breast in this way:

The promotion of these images of 'perfect' breasts makes the average woman feel imperfect, and makes her conceptualise her visible breasts - rather than her less visible vulva, - as her main erogenous zone ... Young women fear that their breasts are too large or too small; not the 'right' shape; the nipples not the 'right' size. Satisfaction is rare.

Ussher makes the point that in society women rarely perceive their breasts as 'normal' because the image that average women have of breasts is the so-called 'perfected

glamorous' representation. However this stereo-typed image is no more representative of the diversity in shape, colour, size and texture of women's breasts through the lifespan than are those of a barbie-doll. The same author claims that this preoccupation may result in mastectomate women requiring psycho-sexual counselling after breast surgery. Of course, this need for counselling has been long acknowledged, but what of the complex feelings that fashion and refashion the mental image of one's own body? If women are less than pleased with their normal breast shape, then it is little wonder that some women have significant disturbances in their body image following surgery, not withstanding their knowledge of surgery as a life preserving act.

Neuro physiological and Psychoanalytical Constructs of the body

Grosz (1994) observed, that while there has been some theoretical literature examining the complex notion of phantom experience, much of it seems to involve a neurophysiological analysis and is quite complex. Schilder's seminal work on the body-image in the 1920's and 1930's followed Sir Henry Head's neurophysiological concept of a postural model of the body, which he developed as a result of his study of aphasic patients. According to Grosz (1994), Schilder's work was influenced by Head's theories, but was based more on the tenets of psychology than neurophysiology. It is worthwhile to include Schilder's (1979, p. 62) psychological analysis of the phenomenon of phantom limb at length, as it further clarifies the body disturbance due to surgery.

It is clear that the final picture of a phantom is to a greater extent dependent on the emotional factors and the life situation. Probably, the way in which the schema of the body is built and appears in the phantom has a general significance. It is a model of how psychic life in general is going on. Something is happening in the periphery of the body. But only the interaction between the periphery and the centre [consciousness] makes the final appearance. This interaction is based upon the playful multiplication of psychic experiences. The shaping of the experiences repeatedly uses actual sensations. but the real meaning, the real significance of an experience is due to the emotional attitudes, or, in other words, to the life situation. Our own body and the image of our own body is, of course the object of the strongest emotions. After the amputation, the individual has to face a

new situation, but since he is reluctant to do so he tries to maintain the integrity of his own body. According to Riese, the phantom is the expression of a difficulty in adaptation to a sudden defect in an important peripheral part of the body.

I agree with Schilder when he claims that, the real significance of an experience is due to the emotional attitudes, or, in other words, to the life situation. Our own body and the image of our own body is, of course the object of the strongest emotions, and these phantom emotions are the so- called 'externally felt' and internalised result of trauma to an important part of the body. Even while it may be unlikely that any women in this very small sample will describe phantom breast symptoms, because mastectomy involves amputation, his observations concerning the linkage of physical and emotional responses to radically injured bodies has particular application to the analysis of body-image following mastectomy.

Schilder (1950) also tackles the problem of pain, (or, as I would prefer to call it alteration in comfort when applied to feelings such as numbness), and how these feelings impact upon the psychic body image of the person.

When we suffer from organic pain, the model of the body changes immediately in its libidinous structure. All energies now flow to the diseased organ, as Freud and Ferenczi have emphasized. The postural model of the body is overloaded with narcissistic libido in the aching part. Paraesthesias and bodily discomfort have of course an effect very similar to that of pain. With the erotic, a change in the perception goes on The aching organ becomes a centre of renewed experimentation with the body. It takes a part usually taken by the erotogenic zones (p. 126).

While this psychoanalytic, 'eroticised' interpretation of bodily pain is somewhat perplexing, it does highlight just how self- absorbed the pained person becomes with her/his pain. Schilder infers that pain alters the person's 'body mapping' and invests meanings to bodily areas, which the individual was hitherto unaware of.

An Empirical Study into Body Image

The only empirical study of body image was conducted by Secord and Jourard (1953), in which they appraised the body-cathexis of body perceptions and the self. By body-cathexis, they meant the degree of feeling of satisfaction or dissatisfaction with the various parts or processes of the body. They tested three hypotheses: (1) feelings about the body are commensurate with feelings about the self; (2) negative feelings about the body are associated with anxiety, in the form of undue autistic concern with pain, disease or bodily injury, and (3) negative feelings about the body are associated with feelings of insecurity involving the self. The questionnaires were based on Schilder's (1938) earlier semi-objective questionnaires probing feelings and body awareness, the use of a homonym word-association test, and Maslow's test for measuring psychological security/insecurity. All three hypotheses were upheld by statistical analysis. This is a very small study (47 males and 43 females), and it needs to be replicated now with a larger population to enable us to make useful generalisations in this study. It does give evidence of quantifiable valence between body and the self-image.

Summarising the exploration of theories and research concerning body-image, it is clear that the body is a complex phenomenon, which can be partly understood by utilising different constructs. These ideas will provide a framework to assist the reader in integrating and understanding the meanings which men and women affected by this surgery attribute to breast amputation.

In conclusion, from the review of the literature, it is clear that the study of intimacy, mastectomy and body-image are integrally connected within the context of the sexual partnership. When couples are so closely linked to one another in terms of their sharing bodily lived time and space, any impact on one person's emotional or physical status is bound to be reflected in both partners. This Chapter has revealed that mastectomy is a complex event, both in terms of the physical, sexual and emotional consequences to women and their partners. As relatively little is known about the shared experience of couples following mastectomy, as the people experiencing these events describe them, this study will shed light on the mundane and the extraordinary stories of men and women, to elucidate the sense they make of this phenomenon

CHAPTER THREE

Methodology

Methods are like maps: They focus inquiries and lay out paths that, if followed, are supposed to lead to valid knowledge of how the world works. But like maps we consult in everyday life they contain assumptions about what is important. Different maps make certain features in the terrain visible, and obscure others ... Not objective pictures, maps are instead representations of reality that reflect the interests of the map maker, a point of view.... Like research methods, maps are powerful tools for making statements about social life, different ones connect us to realities we could not know without the map (Riessman (1994) cited by Bill Healy 1996, p. 72).

The Paradigm

A qualitative design within an interpretivist paradigm was selected to explore the intimate experience of couples following the woman's mastectomy. The interpretivist paradigm aims to elucidate meaning from the unique perspective of the persons experiencing the phenomenon, in context specific detail. This chapter will discuss the meanings and broadly delineate the differences between qualitative and quantitative paradigms, before discussing the qualitative methodology, and some of the philosophical tenets which are integral to its genesis. This same discussion will be enclosed within the format of a debate centering on the work of a phenomenological scholar, and address how this research proceeded in the light of this debate. This will be followed by a step-wise description of the research, the data collection process, the 'doing' of Colaizzi's (1978) methodology, a discussion concerning reliability and validity, and finally, the ethical dimension of the study.

While there is currently much debate as to the definition of a paradigm, and the appropriate division of different perspectives into paradigms, this thesis has taken the position advocated by Knaack (1984) and C. Oiler (1985) in which only two paradigms are identified. This is not to suggest that both perspectives are, or should be mutually exclusive within a research design, for researchers have frequently employed both paradigms to complement their research.

Referring to Riessman's (1994) quote at the beginning of the chapter, the metaphor of the map relates to research paradigms as well as to research methodology. A paradigm refers to a particular way of looking at the world or, as Patton (1990) believed, a way of simplifying or revealing the complexity of the world. Obviously, there are infinite varieties of world views held by individuals and/or intellectual, religious, political or social groups across the world, but for the purposes of research, there are presently two quite different perspectives available to the researcher interested in inquiring into human behaviour.

These two paradigms differ significantly in many ways, and are known as logical positivism and interpretivism, and essentially reflect very different understandings about the nature of reality. Colaizzi argues that the historical roots of logical positivism began many centuries ago, developing over the course of history but rapidly taking shape around the time of the Renaissance, a time in which religious certainties of life were undermined (Colaizzi, 1978). As religious authority eroded, metaphysical views were seen as fallible, particularly if related to matters of scientific inquiry. As a consequence, an increasingly sceptical attitude in thinking developed within philosophical circles. After Galileo's discoveries and later, the philosophy of Descartes, revealed that all material things, being 'given us' by perceptual experience, could be quantitatively measured by mathematical formulae, the schism between theory and experience became severe (Colaizzi, 1978). While this gradual, historical shift to scientific materialism provided huge fillip to human discovery and progress, it nonetheless demeaned human experience, because it could not be observed, measured or 'objectified.'

Since the quantitative conceptualisation of physical objects lends greater exactitude and precision to them than does viewing them experientially, the quantification of

physical objects quickly acquired scientific supremacy over experience. And since conceptual quantification is an event of knowledge and a mode of theory, experience was almost entirely displaced by theory. In all dealings with physical objects, experience was doubted and distrusted. Physical science began as the relegating of experience to an ever so untrustworthy, unreliable and insignificant role, dispossessed of scientific validity in favour of theory, especially in terms of quantified, precise and exact theory (Colaizzi, 1978, p. 50).

This intellectual discipline of scientific materialism, evolved and gained legitimacy as the only truly scientific means of inquiry. In some ways, this was perhaps not so surprising, as in the Western philosophical tradition, the scientific revolution has spawned previously undreamt of benefits to humanity, particularly in terms of overcoming infectious disease. In the Nineteenth Century, men (and very few women), unlocked the secrets of the human body with studies of pathophysiology and microbiology, and the objectification and reductionism of the human body became institutionalised in a separate and increasingly influential institution - medicine. Positivism became widely accepted in the Western industrialised nations as a philosophical basis for knowledge and scientific inquiry (Chung & Nolan, 1994). Nurses were also in the vanguard of the push towards knowledge built on these mechanistic assumptions, following the lead of medicine (Munhall, 1989).

Fritjof Capra (1982), also wrote about the schism between theory and experience. The apparently irreversible split between the two paradigms was 'blown out of the water' by the new physics in the first half of the century, but even so, biomedical scientists up until the the 1960s elaborated mechanistic models of health and illness. Then the subatomic and atomic physics finally revealed the limitations of a mechanistic world view and moved to an organic/ ecological concept of reality, for twentieth century physics views the universe no longer as a machine, but as a complex web of inter-relationships. This 'new science' acknowledged that subject and object are not separate, but inter-related. In this sense then, there is a clear understanding that the experiment/experimentor is effected (or related) by the experimentation process. In his critique of the mechanistic approach of the medical sciences, Capra contrasted nursing as a humanistic, holistic alternative to traditional medical care.

For centuries, science dealt with inanimate objects or the depersonalised, objectified aspects of human existence, and investigated them experimentally. Investigative psychology began in 1879, when “Wilhelm Wundt gave birth to scientific psychology and baptised it with the experimental method (Colaizzi, 1978, p. 50)”. Logical positivism maintained a virtual hegemony in North America studies until the 1960s, when psychologists became aware of the European phenomenological movement, and applied it to their own study of human experience

The other human research paradigm is known as interpretivism. The interpretivist paradigm employs qualitative rather than quantitative methods and seeks to uncover the meaning of human phenomena by analysing the subject’s responses and descriptions within their own environments. The interpretivist perspective represents the view that humans are not objects of experimentation, but sentient beings with values, beliefs, desires and purposes which, when investigated require empathic understanding by the researcher, as opposed to objective detachment. This is opposed to the idea that the researcher aims to control, explain and predict human behaviour that characterises the positivist view (Howe, 1988). The phenomenological researcher uses qualitative and humanistic approaches in order to inductively and holistically understand human experiences within specific situations. Knowledge gleaned from human experience is expanded by allowing the phenomena to show itself without reference to the predictive prescriptions of experimental methods (Parse, Coyne & Smith, 1985). The goal of qualitative research is to gain a deeper insight and knowledge into human experience in order to improve the human condition.

Summary

The qualitative, interpretivist approach is the most appropriate for this study, as couples’ feelings, perceptions and experiences of intimacy following mastectomy cannot be quantified, and need in-depth analysis in order to improve health care worker knowledge and improve support.

Philosophical/Methodological Angst within the Dynamic Process of “Thinking about”and “Doing” Phenomenology

Before I set myself the task of writing this chapter, I had in mind it would amount to a rather straight- forward revision of my earlier readings into qualitative nursing research, scanning new publications, and ‘writing it up’ the classic academic style. However, this approach would certainly not have indicated the difficulties I had encountered as a neophyte researcher. So, at that time, I had a fairly clear idea of ‘a censored version’ of my relation to phenomenology, but, since reading Michael Crotty’s (1996) book, *Phenomenology and Nursing Research*, this initial approach has been jettisoned. Crotty’s work rekindled my interest and doubt concerning what I perceived were innate difficulties involved between the philosophy and ‘doing of’ phenomenology; and particularly, how nurses applied philosophic tenets to their research activities. These questions I had frequently ‘mulled over’ in my mind, but had no prior exposure to the keen analysis with which Crotty approached the phenomenological movement within nursing. Thus, while I had anticipated writing in the omniscient voice, the nature of my recent enquires have been so personal, so linked to the ‘whys and wherefores’ of the ‘doing of phenomenology,’ that I have returned to the subjective voice, as, in the end analysis, my interpretation of phenomenology and the data has to be seen as valid. Indeed, the following chapter ‘sets sail’ into a critical journey, (though by no means an exhaustive one), into phenomenology within nursing, and the nature of subjectivity which seems to plague phenomenologists.

Hence, I stand in debt to Michael Crotty, whose critical acumen lured me into this debate. This scholar, who lectures in education and research studies in the Faculty of Health Sciences at Flinders University in South Australia, is an educationalist, with a thirty year long interest in phenomenology. His thesis challenges the ‘received view’ of thirty nursing phenomenologists who believe they have undertaken phenomenology in the sense originally intended by the philosophers they cite. He believes that nurses (following the lead of American social scientists) are unaware they have inherited an altered (or new) phenomenology far removed from the tenets of the foundation (or mainstream) phenomenologists. From within the perspective of the new phenomenology has unwittingly laid itself open to charges of a radical

departure from the its qualitative research stance of objective science a realm of subjectivity. These challenging ideas have assisted me to organise my former, somewhat inchoate thoughts about the subjectivity debate, and have invigorated my search within the nursing and philosophical literature.

This chapter then, will briefly explain some of the central ideas of those phenomenologies most utilised by nurses, that is: Husserl's transcendental consciousness; Heidegger's ontological/ hermeneutic approach to human being (or *Dasien*); and the existential ontology espoused by Merleau-Ponty. Within these explications, the debate raised by Crotty will be woven into the fabric of the dialogue as I uncover the genesis of my thought in relation to phenomenology and the issue of subjectivity. My hope is, albeit with the weight of scholastic opinion to reinforce my argument, to give the reader a 'whirlwind entree' into the phenomenological realm of thought, while being solidly grounded as to where my interpretation of the phenomenological philosophers lies in relation to the 'working through' of the philosophy in research that is meaningful to nurses, or people interested in social science. Put more simply, I attempt to illustrate how I have integrated phenomenology into my research practice.

Firstly, how is phenomenology defined? Palmer (1969, page 127), invokes Heidegger's definition, derived from the Greek roots of the word;

.. phainomenon or phainesthai, and logos. Phainomenon, Heidegger tells us, means "that which shows itself, the manifested, revealed." The pha is akin to the pho, meaning light or brightness, 'that in something can become manifest, can become visible.' Phenomena, then, are, "the collection of what is open to the light of day, or can be brought to the light."

Heidegger's definition of phenomenon is itself suggestive of an uniquely human 'discovery' involved in phenomenology. The process of discovery usually involves mental discipline and hard work before the discovery makes itself manifest. In this sense, much of the literature pertaining to phenomenology is a quest, of trying to uncover the enigma of human experience within the complexity of language. Palmer (1969, p. 45) makes the point that our speech reveals our humanity thus;

Philosophy today is already focused on language; it is then, already, in a sense, a hermeneutics; the challenge is to make it creatively hermeneutical.

The nursing literature on phenomenology and its methodology is often reported as a philosophical rather than a prescriptive approach, as phenomenology is both a philosophical movement and a research method, in which the main aim is to describe and scrutinise phenomena as they are consciously experienced (Anderson, 1989; Oiler, 1982; Omery, 1983, Spiegelberg, 1960). Thus, phenomenology is the study of “lived experience” insofar as it attempts to understand the meaning of what it is to be human, what it is that is experienced when people perceive the world. Phenomenology seeks deeper understanding of the nature or essence of day to day existence (Merleau-Ponty, 1964; Oiler, 1982; van Manen, 1990).

Phenomenological method does not attempt to predict or control behaviour, nor to discover causal relationships, but rather interpret and understands phenomena by describing, analysing and intuiting (Keen 1985).

As a method of inquiry, it first appeared last century in the work of the philosopher Franz Brentano (1838-1917) an outstanding philosopher and psychologist. It was Brentano who first coined the word, ‘phenomenology’ as an alternative to a course he gave called descriptive psychology (Crotty, 1996). Somewhat ironically, Brentano described himself as an empiricist, and his leanings were towards psychology rather than philosophy. He wrestled with the problem of making a distinction between physical and psychic phenomena. In working through this question of ontological duality, he invoked a medieval term derived from religious Scholasticism which is ‘intentionality’ or mental in-existence. By this Brentano meant;

.. intentional in-existence is characteristic exclusively of mental phenomena. No physical phenomenon exhibits anything like it . . . What is intentionality, then? It is the idea that, as Brentano pointed out, every thought is a thought of something... consciousness is always and essentially related to objects. In short, there is an indissoluble union between subject and object Crotty, 1996, p. 37)

In outlining the key concept of intentionality, Crotty does not suggest that phenomenologists believe that subject and object are the same, but rather that subject and object are bound inextricably with one another. In this way, he argues that phenomenologists reject the Cartesian, Newtonian dualities of the separateness of subject and object. For the phenomenologist then, the world doesn't exist outside of consciousness (Smith, 1983). The concept of intentionality seems to be the very foundation stone on which phenomenology rests, and Crotty (1996, p. 41), cites other scholars to reinforce this point:

as Calvin Schrag observes “Heidegger is at one with Brentano and Husserl in his view that intentionality is the presupposition of the phenomenological method” . . .

Later phenomenologists continue this emphasis. We find Natanson describing intentionality as ‘the axis of phenomenology’, while Ainsley asserts its “undeniable centrality to phenomenology”, claiming that the initial intent of placing intentionality at the nexus of the phenomenological approach was to save it from the errors of both dogmatic objectivism and subjectivism.

The ontological significance of intentionality is not lost on Merleau-Ponty, who envisaged humans as embodied beings-in-the world, and that human action and experience could not be separated. Moss (1978), whose interpretation of phenomenology derived from the work of Merleau-Ponty, commented on the tendency of psychologists who have often assumed that the existential phenomenological approach reverses the behaviourist paradigm because it studies what they believe is the internal or ‘mental’ attitudes of the person, which are inaccessible to observation. Actually, what the phenomenologists attempt is to study the whole individual, both as an embodied person and as a person living and interacting with the world. Again, for the phenomenologist, the mental (subjective) life and the embodied (objective) life cannot be understood independently (Moss, 1978).

The early European Phenomenologists (who Crotty referred to as ‘mainstream phenomenologists’) had in common their insistence on the description of human phenomena stripped bare from the preconceptions and presuppositions of everyday existence and the imposed meanings and values ascribed to such phenomena. They

believed that it was these accreted, socio-cultural beliefs which resulted in distorted perceptions of human phenomena. Husserl strove to describe with an almost empirical fervour the very essence of the subject's experience (of the object or phenomena under study) in a pre-reflective, primordial way, that is, as immediately experienced. To do this, Husserl borrowed a technique from his former discipline of mathematics, and elected to 'bracket' (Mitchell & Cody, 1993) *his* (not research subjects) preconceptions in order to faithfully describe the objective phenomena in a totally spontaneous, bias free way (Walters 1994). Husserl and Heidegger called on researchers to 'get back to the things themselves', and similarly Spiegelberg strove to return ". . . to the unadulterated phenomena ... to the pristine innocence of first seeing" (Crotty, 1996, p. 204). Likewise, Merleau-Ponty wanted to recapture 'a direct and primitive contact with the world.' Thus, European phenomenologists strove to describe human phenomena in its raw sense, untrammelled by reflective cognition, they strove to capture our experience as it is immediately given to us - that is before we make sense of it. This technique of the bracketing of prior knowledge and assumptions in the subject of the study, is a crucial element which underpins mainstream phenomenology both as a philosophy and a research methodology.

Thus, bracketing is always described in the research literature and, while most nursing scholars mention the lack of conformity in phenomenological approaches, to my knowledge Crotty (1996) is the first recent non-European scholar who has systematically critiqued the philosophical and methodological implications of the radical changes between the first, European (which he calls 'mainstream') phenomenologists, and the 'new' North American phenomenological movement. Thirty years ago, Natanson (1966, p. 3), wrote trenchantly about the philosophical misunderstandings underpinning non-European phenomenologist's beliefs:

.... misunderstandings of Husserl's method and outlook are the rule rather than the exception in Anglo-American circles. But there is a totally different kind of reason for the failure to understand and appreciate the phenomenological philosophy ... and that is the rootedness of both the commonsense and most non-phenomenological philosophy in what Husserl calls the "natural attitude." The central effort of phenomenology is to transcend the natural attitude of daily life in order to render it an object for philosophical scrutiny and in order to describe and account for its essential structure. Common sense and

those philosophies which share its fundamentally naive, realistic view of the world are defined, phenomenologically, by their urgent yet implicit protest against such an examination.

From the European standpoint of Natanson, the anomalies in the anglo-American phenomenology are so glaring as (Natanson infers) - to be non-phenomenological. Why have nursing phenomenologists not given any attention to the fact that there is a very significant difference in the way that the Northern American existential phenomenologists and their European forbears have interpreted bracketing? Crotty finds this omission somewhat baffling. When he analysed thirty phenomenological studies of well known nurse researchers, he found that while many recognised the work of Husserl, Heidegger and others, they failed to observe the quite different techniques of bracketing undertaken by North American interpretations of phenomenology. Unlike the foundation phenomenologists, influential American scholars (Colaizzi, 1978; Goirgi, 1970; van Kaam, 1969) bracketed the assumptions and presuppositions of the researcher, which, to my mind, must have altered the complexion of the phenomena under study, in the sense that it would not elicit from the person studied a direct, primitive, pre-reflective reaction to the world. This is not to say that meaningful phenomena could not emerge from data collected in this manner, but that the 'bracketing shift' away from the 'researchee' surely points to an increased difficulty in eliciting such pre-reflective 'phenomenological essences.'

I reiterate my debt to Crotty, as his work has had the effect of clarifying the considerable disquiet I have had in my own readings of the philosophical literature - most particularly as it applies to this study. Nurse researchers do not address the issue of the pre-reflective aspects of describing phenomena, and I was perplexed about how the post-mastectomy phenomena of intimacy could be described in anything but a reflective manner. I assumed that the potential for the 'abstraction' of the meaning of intimacy, (and sometimes, mastectomy) made the task of pre-reflective description an almost insurmountable burden. Since analysing the data, this assumption is partly right and partly wrong. It is partly right because the participants' conceptions (definitions) of intimacy following mastectomy were described in a largely positive light, while they were expressed within an awkward, embarrassed, haltingly reflective way. Almost all the participants explicitly revealed that the mastectomy had not

affected their intimate lives. On the surface level of inquiry, this reflective attitude of the participants' responses inferred there were no situational, emotional or physical alterations to the lived experience of these couples' intimate associations resulting from the mastectomies of the women.

On reflection however, the assumption that I would be unable to obtain rich phenomenological data concerning intimacy following mastectomy, was also only partly true. As each conversation followed each other, it was equally clear to me, that what was said in other contexts (perhaps less difficult contexts, relating to more concrete areas of shared existence not seen to relate directly to constructs of intimacy), what was spoken, or inferred, and the participants' affective presentation, revealed a more subtle and complex web of thoughts and feelings which suggested otherwise. That is to say, that the mastectomy had a much larger impact on the intimate partnership than some individuals or couples seemed aware. Thus, the submerged, or obscure meanings which emerged from the data revealed a somewhat less reflective, less 'censored or socially acceptable stance,' even though there was no sense of me asking the participants to bracket their own prior knowledge. I am not suggesting that the participants were able to return to the Husserlian 'get back to the things (phenomena) themselves', but that on occasions, their verbal accounts, particularly of the shock of diagnosis or of seeing the mastectomy, their immediate awareness of their/ their mates body and/or mastectomy scar approximated the essence of a 'first seeing.' In a serendipitous way then, and in the light of a hermeneutic interpretation, I believe my study probed at the phenomenon itself (the experience of intimacy within mastectomy), even while it did not seek to bracket the couples' experiences, and even as it described their subjective realities.

Crotty argues that there appears to be a distinctly different or 'new phenomenology' of nursing evolving, as opposed to the mainstream phenomenological movement which nurse researchers feel themselves in continuity with. He argues that this difference is not being critiqued (by nurses) as unique and valuable in its own right. Publishers Churchill Livingstone, (in their back cover notes on Crotty's book) provocatively state that the mainstream phenomenology-

. . . is not the phenomenology to be found in contemporary nursing research. For nurse researchers, as for Anglophone

researchers generally, phenomenology does not mean anything like a search for the pristine innocence of first seeing. Far from being radical, untamed critique of culture as viewed by the phenomenological movement, the phenomenology found in nursing research turns out to be an uncritical exploration of the very culture which has tamed us and taught us to understand the world in the way we do. There are thus two phenomenologies (Churchill Livingstone).

So what is wrong with a new approach emerging and calling itself phenomenology, even if it differs radically from the standard version? Is there any problem with that? Yes, there is. In fact, there seem to be two problems. The first is the failure of the new phenomenologists to recognise the newness of what they are doing. The second is more serious: their failure to recognise the value of what they are not doing (Crotty, 1990, p. 2)

According to Crotty, nurse researchers are not acknowledging their shift from the study of the pre-predicative experience of the phenomenon, to the subjective effect of the phenomenon, or rather to the subjective meanings that people ascribe to phenomena. European, (or mainstream) phenomenology seeks to find the sense that people make of phenomena (objects in consciousness), elucidating what people experience pre-reflectively, rather than what they feel, perceive and understand following their reflection upon phenomena which is what nursing research hopes to elucidate.

Mainstream phenomenology has at its roots the premise that bracketing,

“is much more than a suspension of assumptions. The phenomenological reduction is a change of attitude that throws suspicion on everyday experiences (Crotty, 1990, p. 4, citing Armstrong 1976).”

This stands in stark contrast to the claims of the ‘new phenomenology’, which seeks knowledge of the everyday meanings which research participants make of their world. Nursing and feminist research perceives this ‘everydayness’ of banal existence as a particular research strength. However, I support Crotty, for if phenomenologists fail to bracket the presuppositions of the participants, and applaud rather than suspend belief in everyday experience, how is their testimony to be regarded as phenomenology in the Husserlian sense? Furthermore, how can their research be a pure form of the

'essence of phenomena'? Surely, there is a movement towards greater subjectivity in the new phenomenology, where nurse researchers interpret the reflective essence of human responses to phenomena, rather to the pre-reflective lived essence of the phenomena. Crotty points out that the shift from foundational phenomenological focus within nursing phenomenological research has its roots in the trans-Atlantic transplantation of European phenomenology. European phenomenologists did their own phenomenology, that is, they studied themselves, and how phenomena appeared to them. In this sense then, European phenomenology represented a first order construct of the world. In other words, they simply (sic) interpreted themselves. The American psychological tradition was based on a far more outward looking, pragmatic approach. In the American tradition of psychological inquiry, researchers examined researchees. Thus, the focus swung away from the bracketing of the suppositions of the single subject/researcher, to the bracketing of the researcher only.

Instead of being absorbed and integrated, critically or otherwise, into the mainstream of the American tradition, the new European ingredients were assimilated to that tradition. This strange Continental mode of thought and inquiry was transposed into something more familiar, with humanistic psychology proving an effective instrument in this Americanising of phenomenology. Already part of the tradition referred to, humanistic psychology had succeeded in setting down deep roots and was not about to be dislodged or even challenged. Among the areas where humanistic psychology became so well established are the 'caring' or 'helpin g' professions such as nursing (Crotty, 1990, p. 119).

Thus, Crotty views the impetus to a 'new phenomenology of nursing' has its genesis in an already radically changed phenomenology spawned in such diverse streams of American thought; as symbolic interactionism, ethno-methodology and anthropology.

While Crotty is the first scholar to focus exclusively on the transforming impact that nursing has had on mainstream phenomenological inquiry, he is by no means the first writer to highlight the difficulties in interpretation that attend the passionate researcher using phenomenology as a paradigm. Anderson (1989), pleads with nurse researchers to be critical of their phenomenological methods, and -

... instead of trying to find ways to combine different paradigms in nursing research, [She suggests that] the energies of nurse researchers could be more profitably spent on addressing some of the nagging questions about the actual doing of phenomenological research (p. 21-22) [my italics].

Anderson's critique seem to predict the concerns of Crotty, but paradoxically, she finds that phenomenological description in nursing seems to be plagued by 'objectification and reification' (rather than subjectivistic descriptions which Crotty believes characterise nursing research). Anderson believes this occurs because meanings are inter subjectively constructed by the researcher. Unfortunately, Anderson doesn't reveal what exactly she means by objectification and reification, but, in citing Shutz, it seems probable that she actually means the same as Crotty does in referring to subjectivism. Anderson notes (citing Schutz, p. 6) that:

the thought objects constructed by the social scientists refer to and are founded upon the thought objects constructed by the common-sense thought of man[/woman] living his everyday life among his fellow-men[/women] Thus, the constructs used by the social scientist are, so to speak, constructs of the second degree, namely constructs of the constructs made by the actors on the social scene, whose behaviour the scientist observes and tries to explain in accordance with the procedural rules of his science (Anderson, 1989, p. 23).

Anderson argues that we should realise that meanings are inter subjectively constructed (-that is, in our conversations with one another), and that the phenomenologist's constructs are second order constructs. This underlines a fundamental contradiction. Her own unease with this approach seems to foreshadow Crotty's (1996) thesis, as she questions the phenomenological approach. She seems as perplexed about phenomenology as I sometimes found myself. She asks, if this is the approach/method taken by social scientists, then they are required to "transform the structures of everyday life into the life and language of their scientific discipline, and this means " there is a tendency towards reification and objectification (Anderson, 1989, p. 23)." For Anderson,

.. the problem of reification and objectification seems to plague phenomenological description. A convincing argument may be made that inter subjective construction of meaning could be seen only to take place in those instances when

researcher and informant are involved in documenting an event. (Anderson, 1989, p. 23)[Anderson's italics].

However, even if careful attention is given to transcribing the researchee's words and then having this validated with the researcher's interpretation, it needs to be explicit that in the first analysis it is the researcher's structures which have been validated, not the researchee's. As Anderson, (1989, page 23) argues

the problem is not that researchers, of necessity, must impose a structure on the data, but that it is often unclear to the reader that these are the researcher's structures. (Anderson, 1989, page 23)[Anderson's italics].

This view is refreshingly iconoclastic in scholarly nursing tracts, and suggests that nurses do transform the shape and 'structures of everyday life' into the language of their discipline.

Crotty (1996) clearly states that "it is not the case that nurses have developed their own phenomenology". In his critique of an earlier draft of this chapter he said:

It seems to me that nurses have eagerly grasped a form of phenomenology that developed around them and suited their purposes rather than developing a phenomenology all their own (L. Amor, personal correspondance, December 15th, 1996).

Crotty found that nurse researchers have embraced an already reworked interpretation of phenomenology towards uncovering human feelings and perceptions concerning phenomena. It seems clear we do interpret the philosophy in our own way, which may be different from that of the 'phenomenologically driven' subject of the research process, given that he/she was invited to construct independent meanings. From the point of view of this study, I am aware that my own structure is stamped on the data, as the participants' surface descriptions commonly refuted that their intimate lives had been affected by the mastectomy. The hermeneutic interpretation of this data revealed that on a deeper level, rather than on a mundane, 'commonsense' analysis, the participants' intimate lives were keenly affected by the lived experience of mastectomy. This interpretation devolved from me, but through the descriptions and observations derived from co-researchers in the field study. These interpretations

were validated by the participants in our last interview, after reading the themes, and reading parts of the manuscript, and also by my academic mentors.

Munhall and Oiler's (1986), thoughts concerning the philosophical foundations of qualitative research give their clear understanding of nursings' pragmatic shift from the study of phenomena, to that of the effect of phenomena. While they openly assert that nursing has adapted the science of phenomenology to suit its own needs, with the exception of Crotty (1996) this actual divergence from other forms of phenomenology is not mentioned in the literature. Using the well known work of French phenomenologist Merleau-Ponty as a baseline, they argue that:

Lived experience is the focus of attention in phenomenology rather than the process of experiencing [my italics] (page 54). Perception, in Merleau- Ponty's view (1962), is distinguished from the scientific explanation of it as an act of consciousness, in the same vein as deciding and reasoning are acts of consciousness. Perception cannot be understood through an analysis of sensation as an object.(p. 54).

Reality is not constituted by perceiving representations of reality. Coherence in the world is lived. Relation with the world is a living impulse, non irreducible, and understandable only as a unified experience. It is not knowledge of the world such as posed by an analysis of sensation.

Munhall and Oiler explain that the focus of phenomenology is on experience rather than on subjects or objects, and that, following Merleau-Ponty's line of thought, are 'embodied' in their experience of the/their world/s, which are full of contextual complexity. People only understand 'their worlds' in terms of the context in which they live (experience them). When Munhall and Oiler (1986) analyse how the discipline of nursing has used phenomenology as a paradigm of qualitative research, they assert that nursing has embraced the "*fundamental themes common to the various phenomenologies.*" (my italics, p. 57). In other words, they seem to imply that phenomenology is being interpreted and utilised by nurses in order to enhance nursing knowledge. This implied meaning becomes much clearer in a later passage, in which the writers rightly confirm the 'enmeshed-ness' of the person's mental and physical being 'into' the physical world. In this passage (which is worth quoting at

length) these nursing philosophers assert their clear understanding of the difficulties between the pure philosophical (Husserlian) stance, and the implications and limitations of this stance:

Though the truth of the objective world is not questioned, the qualitative researcher recognises that its life, in any practical sense, is contingent upon human involvement with it. Another way of saying this is that it is what we take for truth, our particular view of it, that constitutes social reality.

There is no inner, private world apart from involvement with what we often refer to as “objective” or “true” reality. In qualitative research approaches, then, we find that the subjective and objective are meshed in a highly tangled, convoluted way that reflects this assumption. *People in all their subjectivity, are inseparably caught up in the physical world in such a way that the truth we search for in nursing research efforts will be grasped only by attending to the realities constituted in individual experiencing. If this is to be termed “subjectivity” or “subjective perception,” there is no*

other reality of interest for the nurse researcher who uses the qualitative approach.

The phenomenological baseline in nursing is the real world of living and experiencing the patient, family, and nurse. *In nursing research and theory, it is a thorough description of our nursing world as it is experienced by the participants* [my italics] (Munhall & Oiler, 1986, p. 58).

If there was any doubt in the reader as to the authorial point of view, Munhall and Oiler reveal their ‘transformed’ phenomenology (from the Husserlian phenomenology) as one:

..direct[ing] us to study human experience with a serious effort to reconsider foundations in our views that lead us to conceptualised, interpreted experience rather than a clear view of what it is we live through (Munhall & Oiler, 1986, p. 59).

These nursing scholars certainly do not ‘hide their lights under bushells, referring openly to the change they have made to the interpretation of phenomenology within the field of nursing research:

Subjectivity means that the world becomes real through our contact with it. Truth, then, is a composite of realities, and

access to truth is a problem of access to human subjectivity. This perspective guides the qualitative researcher in nursing to the subject matter of lived experiences, such as caring, presencing, and the child's view of hair loss (Munhall & Oiler, 1986, p. 62).

Thus, the adaptation of the 'pure phenomenological essences of lived experience' to a perhaps more pragmatic phenomenology of nursing, seems to hinge on the need of nurse researchers to explore the subject's feelings, concepts and experience in a reflective, rather than a pre-reflective manner. This discovery boded well for my research, for, while I welcomed the emergence of themes suggestive of pre-reflective, lived experience, I suspected that this may have been an 'entirely accidental' outcome, given the fact that I was not (in using the Colaizzi phenomenological methodology), asking the participants to 'bracket' their own pre-suppositions. Thus, from this research, I was able to assert with confidence that my aim was to describe the subjective feelings and meanings couples assigned to their experience of intimacy following their mastectomy, rather than simply (sic) the lived experience of couples' intimacy following the woman's cancer-related breast surgery.

As my interpretation of the data unfolded, my doubt concerning it made me search for the meaning (if there was one), behind my very textual analysis of what the participants said on the one hand, and the underlying meanings which their words inferred in a constantly recurring fashion. I was already aware of the historical tradition of biblical exegesis (textual analysis for 'deeper' meanings than apparent on the literal level) and in some ways, I had been deeply involved in the explication of the meanings embedded in text, language and poetry in my own study of literature. Was I on the right track? Was I doing the right thing? Similar to Bergum (1989) I asked, Was I fair? Was I honest? Was I open? - particularly to the research participants' experience ?

Exposure to the work of Omery (1983) gave me a clue. Citing Spiegelberg (1975) a highly respected phenomenological historian, she revealed that he found a common ground within the very diverse spectrum of the phenomenological movement. Within these commonalities, Spiegelberg found six 'foundational processes,' or, 'types of phenomenology' which, while not being mutually exclusive, are as one in the aim of describing human phenomena as faithfully as possible.

- **Descriptive Phenomenology**
A direct investigation, analysis, and description of phenomena aimed at maximum intuitive content. Aims to be as free as possible from preconceived expectations and presuppositions.
- **Essential (Eidetic) Phenomenology**
Perception and probing of the phenomena for typical structures or essences. Seeks to explain these essences and their relationships.
- **Phenomenology of Appearances**
Attends to the ways in which the phenomena appear in different perspectives or modes of clarity. In other words, determining the distinct from the hazy surrounding it.
- **Constitutive Phenomenology**
Studies the processes whereby a phenomenon establishes itself, or takes shape in our consciousness.
- **Reductive Phenomenology**
Suspending belief in the reality or validity of the phenomena. This process has been implicit since the inception of the method now becomes explicit through the use of 'bracketing.'
- **Hermeneutic Phenomenology**
Interpreting the concealed or hidden meanings in the phenomena not immediately revealed to direct investigation, analysis, and description.

I was drawn to three of Spiegelberg's six foundational processes; 1); Constitutive Phenomenology 2); the Phenomenology of Appearances and 3); Hermeneutic Phenomenology. This inevitably led to my introduction to Heideggerian phenomenology, which is inseparable from hermeneutics.

What then, was this hermeneutic approach - of which I was only dimly aware. I found it meant the interpretation of hidden meanings in the phenomena that are not immediately revealed to direct investigation, analysis or description. I thought that this foundational process then, was the process that seemed to dominate my study,

and determined to find out more about what it meant, as it appeared to justify the approach about which I was formerly unsure. How did it relate to Husserlian phenomenology? Would I 'use' this hermeneutic approach in a Heideggerian way? Before turning to Heidegger's concept of hermeneutics, let us inquire briefly into some key aspects of his thought.

Although Heidegger owed much to Husserl in the early development of his thought, which had opened up the realm of pre-conceptual apprehension of phenomena, essentially his phenomenology is a very different type of phenomenology from that of his mentor (Palmer, 1969; Spiegelberg, 1960). In a scientific way, Husserl sought to uncover consciousness in a transcendental subjectivity, whereas Heidegger held that Being went beyond human consciousness or knowledge, and was inseparably connected to the world, both in regard to temporality and historicity (Palmer, 1969). Spiegelberg (1960) believes, that:

Husserl is interested primarily in the epistemological aspect [of man/woman] (How do we know about man?), Heidegger in the "ontic" angle [of man/woman] (What is Being and what are the foundations for philosophising and phenomenologizing in the midst of it?). Heidegger undertakes to shift the centre of gravity of phenomenology by making human being, rather than consciousness, its hinge. For those who do not share his

ontological concern, this amounts to an entirely new phenomenology with an anthropological foundation. The phenomenology of his *Sein und Zeit* [early canon] is still subjectivistic to the extent that it makes man its point of departure (page, 303).

This Heideggerian focus on man[/woman], rather than simply his [her] consciousness, at the purely 'ontic' level, seems less abstract. Of this, Palmer (1969) writes that,

Heidegger puts the matter plainly; Interpretation is never a presuppositionless grasping of something given in advance (page 136). [and goes further in asserting]. that all understanding is temporal, intentional, historical. He went beyond previous conceptions in seeing understanding not as a mental, but an ontological process, not as a study of conscious and unconscious processes but as disclosure of what is real for man (p. 140).

So, Heidegger viewed people as occupying a space/time continuum, who are 'intentional' in their being, that is, at once separate but inseparable from the world. This sounds like the philosophical grist of qualitative nursing research, but what does the philosophical term 'ontological' mean? A clearer understanding of Heidegger's ontology arose in Crotty's (1996), analysis:

Heidegger, even in *Being and Time*, insists that the task he is setting himself is not 'ontic' (i.e. dealing with 'real life' issues and circumstances. the concrete acts of day-to-day existence) but 'ontological' (i.e. pertaining to a deeper level of intelligibility where the underlying structures of being are to be found)(page 78).

Crotty (1996) infers that for Heidegger, the ontic or everyday world is analogous to Husserl's -

“. . . 'presupposition[s]'" in relation to the themes of his investigation. The presupposition is *Dasien* [the term Heidegger preferred to human being}. The theme is Being (p. 77).

Crotty insists on Heidegger's total disinterest with 'the being of beings,' (that is, in the sense of how people *feel* about experience) and that (like Husserl), he wants us to 'return to the things themselves.' Heidegger's goal is God-like in the immensity of its aspiration, and it is perhaps not surprising then, that Crotty found he (Heidegger) was not interested in the mundane, or the commonplace. Already, we can see Heidegger seeks hermeneutic meanings rather than everyday meanings about existence:

Looking at subjective everyday experience and discerning its visible meanings (or even its 'hidden' or 'implicit' meanings,.... is not what Heidegger is about. Heidegger was after the meaning of being itself. He is not intent on divining the meanings of real-life experiences. His goal is not to render the real life experiences intelligible in that sense or by that path. While Rather, and countless others consider the meanings of real life experiences to be 'possible meanings of Being', this is not the case with Heidegger. To rest content with meaning of that order would be, for him, to fall into the trap in which metaphysics still finds itself enmeshed. *It would mean surrendering Being itself, for the mere being of beings* [My italics] (Crotty 1996, p. 77).

Indeed, this mere 'being of beings', the mundane, the commonplace, is precisely that which interests nurses, and, while phenomenological nursing research may involve aspects of ontological (metaphysical knowledge), nurses are interested in people rather than Being.

What did my nursing research have in common with the essentially metaphysical flavour of Heidegger's philosophy? His belief in the human being as a 'being-in-the-world,' inseparable from temporal and historical 'facticity' was certainly an attractive basis from which to begin a qualitative study, and his philosophy was anchored to the world in terms of his *Dasien* (if not his pursuit of Being). Heidegger's 'ontic' realm of his Being-in-the-world has far better 'fit' for a nursing study I believe, than the 'psychological transcendancy' which Husserl offered. However, I am not so comfortable with the sublimely metaphysical Heideggerian ontology. The nature of his philosophy, and its level of abstruse-ness seems beyond the ken of this study. This is not to say that suggestions of ontological meaning may not emerge from the data, but that I remain sceptical. Perhaps, because I am 'new to phenomenology,' I may not be sophisticated enough to recognise it.

In a way then, my approach only resembles the approach of Heidegger and Husserl, for, although I strive towards 'going back to the things themselves,' I do so with radical differences. If 'nursing phenomenology' is evolving as some sort of hybrid phenomenology in which subjectivity prevails, then, acknowledging Michael Crotty as the principal catalyst (and critic) of my thought, I am a part of this evolution. Pre-eminently I wanted my research to be grounded in the complexity of the subjectively described, human experience. I did not seek the 'essence of Being (existence) behind the being', nor did I believe a 'much transcendent consciousness' was possible in a 'bracketless' participant. However, this does not mean that I wish to 'not see' what I am doing with phenomenology, as I do it. I want to remain open and self-critical, that is, subjectively objective about my relation to phenomenology in nursing, to gather data which is rich in participants subjective meanings, while striving to describe the phenomena itself. This fresh awareness has not had the effect of diminishing my original concerns about subjectivity in phenomenological research, which will be discussed again below.

Where does the hermeneutic phenomenological approach fit into my study, and is it justified? As already mentioned, in philosophical terms, hermeneutic phenomenology is linked to Heidegger, as he considered it integral to his analysis of being. Heidegger tells us (similar to his definition of phenomenon), that :

The -ology suffix in phenomenology goes back, of course to the Greek word logos. Logos, Heidegger tells us, is that which is conveyed in speaking; the deeper sense of logos then is to let something appear. . .

The combination of *phainesthai* and logos, then, is phenomenology means letting things become manifest as what they are, without forcing our own categories on them. It means a reversal of direction from what one is accustomed to: it is not we who point to things; rather things show themselves to us [through language} (Palmer, 1969, page 128).

For Heidegger, language uncovers meanings about human Being, and he seems to suggest that it mostly happens in pre-reflective, ways, for -

The mind does not project a meaning onto the phenomenon; rather , what appears is an ontological manifesting of the thing itself (Palmer, 1969, p. 128).

This means that language precedes meaning, and if we think about that, (as Heidegger intended) there are remarkable possibilities for phenomenological interpretation.

Palmer (1969) makes the point that language is often categorised as a science, and that this is especially true in relation to logic which takes the instrumental view that language is merely 'consciousness manipulating statements and ideas.' Palmer reveals that Heidegger's view of language is far more complex and is an active agent of being-in-the-world:

For the true foundation of language is the phenomenon of speaking, where something is brought to light; this is the hermeneutical function of language. In taking speaking as the start, one goes back to the event in which word functions as word, one goes back to the living context of language (Palmer 1969, p. 139).

While the anthropological basis and hermeneutic aspects of Heidegger's thought are intellectually exhilarating, and have 'good fit' in terms of this study, my application of his concepts will not have the same philosophical ends. While the obvious elements

of 'discovery' and language as a hidden treasure trove of meaning have a certain resonance in this research, I will not have the same philosophical ends as Heidegger. That is, I hoped to find the inner reality of the person's description of the phenomena, but I didn't wish, as Heidegger did, to apprehend Being beyond phenomena. If I gleaned 'phenomenological moments,' (as Crotty calls them) in which phenomena are existentially described in the subjective feelings of participants I was pleased. I was pleased because Heidegger's vision did not seem inclusive of people, rather, he was interested in the abstract notion of Being, rather than the person. As a basis for nursing theory and research I believe his philosophy has rich meaning in terms of its existential foundations (being-in-the-world), and its hermeneutic approach to language. As a whole philosophical basis for nursing inquiry however, Heidegger's phenomenology lacks warmth or empathy for the human condition, so evident in nursing. Heideggerian hermeneutics presents as an exhilaratingly brilliant, yet glacial intellectualism seeking abstruse, almost religious truths about existence. As a philosophy of, or for life, it appears devoid of empathy.

Merleau-Ponty, developed Heidegger's (disavowed) existential concept of being-in-the-world into a much more 'embodied,' 'person-in-the-world' sense. While Merleau-Ponty seeks, as did Heidegger and Husserl - to 'return to the things themselves' he seems to link perception into a truly 'embodied', 'corporeal' space. Of the three phenomenologists' work, I have the least scepticism and most admiration for Merleau-Ponty. In contrast to Merleau-Ponty's canon, Husserl's phenomenology appears too scrupulously 'transcendental,' too disembodied; and, even though Heidegger's philosophy was pleasing in its focus on man [/woman] and language, his (Heidegger's) human being (Dasein) is almost disembodied-being-in-the-world, and his search for the Being behind phenomena has an almost religious tone. The body is never mentioned in the secondary Heideggerian sources, and this seems a curious omission if the body is the living envelope of our existence within the world.

As I have already discussed the work of Merleau-Ponty in the literature reviewing concepts of the human Being, it is not my intention to discuss his work in depth again, other than to reinforce that he too, like Husserl and Heidegger before him, strove to find pre-reflective knowledge about the phenomena of experience or Being. As a nurse, I have to deal with real, sometimes pained, vulnerable 'embodied patients,' it

is therefore, perhaps not surprising that I am attracted to his view of the body, which is a radical departure from the medical model of the human, as opposed to human Being. As previously discussed, it was Merleau-Ponty who coined new phrases like the lived-body (Crotty, 1996; Moss, 1969). While retaining the philosophers goal of trying to unearth the pre-reflective human experience, Merleau-Ponty's thought, rich in his embodied -in- the -world understandings of human existence, (which reflect his study of psychology, neurology and physiology) underpin his essentially existential, humanistic phenomenology. As this study involves seven women who have had a surgically mutilating procedure in order to live longer lives, their seven partners and as it also involves couples' intimacy, Merleau-Ponty's phenomenological thought is considered germane to this descriptive study. Unlike Merleau-Ponty though, I want to explore the mundane, everyday, subjective responses to phenomena, not just the phenomena themselves. As a nurse researcher, I am more interested in all the participants' subjective feelings and descriptions, while his only focus would involve their descriptions of pre-reflective phenomena. If I glimpse pre-reflective 'phenomenological moments,' within the participants' narratives, then I will be pleased, as perhaps I am in the process of becoming at least in a modest, tentative sense, a mainstream phenomenologist.

Crotty (1996) remarks that nurse researchers often invoke mainstream European phenomenologists as 'humanists' and use this humanism as a *raison d'être* for their own work. According to Crotty, these nursing scholars generally fail to recognise that the humanism within nursing has its roots in one of the branches of the new phenomenology, - most particularly, the humanistic psychology of Carl Rogers and Abraham Maslow. Rogers posited three kinds of knowledge: firstly, subjective knowledge, which relates to our own inner states; secondly, objective knowledge, which relates to our knowledge of the outside world; and, thirdly, empathic knowledge, which emanates from our knowledge of others inner states. It is this third aspect which I pursue

What validates this third form of knowledge is empathic understanding, for it enables us to enter into other people's private world of meanings. Significantly, Rogers calls it 'interpersonal' or 'phenomenological' knowledge.

Underpinning Roger's pivotal notion of empathy and the therapeutic approach it informs is a particular view of human being and inter subjectivity. This, it can be argued, is very much the understanding embodied in phenomenological nursing research (Crotty 1996, p. 112-113).

To reinforce his argument, Crotty (1996, p. 113-114) cites Arnett and Nakagawa, who identified six principles in Roger's concept of 'empathic listening,' which they also identified as common denominators of humanistic psychology generally. Briefly, these six principles were as follows:

- A normative emphasis on a subject's unmediated, personal and direct experience of other's internal states,
- Concomitant concern for accurately reflecting the internal experience of oneself and the other,
- The assumption of the innate goodness of the human being,
- The 'presentness' of interviewer to interviewee,
- Equality of the participant's experience, with avoidance of power, coercion or manipulation,
- A non-evaluative, supportive climate is called for.

Even this regrettably brief perusal of these principles reveals the essential 'inter-subjective' commitment to the shared reality of the human inter subjective conversation, which has a much more socially concrete reality than the abstract conceptual view which mainstream phenomenologists espouse. Crotty argues that these principles are in absolute accord with the humanistic, caring approach which nurses have embraced so warmly, and that these humanistic concepts have been crafted into a new phenomenological movement.

Returning to the notion of subjectivity within phenomenological research, before discovering Crotty's analysis, I remained in a state of perpetual perplexity by what I perceived to be a problem of researcher subjectivity in intuiting the phenomena as the (what I now know only the mainstream) phenomenologists did. How could researcher intuition be less than a subjective, somewhat poetic interpretation of the

data? How could I arrive at pre-reflective 'essences', 'manifestations' or 'given-ness' of phenomena, when my analysis was a second level construct? Researchers spoke of 'exhaustive descriptions' or 'thematic patterns' within the data, and that these themes constituted the 'essences' of the phenomena. I found the elucidation of phenomenological essences hard to understand, and found I agreed wholeheartedly with Crotty's critique when he opined:

In these terms, the phenomenon must be seen as a construct created by the researcher. This contrasts with mainstream phenomenology in which the phenomenon is not constructed but intuited (and therefore grasped first and foremost, it must be noted, by the subject and not by a third party, whether a researcher or anyone else). Merleau-Ponty states it succinctly: 'The real has to be described, not constructed or formed' (p. 56-57).

As the analysis of this research was undertaken prior to my acquaintance with Crotty's critique, in retrospect, I feel that I was 'working in the dark' plagued by feelings of helplessness in regard to what I felt were my own incomplete, or too sceptical opinions on the methodological implications of phenomenology. So, notwithstanding my misgivings, and, cognisant of the fact that I was the one interpreting the data - I strove to ensure that, the descriptive themes of the participants were allowed to emerge as naturally as possible, and as free as possible from my bias. Having said this, as a novice phenomenologist, I was/am acutely aware that this research has been 'a tentative beginning,' in phenomenological research, and I remain as sure as I can be that I 'opened myself up' to data meaning outside the range of my own experience, I found this part of the 'macro' analysis particularly difficult. The themes which did emerge, seemed to arise somewhat laboriously from my intense scrutiny of the data, though I did not ever believe that I came to understand the emergent themes on a deeply intuitive level. While I believe I may have intuited some 'micro' meanings within the language of the participants, (which as we have seen involved a hermeneutic 'process'; I believe that (at least on a conscious level) my 'macro' interpretation of the emergent themes indubitably lay within the common-sense, hardworking, pragmatic approach of the novice phenomenologist chipping away at the coal face of meaning. In other words, it was this process I found most difficult, and while (again), I strove to 'open myself to the possibilities' of the data set, to my mind, the themes which emerged from the

conversations I had with these seven couples have a distinctly prosaic, rather than poetic /‘intuited’ flavour. Even though I felt somewhat inadequate in the face of the my responsibility in interpreting the data, in retrospect, I believe that the themes do belong to and emerge from the voices of the participants, even though I have been the active cipher, or interpreter of their narratives. Notwithstanding this, if a person from another social science discipline had access to the same data set, it is highly likely that the interpretation would have been quite different. This comes back to the point then, that the interpretations can still (at least partly) reflect the life world of the researcher. As an example, if a psychologist were to analyse the data, would she/he have uncovered/discovered the ‘strange body sensations’ as a theme of significance?

Spiegelberg (1966) asked the question, “How safe, then, is non-transcendental phenomenology from subjectivism?” (p. 141). By subjectivism he meant “... the view that everything is personal and that there is no objective world, but only more or less unrelated private worlds?” (Spiegelberg 1966, p. 140). Spiegelberg reveals that there is a danger that the subject-relatedness to the phenomena under scrutiny may relate to subjectivism, insofar as it may simply reflect the personal differences of subjects, and not reflect the phenomena themselves. In many ways, this research is not immune from this criticism, as it reflects the participants’ direct reflections on their feelings about mastectomy with far more clarity than it does the phenomenon of intimacy following mastectomy. Returning to my earlier point regarding the researcher’s position within the subjectivism debate, Spiegelberg stated,

what is much more serious, there seems to be concrete reasons for worrying about the fact that phenomenologist, non-transcendental as well as transcendental, seem all too often not to agree in their verdicts about [phenomenological] essences. And all of them seem to base their claims on self-evident intuition of the phenomena. Thus it would seem that the subjective factor in the phenomenological approach lays it wide open to subjectivism (1966, p. 137).

Spiegelberg (1966) calls on researchers to make every effort to purge ‘lazy thinking’ by remaining vigilant and self-critical at every turn. He seems to infer (unlike Crotty) that the researcher is still able to utilise intuitive knowledge in the uncovering of phenomena;

Not until the claimant to self-evidence can give himself[/herself] and others proof that he has made every effort to deactivate his [/her] personal and institutional biases, and to fill out with intuitive content (intuitive fulfilment) all the empty or signitive anticipations of his thought, has he [/she] the right to claim anything approaching self-evidence (p. 141) .

Spiegelberg suggests that phenomenologists may turn to other, less essentially private means by which to uncover phenomena. That is, to seek an objective, more public approach most usually associated with the positivist research stance. There does seem sense in further research into phenomenological methodology. This could take the form, as Anderson implied above, of more actively opening up the interpretation of new phenomenological research to the utilisation of participant as narrator and as actively involved joint interpreter, who brackets experience as well as the research 'convenor.' There are doubtless pragmatic reasons why such approaches would be unwieldy, like the difficulties in managing the huge amounts of data, time constraints, budgetary considerations and possible conflicts in interpreting the data. Ingamells (1996), a community worker and academic, found that in undertaking her qualitative research, even though she wanted the practice based research she instigated to be fully participatory and collaborative, her colleagues resisted her attempts to make the research a truly egalitarian process. Even so, she was able to share aspects of the interpretative process with her peers -

This group of fifteen workers had vested in me the power to construct meaning from their accounts of their practice. The only perspective from which I could authentically do this was my own. Nevertheless, I stayed in touch with workers through the period during which I was working with the material and we did go through all the drafts together (p. 153).

The seeming inflexibility of the new phenomenology appears to have precluded the creation of other, perhaps more efficacious phenomenological methodologies. Thus, it would appear that the way is open for qualitative nursing researchers to create different research techniques or tools in the future quest towards phenomenological knowledge in nursing.

The above paragraph points to the position of the researcher as occupant of a privileged, more powerful position than the participant. To my knowledge, nursing

researchers have not commented on the essential inequity of the researcher's interpretative position in relation to the data set. Nursing researchers frequently comment on the humanistic principles of the interpersonal process involved in the interview context, but don't acknowledge the power (or vulnerability) they hold as interpreters, or how this power (or lack of) could effect the data.

Feminist research has tended to be much more critical of the researcher/researchee relationship. Feminist critiques of positivism have led to the development of alternative epistemologies and research methods (Harding 1986, and Neilson 1990). Gilbert (1994), a social geographer, openly acknowledged the issues outlined in the above paragraph. She found her feminist research with working class women in Worcester, Massachusetts was theoretically and personally problematic, insofar that her practical research situations with women failed to support many of the central tenets of feminism theory and practice. In some ways she seemed to suggest that the process of research creates and sustains inequity.

This relative power, probably results from the tradition that has grown out of the positivist paradigm, involving as it does an inevitable inequitable position, between the helper (always hierarchically positioned) and the helped; these (dialectic) doctor/patient, psychologist/client, nurse/ patient and researcher/researchee relationships. Despite the fact that nursing researchers dress up the phenomenological relationship within the interview in humanistic clothing, it should not make us any less critical of our privileged position as 'masterminds' of the conversations, or of the fact that these conversations also have less social, humanistic goals as an existential sub-text. That is, while I have enjoyed being a researcher, and aspire to humanistic goals in undertaking this study, I am also aspiring to no less personal, but much less altruistic, more elitist, individualistic, careerist ends in aspiring towards a higher degree, which (hopefully) is the end product of the inquiry. While the researcher's aim is acknowledged on the title page it may seem that this point should hardly need iteration. Nevertheless, it is one of the driving forces of the research process, and, while it may seem a little self-conscious to lay it 'into' the text, there is no doubt that research participants are very aware of the ineffable nuances of the social stratification of people, of which higher education is but one dimension. Munhall hints at this within the context of the vexed question of bracketing, in a transcript of a

conversation she had with Bergum and other nursing phenomenologists (cited by Morse, 1989, p. 12). Referring to these social nuances, and how they may effect qualitative research outcomes, she said:

When Joan said that those people would have reacted differently if she had have been in a tweed suit, it's almost as though our subjects need to bracket - because they may have given her different information. They had pre-suppositions that they may not have given up.

I am left with several questions. By taking Crotty's critique as a logical framework for this chapter, have I shot myself in the foot? Have I immersed myself in subjectivism, so inimicable of the mainstream phenomenologists? Perhaps I have 'wounded' mainstream phenomenological inquiry by the everyday, mundane, subjective descriptions of the participants. Coming late to Crotty's analysis as I have, I suspect that my research has in some ways vindicated his critique of phenomenology in nursing as a new phenomenology, meaning that I too, belong in this camp. However, I believe that his work has forced me into a critical dialogue within the dual phenomenological world of philosophy and phenomenological research practice. I believe I have been forced to critically challenge my own relationship to the research participants' narratives. When I cast back over this chapter, I remain aware of some nagging doubt that I have been a 'fence-sitter' in roughly sketching out the mainstream phenomenologists philosophical beliefs (and my departure from them) from within the conceptual haven of Crotty's incisive critique. The reader will be the best judge of this.

Last but not least, is this study free from the subjectivity which mainstream phenomenologists eschew (the subject which has woven a thread through this chapter)? Notwithstanding the 'mainstreamers's' transcendental strivings, I continue to disavow this vehemently, and in defence of this position, cite Spiegelberg (1966, p. 142-143) who said of this -

There is no escape from subjectivity. The only cure for subjectivistic subjectivity is more and better subjectivity, more discriminating subjectivity, and more self-critical subjectivity, which will show the very limits of subjectivity.

I conclude that all phenomenology as a study of the phenomena is subjective in the sense that its objects are subject-related, but that not all phenomenology is subjective in the sense that it makes phenomena completely subject-dependent. And there is no compelling reason why phenomenology should end in subjectivism. There is merely a risk which, with adequate care, can be reduced to proper proportions.

I believe that Crotty's philosophical mentorship has helped me to reduce the risk of subjectivism to proper proportions, for this study involves more than 'unrelated private worlds' of the participants. While every person's stories are unique and individual, they nonetheless share common, phenomenological moments. Has this research uncovered phenomenological essences? Rather than this, I believe that this study has been enriched by brief, 'phenomenological moments', fleeting 'glimpses' at experiential truths, rather than the raw, 'given-ness' or 'essence' of the phenomena of couples intimacy following mastectomy.

In summary then, following Crotty's (1996) lead, I found that nurses have adopted phenomenology as a philosophy and a methodological approach, but have not asked questions. Rather, they have assumed an understanding, leaping in without acknowledging the complexity within the conceptual versus practical "perplexities" of the philosophy. Since this adoption, nursing as a culture, (following the lead of other human sciences) has begun to parent and shape its philosophical child in an image reflective of that culture's needs. Nurses have been critical of phenomenology, to the extent that they wish to bend it to their humanistic needs, but have ignored the historical and intercontinental changes that have radically altered some of the central premises of the mainstream, European phenomenologists. Nursing scholars frequently invoke European phenomenologists' conceptual tools ('essences', 'given-ness', 'intuiting', and 'Being') when they have not realised that the 'doing of phenomenology' (in the North American sense) actually precludes the use of such terms. Indeed, it can be seen that this lack of awareness has fostered a shift away from the very phenomenological goals to which they aspire. There can be no doubt that qualitative nursing research focuses on the subjective, ordinary, day- to-day feelings, perceptions, and experience of people. Nursing cannot escape the primacy of subject oriented study.

Perhaps we need to celebrate more the humanism within nursing philosophy, and realise that the same majestic subjectivity and 'ordinariness', that typifies it also makes us vulnerable to claims of subjectivism, rather than 'pure' (is there such a thing?) phenomenological insights. As Spiegelberg said, the researcher must be ever vigilant to reduce the risk (of subjectivism) into proper proportions. To those nursing phenomenologists who feel I have been too critical, most nursing texts on research methods exhort their readers to be intellectually disciplined, and, even though I feel as though I've covered some phenomenological distance, like many other nurses who have laboured long and hard with this methodology, (even at the end) I still wonder if I've "really done phenomenology." Was the purpose of this study to "do phenomenology" or to seek understanding of couples experience of intimacy following mastectomy? I believe I have achieved the latter, and, in using phenomenology have unravelled some philosophical meanings which are appropriate to this study. At the same time, phenomenology as a research process has been problematic and perplexing.

Finally, while I firmly believe that Crotty (1996) has pursued a valid audit of phenomenology in nursing, this doesn't mean that nurses should 'throw in the towel.' Rather, they should boldly throw down the gauntlet and embrace phenomenology even more critically in the wake of this unique and challenging Australian critique of a largely American research phenomenon. Indeed, perhaps Australian nurses can lead the way in pursuit of different methodologies, more in keeping with mainstream phenomenology tenets. Conversely, in the wake of Crotty's debate, it is possible that some nurses may re-evaluate mainstream phenomenology, for, perhaps nursing's current divergence from it could signal that it has outlived its usefulness.

Finding a Phenomenological Voice

In concluding this particular debate, I acknowledge that my understanding of Michael Crotty's work has been a catalyst towards the enrichment of this study, and has given me the courage to find a phenomenological voice. So, while the completion of this endeavour would formerly have heralded a journey's end, I now suspect it is only the beginning of a much longer phenomenological journey.

The Study Design

The design for this study was a field study. I used a combination of data sources which included interviews, observations, and observational field notes (memoranda).

The Sample

A non-probability sampling technique known as purposive or judgeable sampling was drawn, consisting of seven couples of which the female partner had undergone cancer related breast surgery. This entails selecting a group of people with specific characteristics, experience or behaviours considered to be important to the research and stands in contrast to the random samples taken from cross sections of the population (Walker, 1985). This sampling method is considered a sound method in generating ideas about a subject area that may not be as fruitful using other sampling techniques (Burns & Grove, 1987). The rationale and potency of purposeful sampling lies in selecting information rich cases to provide detailed descriptions of the phenomena under scrutiny, in order to gain new insights relating to the research purpose (Patton, 1990). It is common in phenomenological research to recruit small samples of eight to ten from an homogenous group in order to evince common shared meanings of their lived experience (Field & Morse, 1990). The sample of seven couples (fourteen participants in total) provided a wealth of descriptive data, given the in-depth nature of the interviews and data analysis, and the time limits imposed on the study.

It was envisaged initially that I may obtain all participants from a word-of-mouth, or snowballing technique. This proved to be rather slow going, and I only succeeded enrolling three couples over two months in this way. Frequently, a woman was keen to volunteer, but her partner wasn't. Eventually the rest of my sample was drawn from volunteers responding to an article in the Western Australian *Sunday Times* newspaper (Couples and breast cancer, 1994) published during the national Breast Cancer Awareness Week. In this article, I described the paucity of local or Australian studies concerning the impact of cancer-related breast surgery on couples. The following selection criteria were identified. Firstly, couples were to reside in the Perth metropolitan area, in an effort to limit the expense of the research. Secondly, the

woman was to have been in cohabiting partnership for at least six months, and not have had the mastectomy earlier than six months prior to interviews. This was seen as a reasonable period of time to get to know a partner and for wound healing resolution to have been established. Thirdly, women involved were not to be actively treated by medical therapies such as chemotherapy (other than Tamoxifen) or radiotherapy, because of the potentially debilitating effects and questionable ethics of interviewing them at this stressful time. Fourthly, couples were to be aged 30 or over. This age chosen on the basis that as I was forty-five years of age, any younger couples may feel I was too old to identify effectively with, and this age difference may interfere with the potential richness of the data. Lastly, couples were to be available for the required interviews.

Profile of Participants

The collection of demographic data such as length of relationship, date of cancer-related breast surgery, marital status, religion, occupation, nationality and educational level was important, (see Appendix A), as the social milieu in which the participants live helped to explain and enrich the data. Additional information asked related to the type of surgery/s performed, whether they had related treatments and when, and if there were incidence of cancer in the genetic family.

Procedure

Prior to conducting the interviews, I was careful to revise my knowledge of current and past surgical-medical techniques and technologies, in order to be able to understand and empathise with participants if they chose to focus on any treatment related matters. (This background preparation was useful, and by enhancing my understanding, I was more sensitive to their feelings, having little need to interrupt their conversational flow in order to seek understandings).

As already mentioned, three of the couples participating in the study were enlisted via a snowballing, or word-of-mouth, technique, while four others were drawn to participate by reading the magazine article. While this article had specifically called for Perth metropolitan participants, the first call on my answering machine was from a

country woman, who keenly wanted to be a participant. Her telephone conversation was dense with narrative and emotion, and I was at pains to curtail her need to speak at length. My research plan proposed that six couples would comprise the study, but, after consultation with my supervisors, it was decided that I could extend this to seven. This woman's phone demeanour was not unique, for all the people who responded to the newspaper article seemed to have an urgent need to talk and 'get things off their chests.' Only six heterosexual couples (represented by the female partner) initiated phone contact, and of these four were enlisted in the study. The remaining couples lived hundreds of miles away.

Potential participants who responded by telephone, and those I obtained via a 'snowball' technique, were given a brief description of the research and sent a letter (see Appendix B) explaining the purpose of the research and ethical safeguards to maintain confidentiality. Interested people were met informally at a mutually convenient time in their own homes, and all participants gave informed consent to have the interviews audio taped (see Appendix C). Participants were assured of their right to withdraw from the study at any time without penalty. Arrangements were made for three audio taped sessions: the first with the female partner, the second with the male, and a third, paired interview. The first and second interviews were conducted privately and were usually back-to-back, and the third followed within three weeks of the first. A follow-up, (untaped) interview was scheduled when the data analysis was almost complete.

I was aware of the need to create as empathic an atmosphere as possible for the interview, and I was a willing recipient of any hospitality offered. The prelude to all the interviews involved a friendly 'get-to-know-you' conversation over a cup of tea or coffee, and occasionally, a tour of a garden or fondling of family pets. This 'home centred' interaction had the effect of breaking the ice and allowed for a degree of spontaneity to enter into their narratives, and also reduced my own novice researcher performance anxiety. I believe I communicated empathic awareness of the participants through maintaining eye contact, adopting an open, alert body posture and giving frequent verbal or facial affirmations.

Interviews were open-ended and unstructured in format. Participants were requested to make themselves as comfortable as possible, the audio tape was turned on, tested, and the interview commenced. A question guide, (see Appendix D) comprising open ended questions and prompts was used during each (first and second) interview, but was not used in the third interview, in which the couple came together. The first question I asked was “How has the mastectomy affected you as a woman/man?” and I encouraged them to describe as fully as they could how the mastectomy had affected their lives and their intimate associations with partners. I was cautious not to prompt with leading questions, and to let them reveal their own feelings or perceptions. My responses were often by way of reflective listening comments (and murmurs) or questions involving clarification of statements. Thus, the narrative content flowed in the natural direction of the narrator, with minimal redirection or stimulus from myself.

While I consciously aimed to minimise my own verbal intrusion in the participants’ stories, I concentrated intensely on the process of the interview, analysing the participants verbal and non-verbal responses, and their behavioural reactions to the questions I was asking. The non-verbal phenomena were described in field notes. I also strove to interpret what the meanings of certain responses or interview processes were. Every effort was made towards being as focused as possible throughout the interview, and to write memoranda notes as soon as possible following the interview as possible. It was necessary for me to ‘make time’ to do this in a quiet space, so that I could reflect and scribe my impressions of the interview ease (or otherwise), any non verbal cues and any relevant observations or conversations elicited in ‘off-tape’ time. These field observations (memoranda), were useful as a cross-reference during the analysis of the interviews, because they provided a rich source of information concerning the emotional, physical and social environments of the couples (See Appendix E).

Data Analysis

Prior to each interview, I acknowledged the essential phenomenological method of setting aside or bracketing my own preconceived ideas concerning mastectomy and intimacy so that the data remained unpolluted by my own assumptions concerning the research. I did this in a formal manner by documenting these presuppositions, which

were reviewed and reflected upon prior to my visit to each participant (See Appendix F). In this way, I attempted to limit my personal biases from intruding into the data collection, interpretation and memoranda.

Data analysis commenced at the time of the first interview, and even as the participants spoke I was analysing and reflecting on all the environmental, situational, verbal, emotional and non-verbal cues extant within the process and content of the interview. I do not wish to suggest that this analysis was simple, or that I did it well. Again, although I know that I attempted to analyse and reflect within an empathic, emotionally open stance, I believe I succeeded regarding my emotional open-ness in the reflective process, but (as I have already argued in the discussion concerning the methodological difficulties in interpreting the philosophy of phenomenology), I am not so sure about my ability to become even partly 'transcendentally subjective,' or 'intuitive' in my analysis of the data. As I have contended above, I am aware of my subjectivity, and while I did not want my research to be biased, it seems clear that my cultural bias as a nurse is not far beneath the surface of this thesis. I believe the themes of this study are a case in point. Notwithstanding these admissions, I believe my subjectivity has been tempered by critical insight regarding my own relation to the data. Thus, the data was collected and analysed in a non-linear or circular manner.

Formal analysis of the data was undertaken in accordance with the procedures outlined by Colaizzi (1978). Every transcript of the participant's oral accounts of intimate life following cancer-related breast surgery were analysed utilising Colaizzi's (1978) phenomenological methodology. Following Colaizzi's six procedural steps.

- All the subjects oral or written descriptions were read in order to get a feel for them. This involved listening to the tape first, and then transcribing it verbatim. The arduous task of transcription was jointly undertaken by a professional typist and myself. When the transcript was completed, it was checked for accuracy by a simultaneous audit of the oral recording. A copy of the transcription was given to relevant participants.

- From each transcript significant phrases or statements that directly pertain to the intimacy between couples [following the woman's breast surgery were extracted]. This involved listening to the tapes several times in order to increase my awareness of covert meanings implied in variations in the participants voices. When implied meanings were elucidated in the data, these were noted in parenthesis within the borders of the transcripts. It was also useful at this time to scan the memoranda recorded following the interview. In an effort to manage the volume of data, as well as locate (or contextualise) statements I worked sequentially from interview to interview, separating the women's significant statements from the mens, and coded every statement to identify sex, couple number, and page number [F1:p1]
- Meanings were formulated from those significant statements and phrases. This was the most difficult part of the research. Of this process of 'the formulation of meanings,' Colaizzi (1978, p. 59) has stated that:

the phenomenological researcher engaged in something which cannot be precisely delineated, for here he [/she] is involved in that ineffable thing known as creative insight; he [/she] must leap from what his subjects say, to what they mean. This is a precarious leap because, the meanings he [/she] arrives at and formulates should never sever all connection with the original protocols [descriptions]; his [/her] formulations must discover and illuminate those meanings hidden in the various contexts and horizons of the investigated phenomenon which announced in the original protocols.

- Towards this end, and moving sequentially from the first to the last of the twenty one transcripts, direct quotations which related to the experience of intimacy between partners were extracted as significant statements and these descriptions were assigned meanings. As the work progressed, clusters of meanings began to emerge. These clusters of formulated meanings became the themes of this study. It was necessary to refer these clusters of themes back to the original descriptions in order to validate them. This was not always easy, as much of the methodology involved an essentially hermeneutic analysis. For example, many participants made

clear statements that the mastectomy had no impact on their lives or intimacy, but indicated in other ways that it had enormous impact.

The way in which I arranged the data physically was important. At this stage I found it impossible to manage the data and conceptualise themes by working on the computer, and worked on a large open floor. I chose to separate the females and males significant statements onto hard copy, adhering them top and bottom, code the significant statements according to their meanings, and observe as aggregates or clusters of meanings emerged on the long strips of data. The separate themes were easy to identify visually on these somewhat unwieldy lengths of paper, because I had coded the themes (See Appendix G)

- The results of the data analysis were organised into an exhaustive description of the intimacy between couples following the woman's Breast surgery.
- To achieve final validation, I returned to the participants with the exhaustive descriptions. Any new relevant data that were obtained from the participants were incorporated into the fundamental structure of the experience.

Validity

In the last decade, there has been much healthy debate in research circles concerning what constitutes reliability and validity within qualitative research, and many scholars have discussed the issue in depth (Leininger, 1985; Sandelowski, 1993; van Manen, Guba & Lincoln, 1985; Munhall, 1994). Sandelowski (1993, p. 29) suggests that -

.. the debate surrounding the methodological rigour of qualitative research is confounded by its diversity and by lack of consensus about the rules to which it ought to conform and whether it is comparable to quantitative research.

Validity issues within this research are based on the four criteria proposed by Guba and Lincoln (1985) as outlined by Sandelowski (1993). Guba and Lincoln developed these factors, relating them to the tests of rigour in positivist scientific research and what they called 'naturalistic'(qualitative) inquiries. They did so because these categories provide a useful framework for comparing the similarities and differences between qualitative and quantitative perspectives. These factors are: 1) truth value; (or, internal validity versus credibility); 2) applicability or (external validity versus fittingness); 3) Consistency or, (reliability versus auditability); and, 4) Neutrality or (objectivity versus confirmability).

Credibility

Sandelowski (1993, p. 30) believes, that;

The truth value of a qualitative investigation generally resides in the discovery of human phenomena or experiences as they are lived and perceived by the subjects, rather than in the a priori conceptions of those experiences. Significantly, truth is subject-oriented rather than researcher defined.

As truth value is subject-oriented, rather than researcher defined, credibility was addressed in this study by having the participants read and retain a copy of their transcript. Participants were encouraged to scrutinise the transcript to validate its intrinsic truthfulness, (or otherwise) to make written and/or verbatim statements if they chose or to make further comments concerning the dialogue. Bergum (1991), considered internal validity in qualitative studies was not simply an ethical issue, but a moral one. She asked herself the questions, "Was I fair? Was I honest? Was I open? [and] how are you true to their words and yet, never hurt them in any way?"(page 54). Within this study, none of the participants refuted or edited their transcripts, indicating that the data was an honest and truthful replication of the interview. Thus, credibility is the criterion against which the truth value of qualitative research is assessed, and it is present when "... data and interpretations will be at least .. credible to the audiences that are in the best position to judge them" (Guba & Lincoln, 1981, p. 113). So, the truth value of the study was judged by the participants, while judging the fittingness of the study was invested in the researcher and her research mentors.

Fittingness

According to Sandelowski (1993, p. 31) subjects are selected on the basis that they can illuminate the phenomenon, so, fittingness of this study was ensured by the selection of couples who had experience of the study phenomenon, and who were willing to be articulate about it. The findings should be well grounded in the life experiences within scrutiny, and reflect typical and atypical elements.

Guba and Lincoln suggest that fittingness be the criterion against which the applicability of qualitative research be evaluated. A study meets the criterion of fittingness when its findings can 'fit' into contexts outside the study situation and when its audience views its findings as meaningful and applicable in terms of their own experience (Sandelowski, 1993, p. 32).

This study recruited men and women who had direct experience of the phenomenon to be studied, and their narratives had an audience of three independent academic researchers, as well as myself. Thus, it was not only myself who evaluated the fittingness of this study, for, descriptions within the transcripts were read by my research supervisors, and they intermittently observed the unfolding themes as I cut and pasted my way through the data. Hence, independent auditing was a part of the process of the methodology undertaken. I contend that this study has demonstrated its applicability. In determining the fittingness of this research, my supervisors were also actively auditing the work as I moved step-wise through the study.

Consistency

Guba and Lincoln (1981, p. 122) have suggested that auditability be the criterion of rigour or merit relating to the consistency of qualitative findings. Auditability is only achieved when investigators are able to:

Review each decision and the consequent actions, verifying that substantially and methodologically sound options were chosen [which will ensure] ... that documentation of the decision trail (that is, the auditor's trail) can be adequately maintained.

Thus, in this study, it was necessary to scrupulously document the methodological approach . This approach included how I became involved in the study, how I related to the phenomenon (my assumptions-see Appendix F), and the methodological debate above), how the data were collected (the Colaizzi Method). As well as this, as researcher, I was able to use the several data sources available to me as cross referencing, cross validation tools. That is, as I simultaneously listened to the audio tapes and read the transcripts, I was able to review the field notes, memoranda, and frequently return to my bracketed pre-suppositions in an effort to reduce the potential for bias. This process is known as triangulation of the data (Patton, 1990)

For examination of those 'audit trails not covered in the thesis to this point, see examples of coding of transcript into significant statements, preparatory to the aggregations of themes in the data (see Appendix G), and emergent themes (see Appendix H).

Confirmability

Confirmability, as the criterion of neutrality in qualitative research, refers to the findings themselves, not to the subjective or objective stance of the researcher (Sandelowski,1993). 'Neutrality,' refers to the freedom from bias in research. Objectivity, (from the logical positivist's stance), is achieved when reliability and validity are established is the criterion of neutrality. Objectivity is not the aim of the 'new phenomenologist', who aims to;

emphasise the meaningfulness of findings achieved, by reducing the distance between investigator and subject, and by eliminating artificial lines between subjective and objective reality (Sandelowski, 1993, p. 34).

How then does the qualitative researcher defend herself against the claims of lack of objectivity? To Guba and Lincoln, this is of no concern, because of the essential difference in the qualitative paradigm, the researcher values subjective involvement. Rather, she should fastidiously and critically monitor the methodology of the research, to ensure fittingness, confirmability and credibility. Thus, the final

qualitative research criterion then, is confirmability, (or neutrality) and is achieved when credibility (the truth value), fittingness (applicability), and consistency (auditability) are established (Guba & Lincoln, 1981).

Limitations

- The sample group was a purposive rather than random sample, therefore the experience of the couples cannot be generalised to other infertile couples.
- While it was anticipated that this study would encompass a broader range of cancer-related breast surgery, only women who had undergone breast amputation were involved. In recent years, there has been shift in emphasis from surgical amputation, to as much breast conservation as possible, thus, this study has not had the opportunity to explore the experience of couples who have had less mutilating forms of surgery.
- The female participants can be broadly categorised as a middle-aged group, with all partners except one belonging roughly to the same age group. Women were aged from 36 to 59 years, and their male partners were between 37 to 69 years of age. Consequently, although breast cancer is least common in young women, but increases in incidence with age, neither younger nor elderly womens' experience featured in this study.
- One male was born in Holland, while two other males and two female participants were born in Commonwealth countries. All were English-speaking, Christian Caucasians. A more mixed cultural population may have generated an even richer range of responses.
- The women who responded to the newspaper article, may be representative of those who are more motivated to articulate their concerns and feel more strongly than those enlisted from the 'snowball' technique.

Ethical Considerations

Permission was sought and granted by the Committee for Conduct of Ethical Research at Edith Cowan University. Informed consent (see Appendix C) was obtained from each participant prior to the interviews beginning, and all participants were aware of their right to withdraw from the study at any time.

While ethical considerations are of crucial importance in conducting research into any area of human research, the intensely personal and sensitive nature of this study reinforced my resolve that every verbal, documentary and behavioural precaution would be demonstrated in protecting the confidentiality of the participants. All published data was carefully coded to maintain anonymity. Participants were 'renamed' rather than given impersonal numeric codes, and these names were given to them on their consent forms. This was done in anticipation of them wanting access to the published thesis. Participants were assured that only 'their pseudonyms' would be used in published documents or at seminar presentations

Participants were assured that they were at liberty to refuse to answer any question or to exit from the study at any time without penalty. Provision was also made so that if any participant become distressed at any time, they were able to stop the interview and continue at a mutually convenient time. Given the sensitive nature of this research I was cognisant of the emotional status of the participants throughout the interview process, and was careful to allow time for 'review and debrief time' to 'ground' the participant emotionally if he/she was distressed. Before the collection of data began, I was careful to stress my role as researcher rather than nurse or counsellor, and that if this sort of help was required, I sought permission in advance from the participant/s to refer him/her/them to a professional counsellor or support group. In anticipation of requiring this service, I consulted with and enlisted the support of the Western Australian Cancer Foundation, though I did not need to call on their assistance.

As it was anticipated that some participants may not have wanted their partners to have access to their own interview transcript, allowance was made for each person to decide upon the location to which the transcripts were sent. All couples were apparently relaxed about their partners having access to their (single interview)

transcripts, and this was not an issue. Notwithstanding this, both parties were given the opportunity to change their minds about this arrangement as the interviews progressed. Had participants chosen not to have their partners read their transcripts, then appointments would have been made for them to meet the researcher privately for this purpose.

Only I have access to the data; the transcripts, the audio tapes, and the computer discs. All names, addresses, demographic details, codes, audiotapes, transcripts and computer discs are kept under lock and key in a filing cabinet in my own home. These will also be destroyed after a five year period.

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VOLUME TWO

Findings, Discussion and Recommendations

Acts have their being in the witness. Without him who can speak of it. In the end one could even say that the act is nothing, the witness all For what is deeply true is true also in men's hearts and it can therefore never be mistold through all and any tellings. This then was his thought. If the world was a tale who but the witness could give it life? Where else could it have its being?.

[Cormac McCarthy, 1994, p.155]

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Findings, Discussion and Recommendations

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[Cormac McCarthy, 1994, p.155]

Participant Profile

The purposive sample consisted of seven couples (male and female) who shared experience of mastectomy. All the couples were from Anglo Australian and European origin. Female participants were aged from 37 to 59 years, and the male partners were between 37 to 69 years of age. All couples except the youngest, were in their first marriage, and the youngest woman had divorced following her mastectomy. This woman was engaged to a (formerly unmarried) partner at the time of the interviews.

All partners except one male had children, with one family having adopted two children, now adults, while the affianced male was experiencing his first year of step-parenting. All couples were in middle class socio-economic groups, as was evident in their home environments, which seemed comfortable. Two couples were retired, and one couple were unemployed. The occupations of female participants ranged from home duties, to research assistant, sales manager, retired secretary, retired volunteer breast cancer support person, business director and school teacher. Male occupations included retirees, unemployed, diplomats in middle management, tertiary educated professionals and businessmen.

Women experienced mastectomy from seventeen years to one year prior to the interviews (17, 6, 6, 3+, 15 months, 1 & 1). Two women were currently being treated with Tamoxifen, a chemotherapeutic treatment. Three women had other chemotherapy in the post-operative phase, and two had radiotherapy. Of these, one woman had cranial surgery for metastatic cancer spread; another woman had a second cancerous lump excised from her axilla. At the time of the interviews, two women had further breast lumps investigated, and these were not cancerous.

CHAPTER FOUR

Individuals' Perceptions and/or experiences of Intimacy

Intimacy - both one's experience of it and one's ideas about it, connotes a vast area of thought and feeling. Like so many other aspects of life, the maps one uses to understand, explore and guide one through the territory of intimacy are changing. Whereas the dictionary can give a definition of intimacy, one's associations to its meanings are much more complex. One's associations, attunement to the word "intimacy" vary with the kind of meaning - written, spoken, gestural, and symbolic - that one shares.

(Weingarten 1991. p. 285).

Introduction

As part of the research plan, I purposely intended that the participants would define intimacy in their own words. This approach I believed would provide for a rich and meaningful baseline from which to interpret how the couples perceived themselves within the intimate partnership following mastectomy.

I have deliberately 'paired' the couples' statements, so that the reader may immediately grasp a sense of the 'inter-connectedness' or 'separateness' of these participants' thoughts or feelings in relation to one another. As this study involves the very private sharing of deeply personal understandings, I also will formally introduce the reader to these definitions as (at least potentially) 'coupled concepts'. It is hoped that the couples' compared concepts of intimacy will both 'set the scene' and help

'round off' the following thematic conversations in which the reader will become immersed .

I believe that these individual, 'experiential definitions' need to be analysed as linked, or 'coupled' statements, which potentially at least should reveal a lot about the individual as well as the coupled relationship. It was envisaged that these 'wedded thoughts' may prove a special entree into the shared worlds and 'mutual meaning making' of the couples, and provide a conceptual foundation stone for the study of mastectomy and its affect on the partnership.

I owe a conceptual debt to Weingarten (1991), whose idea of intimacy as mutual meaning-making , has been such a help in making sense of the data. I have loosely used Weingarten's concept as an operational definition, or conceptual framework through which to analyse the participants' own definitions, as well as the findings where appropriate. This borrowing in no way undervalues the participants' views, rather it helps to validate the findings in this study. Working from her critique of social constructionist and feminist paradigms, Weingarten (1991, p. 286) argued that:

... people's thinking and understanding shift in relation to the vicissitudes of social processes, processes whereby historically situated people construct views of "reality." Intimacy is one such construct.

Weingarten (1991), believes that these constructs (or discourses) of intimacy are lodged within a discourse, which is inextricably linked to other social constructs of gender, power, domination and sexuality. This scholar suggests that these paradigms direct attention away from the assessment of particular intimate interactions, to the global assessment of the capacity of an individual or relationship to provide intimacy. She believes that these discourses obscure the crucial distinctions that a discourse of intimacy, of "meaning making" would reveal. She proposes a definition congruent with non-global intimacy assessments;

Intimate interaction occurs when people share meaning or co-create meaning, and are able to coordinate their actions to

reflect their mutual meaning-making. Refraining from meaning-making and providing, imposing, rejecting, and misunderstanding meaning are associated with non-intimate interaction. Repeated intimate interaction may produce an experience of intimacy, while repeated non-intimate interactions usually interfere with or inhibit relational patterns that lead to the sharing or co-creation of meaning (Weingarten, 1991, p. 286).

Thus, I have invoked this definition as the conceptual rudder to help guide the reader through the current of the entire research findings.

Participants' Perceptions, Experience of Intimacy

FIRST COUPLE: Jill and Graham.

Jill

Intimacy to me in my relationship with Graham is ah very special, it's a lot of cuddling and close physical contact. We've always been like that and we've ah never been shy too proud to walk around in your underwear or with nothing on. Just being really comfortable with one another. So. Lots of cuddling and [pause] that's the main thing.[F1: p.10].

Graham

S'pose [silence] Intimacy? being a friend, companion, showing feelings, talking out problems ... I suppose being open in most things, (you know) and I hope Jill feels she, she can [be] with me as well. I suppose it depends on the mood people are in and finding the right mood to talk, to talk to people and th: But I think at most times we are , pretty well, pretty well easy, easy to talk to [M1: p.16]

SECOND COUPLE: Gwen and Joseph.

Gwen

I think Australians think of intimacy as kisses and cuddles. They always kiss each other when they arrive and when they leave and this is a little foreign to us. Um, maybe we're a little odd, I don't know. Joseph is a very reserved man. We tend to keep our little, (our 'core' you might say), very closely intim

[sic] away from anybody else. Yes, um Joseph's intimacy would like, would not be - "Oh I think you're wonderful!" - but - "Oh come on woman! Shift your butt, I'll do that!"

I find it hard to actually see what, you know, put into words myself because it's very much a - it is a sense of companionship we've - the sex and that part of the relationship was just the icing on the cake for us [F2:p12].

Joseph

Well I don't think it changed as a result of the operation...I think...it's cooled down. It's probably is to be expected with age... but otherwise...I really don't think that the, the you know, the operation itself had any...made any great difference...At least I can't think of anything. [M2:p7].

THIRD COUPLE: Sharon and David

Sharon

I just feel when I'm lying next to him in bed, um, that you know I might have worries and things like that and I can say something and he'll say, forget about it. Its not important, you know. And I'll cuddle up a bit closer and, ah, so we go, we can, he takes me for a drive in the car and we can go miles without having a conversation. We're not arguing, we're not fighting, we're just quite happy in each other's company, you know... So, you know, that's, that's how I think of intimacy [F3:p9].

David

Ah, just being next to the Mrs - in bed lying close, you know, ah, you know being able to touch her at any time. Um, no hang ups about, um, we, we're in and out of the shower all the time, you know, we don't hide from each other, we've never done that, so, you know, to me that's what intimacy is. I can go up and touch her at any time, you know [M3:p7]

FOURTH COUPLE: Lucinda and Imran

Lucinda

[In a QUIET PENSIVE TONE] Oh... Lots of things. I guess it's when someone looks at you and sees further than what you haven't got. Um.. and to know that you still have two sides. It's just not your left side there's your right side too. And even though I don't have a lot of feeling there. There

is two sides to you. Having somebody just to, ... sometimes just somebody to hold you in the middle of the night if you're not feeling all that wonderful, and terribly secure in what's going on.. yeah.. [F4:p17].

Imran

In general (as in intimacy) in my definition of a closeness um ... Well ok, I suppose um... um... In a way it's just being free with each other, as in not worry about clothes if it's not necessary or not appropriate. um... Cuddling up.. When we look more at the physical senses, the physical sense um... I suppose sharing things, communicating and all that. But from the way I perceive the question I, more of the, just that closeness that it has in the physical closeness um... nakedness without necessarily. ... giving a definition in the sexual context [M4:p2].

FIFTH COUPLE: Tamara and Gus

Tamara

I don't know, s'pose just being in private with the person that you love, with your husband um... I don't know really, How I could describe that? I don't know, I suppose just um, the special moments between your husband and yourself that nobody else knows about I suppose, that's the only way I could really describe it. Yeah, it doesn't necessarily have to be in the bedroom or making love or anything, but (you know) quite often, Gus always says to me, I'm his pride and joy and he couldn't be without me and everything, and I mean just when he says that, that's sort of special to me. (You know) sort of always makes me feel special, like he sort of couldn't do without me. I don't know, just.... I don't know he would just have to give me a bunch of flowers and I would think that was a real special thing too. [chuckle] [F5:p. 16].

Gus

Doing what you want to do I suppose. Giving her heaps. Who knows! You know, I, I'm pretty ah, if it's [the opportunity is] there [I] go for it! I don't know.

Yeah, yeah I suppose it would be a physical thing. Ah, intimate in relationship, to talking to each other, I suppose because I work from here [home], we, we get that all the time, we get our time alone, moments alone, things like that. Ah, no! It's good. I don't know how to really describe it [Chuckle].

Well we have a lot of it, we have a lot of togetherness, because ah, we work from here and sometimes I'm here when other guys are at work and visa versa like that, so there's days when we'll come home, or I might come home and she'll say, well how about coming and having a look at so and so, just take off. So we have quite a bit of time together. And that's enjoyable, I don't know what you'd class that as you know intimate times or not, but ah, yeah we might go and have lunch or tea or something in the middle of the day, or something like that, which is good. I think it's good anyway [M5:p. 10].

SIXTH COUPLE: Gemma and Ivan

Gemma

Well to me. No. to me intimacy is being with a person, sharing all the good times, bad times, um, supporting each other all the time, and basically showing feeling that you have for each other. Whether they be grumpy feelings or, or good feelings you know, you've got to, we've very, very honest with each other um.. and as I said we still walk around arm in arm all the time and we're very demonstrative, we can kiss and cuddle a lot in front of the boys and things like this. um. So I feel just being together - just being together for everything, I think it's just sharing everything together, and showing your feelings whether it be sexually or whether... See sexually, we don't use the word sex, it's never sex it's always love. And how are we showing our feelings? Just loving feelings that we have for each other. Whether they are sitting together painting the room, whether they be out in the garden digging out a stump, whether it be sitting on the motor bike together, going out together or watching a movie. It's just being together [F6:p14].

Ivan

Um... trust in one another, sharing the good and the bad, knowing what other people expect of you and being compatible with that. Quite often you get someone that will expect more of you than you are prepared to give or whatever, and sort of that can create a trouble or something. But no Gem and I have never had that sort of problem, we've always been able to express ourselves to each other very well. Um.... I ... I sort of think that body language has a lot to do with it, you know, you can feel someone's.. um, feeling as soon as you touch them, or give them a cuddle or hold their hand or something, you can.. or ... or in my case when I'm giving Gem a massage I can feel almost what she's thinking and feeling... pretty well [M6p12].

SEVENTH COUPLE: Lauren and James

Lauren

.... Intimacy to me is ah.. well it's not just being in bed together. It's not just having the sexual side of things. I think the sexual side of things is the culmination of all your intimacies, um an expression of all those intimacies, your sharing, your caring, your loving, your giving, your needing, your taking um... Yeah because really if you can't give in the kitchen. I mean if you can't have an argument and get over it the second breath, you've had a disagreement, um, and in the next sentence that you've said, the disagreements over, I mean, that's how..how I feel and it is like that with us, but that's how, that's intimate, because you can do that and it's gone and you've said your piece it's over and done with and it's finished with. Um... by the same token if you can't turn around in the kitchen and respond to a kiss that's been given, or you can't um... express how you feel about what your man has done spontaneously and have that accepted - not necessarily acted upon, just accepted, oh that's the way she is today, that's the way she feels. How can you have those other real intimacies to that extent. That's how feel about it. So to me it's a culmination of a lot of things that end up in an expression in the bedroom[F7:p22].

James

When I'm with my wife I feel that I can, I try and love my wife the best way possible. She wants the emotional support, you know what I mean. Sex to her is a side issue, right, which I understand, for the woman's part of

it you know, but a man's part the other way is the sex part of it isn't it, more

Well I want to give it, [intimacy] but I don't know how. Like I don't, I find it hard to express my- how I feel or because I didn't know myself [M7:p19].

.... she knows she can trust me, put it that way. To me that's ... you've got trust, you've got everything. Um, I find it hard to... you know, to express my feelings, as simple as that, cause I just can't do it, although I want to sometimes, you know I might do a little bit, but, but, I don't even know what it is, intimacy really. Cause I've never experienced it [M7:p15].

I don't know how to do it. I don't know how to be intimate with anybody [M7: p17].

The tentative syntax in the above descriptions reveals the difficult nature of the interview process, and reflects the reality of the participants attempting to define elements of their most personal sense of themselves within the context of their most meaningful relationships. Intense scrutiny of the inner self is probably not entertained by the majority of people in the community, and therefore participants may have found it very difficult to articulate something that is rarely expressed openly. Nearly all of the participants' statements were gleaned when their interviews were well in progress, when they had time to relax and develop more feelings of trust with me. Even though participants were awkward in divulging their feelings in these sensitive interviews, the above responses reveal an extraordinarily rich stream of awareness. At the time of the interviews, I felt my role as a novice researcher quite keenly (and indeed, felt quite awkward myself as I asked such searching questions). Notwithstanding our sometimes timorous 'verbal circling' of delicate subjects, I am pleased with the data collection and feel I (at least in part) won the trust of the participants.

I found that while there were some differences in the way that people described intimacy, most participants mentioned physical closeness. While sexual intimacy was a part of the intimacy phenomenon, it was not seen as the most important dimension of the shared experience. In other words, Weingarten's (1991) precept of intimacy as shared meaning had 'good fit' with the perspectives of the couples. However one couple, James and Lauren had quite different notions of the meaning of intimacy, and did not appear to share the meanings. James stressed the importance of sex, while simultaneously expressing confusion as to what the abstraction of intimacy meant to him. Conversely, Lauren's description of intimacy was quite holistic, or contextually centred in her own life experience.

Joseph too was also unable to describe this slippery concept, except to imply a sexual meaning in deflecting the question back to the impact of age (not mastectomy) having a "cooling down effect" on their relationship. Joseph and Gwen's definitions were perhaps potentially un-intimate in the 'shared meaning context,' but this conclusion needs to be viewed cautiously, because Joseph's brief response may reflect his embarrassment in speaking to me, or his self-avowed difficulty in expressing his feelings. The difficulty in the articulation of feeling should not lead us to suppose that people do not feel deeply.

Jill and Graham's descriptions of intimacy had shared and unshared meanings. The most obvious unshared meaning was Jill's emphasis on physical closeness and cuddling as a key component of the expression of intimacy. The fact that Graham has not included physical closeness in the definition may not mean it is not important to him, for, in his nervousness, he may have forgotten to mention it, or he was too abashed to allude to it at the time.

How then did the mastectomy affect the intimacy between partners? All of the males and four of the females maintained that the mastectomy had no effect on their intimacy, even though a deeper, hermeneutic analysis of the transcripts has revealed statements which clearly indicated that there have been significant changes and adaptations made to their physical and emotional status as lovers and companions. Two couples claimed that their bonds had actually increased as a result of the

mastectomy, and Sharon and David, and Gemma and Ivan were even more positive about their (formerly) strong bonds following mastectomy.

Many of the husbands said words to the effect that: 'She's more to me than just a breast'. Their negative responses to the question of the effect that mastectomy had on their intimate relationship reflected the same pragmatic attitude. However, as many couples revealed the importance of physical closeness as a component of intimacy, the implications of physical and emotional adjustments examined in the following chapters highlight that couples intimacy is affected in quite subtle or sometimes even dramatic ways as a result of mastectomy, even if it is denied or covertly expressed.

As the data analysis proceeded, there was a sense that the narrative stances of the couples in relation to shared meanings of intimacy following mastectomy were either, 'intimate', 'non-intimate', 'connected' or 'separate'. This latter concept was partly supported by the literature. Lang-Takac and Osterwell (1992), revealed that separateness and connectedness have played a central role in schools of psychological thought. As discussed in Chapter Two, Gilligan (1982) posited gender differences in these concepts, with males being more separate, and females more connected. However in this study (at least as regards the concept of the couples' concepts of intimacy) most couples seem to be appropriately 'connected' and shared and co-created meanings.

These statements have tentatively 'set the scene' for what is to follow, and should be viewed cautiously. Whether or not the couples in this study share meanings, or are 'connected or disconnected', will depend on the persuasiveness of the themes which elucidate aspects of the intimacy experience of these seven couples following mastectomy. Thus, the reader will be convinced, not so much by any global, abstract descriptions, but rather by the participants' words and deeds, as they evoke intimate or non-intimate interactions within the narrative framework.

These threads of 'connectedness' and 'disconnectedness' or, shared meanings, actions of intimacy versus non-intimate interactions within couples' experience, and how they connect with the mastectomy event will be discussed in the shared meanings between

themes which emerged from the males and females data analysis. The investigative thread of this study began with me analysing the women's narratives, before proceeding to the men's and couples' transcripts. I envisaged the themes would be written up separately, in 'gendered' themes. As the gendered themes emerged, it became clear that there were loosely shared meanings, even between these men's and women's themes. Thus, there have been serendipitous thematic meanings traversing gender, which I believe bodes well for the overall analysis of the data, given that I have accepted Weingarten's definition of shared meanings as a framework for the analysis of intimacy (following mastectomy).

Reflections

Thus, even while some of the chapters in Section Two have been prefixed as shared meanings between themes, I have still maintained the original investigative thread. I began discussing the women's narratives, then the men's and only then discussed the links between the paired themes as a summary to each thematically linked chapter. While the separateness or connectedness between couples' comments will often be self-evident, I have done this in order for the reader to have the linkages or dislocations of the intimacy phenomenon following mastectomy revealed with greater clarity.

CHAPTER FIVE

Shared meanings within the Themes of:
**Women's Existential Plight in the Wake of their Mastectomy Experiences -
and for Men,
Uncertainty, and Loss of a Sense of Control in their Lives Following their Wives'
Cancer diagnosis.**

It is horrible, just that fear of the unknown. You feel well, you feel fit and everything else but you just wonder if something's going on in the background, and if it is, that you'll find it or you'll discover it and they'll [the medical specialists will] be able to do something about it. Or you hope that everything's been eradicated and that it'll never come back -but there's a lot of 'ifs' in there

[Jill's Transcript; (Wife of Graham): p13].

I think the worst, the worst part about it all (I s'pose) is the not knowing. I think this is a bugger for that, because even when Jill went back for her, her checkup. There's nothing proactive that they do. Rather than a mammogram, they might do some more blood tests or something like that as well

[Graham's Transcript; (Husband of Jill) p 15].

Women's Existential Plight in the Wake of their Mastectomy Experiences

The theme of mortality emerged in response to my open ended question about how mastectomy affected women's lives or how they viewed their future life. While not all the women referred directly to death, they frequently revealed sensitivity to their mortality concerning their cancer diagnosis and their prognosis. The cancer diagnosis triggered concerns about their life expectancy, relationships with their loved ones or their day-to-day health. Many noted that this uncertainty about death is not peculiar to them, but implied that they were now far more conscious of themselves as mortal beings. While it is true that all humans deal with the uncertainty of the future, the insecurity that people in cancer remission have is highlighted by their fear of the disease recurring. These findings are supported by other cancer or mastectomy related studies conducted by Lewis (1993), Oberst and James (1985), Quint (1963), and Weisman & Worden (1976). Lewis (1993) posited that "The diagnosis of cancer challenges the assumptions that everyone is invincible; that things are always good; and that life goes on forever". The insult to women's sense of permanency in the world was one of the most palpable themes of the study, which was openly referred to. This was in contrast to the men, more than half of whom were markedly uncomfortable with any intimations of mortality.

The women's fears and future concerns, both at the time of their diagnosis, treatment, and their feelings at the time of our interviews, indicated that the psychological insult of the cancer diagnosis was more significant for these women than the surgical amputation of a breast. It is impossible to separate the two themes, as the surgical outcome is dependent on the diagnosis, and the seriousness of the diagnosis in most cases elicits the medically desired preventative treatment of elective lumpectomy or mastectomy. This focus on medical prevention and cure via surgery, chemotherapy and radiotherapy in part explains why the women involved in this study tended to downplay their own grief and loss as it related to their body image. They were however able to freely relate to their experience of mortality as the objective of treatment is to prevent early death. This is not to suggest that more open expression of

women's experience is less significant, but that those professionals involved in the hospital/medical milieu tend to focus on physical treatment and prognosis more than on the long term emotional experience of women following mastectomy.

Jill (36 years), who had her mastectomy most recently, said that she was really strong in the beginning (following her diagnosis) -

Because initially I was convinced that - Ok, I'd fight this to the bitter end, have my breasts off. - [she said to the surgeon] "You can take what you like, arms, legs, anything ! I'm not going to give in to this"[F1: p.12]. .

She later experienced intimations of mortality -

We used to refer to the future as the next five years, umm , with the cancer, umm, getting the all clear in the next five years, and I often think in my head, Oh will I see Jason grow up? - and I'd (like) think of the next twenty years and when I'm really bold I think of the next fifty years [Laughter-pause]. And when I'm depressed, I think of the next two years, maybe. I get frightened [Pause] I just get frightened of what life might be. I can't imagine. It's like getting cancer, I can't imagine any more stages and when I'm going to die because I don't want to. But at the same time I know it's a possibility.

Hopefully my mental attitude will keep it vague [the threat of cancer] if nothing else

Jill said that her "bubble had burst"[p.12] on discovering that a former colleague who she hadn't seen for two years had died. She compared herself with this woman, and was aware that unlike her, her colleague had not lost her hair. This was particularly devastating for Jill because she had looked so well the last time she had seen her, so she found herself telling her oncologist that for the first time she had felt "this [her colleagues demise] could be me". This experience shows that not all women connect with a feeling of mortality immediately following their diagnosis. Jill had determined to be strong following her diagnosis, and was well into the period of her chemotherapy when she received news of her colleague's death. It is quite possible

that Jill was unable to integrate and comprehend the information she was given regarding her risk following diagnosis, but it took the 'reality', of the death of a friend with the same diagnosis to make an impact on her. It is interesting to note that, Jill inferred that she had not consciously focused on the long term threat that cancer posed. However, she used the telling words - "Take anything, [any body part] I'll fight it to the bitter end" when recalling her attitude to her mastectomy. This willingness to have the surgeon remove as much tissue as was necessary to minimise the risk of a cancer recurrence was found in five of the women, three of whom elected for mastectomy versus lumpectomy procedures.

Jill described her experience of breast cancer as having most significance in terms of its uncertainty -

Well I feel that probably the biggest thing in the back of my mind is that I'll breathe, I will breathe easier when we get through the next four, five years. It is horrible, just that fear of the unknown. You feel well, you feel fit and everything else but you just wonder if something's going on in the background, and if it is, that you'll find it or you'll discover it and they'll [the medical specialists will] be able to do something about it. Or you hope that everything's been eradicated and that it'll never come back -but there's a lot of 'ifs' in there [F1:p13].

Jill's uncertainty concerning her health lies in the fact that she is worried that "something [is maybe] going on in the background" within her body at a micro cellular, undetectable level.

I think it's just the uncertainty of the future more than anything else, especially with having a child. If I hadn't had James I would certainly still have wanted to be around for the future, but, umm, I lost my Mum when I was a little girl and, for me, having children I always wanted their life not to be like what my life was - what with having one parent. So that's hard for me to cope with when I think about it "[F1:p.14].

The thought of the possibility of her premature death was not made any easier for Jill as she was disturbed by the negative affect her hospitalisation had on her son, who was only two at the time of her mastectomy:

I breast fed him until he was seventeen months old and it [her hospitalisation and mastectomy] did, it had a huge affect on him. He had been a little boy who would go to bed happily and sleep all night... and then when I got home from the hospital we had about three months of having him wake up every night yelling out "Where is Mummy! and "Mummy's gone away!"[F1:p.14].

Jill's experience as a mother who recently breastfed her child and has undergone a mastectomy provides the reader with insight into her emotional life and that of her little boy. Jill's story also reveals the added burden or emotional weight that is possible in women diagnosed with breast cancer who have young children. Some idea of the impact of Jill's experience is implied in her following words:

And very much [he] is always having to check, even to this day), he's going through a stage again now where he's always got to check [where] my other breast is [Pause] to check it. He doesn't just say "I want to touch it , [but] I want to check it." I don't know if it's for a lump. He just wants to feel it and touch it and make sure it's there I think. It saddens me. Well he tells me. Sometimes he tells me that I had to have the other one cut off. I tried to explain to him the best way that I could - that it was making me ill and I had to have it cut off because I was getting very sick and I'm all better now but. He has said to me that that's very sad I had to have it cut off. He did. He became very insecure in a lot of ways. He's been going to sleep every night with me in his bed with his hand on my [remaining] breast[F1: p.4].

The very 'physicality' of Jill's awareness of her little boy's disturbance (from his previously more settled relationship with her) implies that she would have little respite from a constant reminder of her changed body, and more particularly, the reason underlying the change.

Gemma, who has boys aged fourteen and sixteen, also expressed her doubt about what the future held:

There was this beautiful baby outside and I looked at him and I thought "Am I going to be a grandmother?" - and that is something, I really love children, and that is something I guess that I, that worries me a bit. I would really want to see the

(anticipated) short life span, saying: “Try telling a three year old who’s also deaf that she won’t have a Mummy soon”. Unlike the other women in this study, Lucinda was told she was going to die very soon, and had to face the prospect of dying at thirty and leaving her young family. The fact that she is alive seven years later does not diminish the fact that she still understands that life is a precious commodity.

While Lucinda was given the most serious diagnosis of all the women in this study, her outlook was amongst the most lively, perhaps as a result of her continued health. She seemed philosophical about the future, and determined to make the most of it. She has divorced her husband, and is looking forward to a future with a new lover, while contemplating having another child, although she is aware this may be a risk.

Tamara’s, Gemma’s, Jill’s and Lucinda’s stories are linked by their experience of breast cancer diagnosis and their common humanity as mothers, who share the desire to live to see their children and grandchildren prosper. What sets their experience apart from many others is that they have been given in theory at least, an open-ended lottery style ‘death sentence’ based on statistical predictions. This theoretical, one in five chance of not enjoying the expected life-span has obvious implications for women and their families. Nearly all the women in this study remain philosophical about their relative risk of death, many citing the colloquial ‘falling under a bus theory’ to contextualise their experience within that of the wider community. However, this pragmatism does not diminish the fact that the diagnosis of cancer has the effect of challenging day to day assumptions of immortality and has the potential of changing the lives of individuals and families. Women’s feelings of uncertainty about the future with regard to the important role of parenting/grand-parenting emerged in the study.

Gemma has been unable to conceive of a future for a period longer than six months following her diagnosis and mastectomy a year ago. She has focused on the statistical evidence of women’s survival:

You know the number of friends who say to me “Oh you’ve gone twelve months, you’re alright, no worries at all!” And I say, “No. You’ve got five years, then they classify you as a

survivor.” But then I’ve known so many people who have been hit after ten years.

You know I sort of felt , wow! I survived twelve months (you know). Great! Bring out the champers! Um. But there’s that business about the five years. And it is . It does play on the back of your mind. And a few times I must admit I have thought [?] Five years from now how old will the boys be? You know? I guess the Deborah Maybury story has really frightened us [F6:p.27].

Gemma, recently experienced the death of her mother, and her father’s more recent diagnosis of Hodgkin’s disease, which has contributed to her scepticism about ‘counting her chickens too early’.

I’m not as positive [as my husband, well that is] I am positive but I am also realistic. It could [happen], and so I guess in a way I am also preparing myself for it if it does happen[F6:p.25] ...I know quite often when I do bring up, you know about death, he’ll [her husband] get quite - “You’re not going to die!”. I say “I’m not saying cancer is going to kill me, but something is! [Chuckle] [F6:p.25].

She puts a brave face on her narrative, but the fear she implied is now referred to directly :

Um, the only time I’ve become really worried is sort of like just before I go back to the specialist again. I sort of get sometimes [pause] I think you do, you sort of [pause] is it going to be ok? And possibly about one day a month I have a - usually about two o’clock in the morning [chuckle] I wake up Ivan when things seem to get on top of me [F6:p.3].

It is important to recognise that this is the woman who gave her surgeon a written personal account of her mastectomy, in which she was absolutely positive about the whole experience. This is not to say that she doesn’t remain positive, but the current study of her experience suggests that she has other, perhaps deeper layers of experience which she found difficult to commit to paper. As a phenomenological researcher, I strove to elucidate meanings from observation and listening skills, by bracketing presuppositions and by intuiting. Gemma’s public persona, her strong,

positive personality, her open body language and bubbly voice often belied the weighty content and hesitant syntax she employed.

It is unlikely that while she wants to tell her story she will be able to take more interpersonal risks than she has in agreeing to be interviewed. Gemma has been remarkably frank in her interview and has felt comfortable enough to shed some light on her more sombre thoughts. Often, there was some noticeable discrepancy between the content of her language and her positive tone.

I wake up Ivan when things seem to get on top of me. And so of course two o'clock in the morning is when, when I wake him up in the morning and I sob. Yeah I cry a lot with that, you know when I have my down periods. But it's not very often, and it's usually a little thing that instigates it.... And then it suddenly hits me and I think, "Well wow! Am I going to [die]! [F6:p.26].

However painful it has been, Gemma has apparently been attempting to integrate her spiritual awareness into the context of her intimate relation with her husband.

Since having been diagnosed with cancer, Gemma is seeking to portray a positive outlook on life:

every day is wonderful. I've got into a lot of Louise Hay's books of positive thinking, meditations and the power of crystals. We're doing every thing we possibly can - and the wonderful thing about it is that Ivan, he will read these books with me.he's bought me a lot of crystals and we've sort of discussed their powers, and everything we do we're together. We share everything.[F6:p23] I'd like to believe and - I want to believe there's an afterlife, and suddenly, when you're faced with this, this maybe death feeling, suddenly you're, I think you're grasping hold of everything you can. You'll, we'll try this we'll try anything we can to make our life longer, and we often talk together you know [how] we'll meet up together [in the afterlife] - you know - this sort of thing,

and I think it has made me feel a lot [pause] better. yeah, and we've talked about things like how do you want to be buried. It's an important thing that you've got to decide [F6:p.24].

She has pursued the subject of death with him since her diagnosis, and is working through her sadness/ fearfulness in her frequent cathartic episodes in bed at night. Of the couples interviewed, Gemma was the only person who reported experiencing her feelings of mortality with her husband with so much overt discussion about death and the meaning of life, and sharing spiritually oriented pursuits.

Gwen (59 years), who had a mastectomy seventeen years ago, still finds herself 'drawn up' by her diagnosis. She exploits past tense when referring to her cancer, while the statistical evidence suggests her cancer is always present:

My] Doctor suddenly said, "How long have you been in remission?" And I suddenly thought, "Christ! I thought I was cured!" It was quite a shock. But you do get a sense of urgency I discovered, because I know, (and the figures sort of prove), that twenty years is your average; ie. you're going to be pretty lucky if you get more than twenty years after breast surgery. Um, so once I found that out, then I had a certain sense of urgency for whatever I've got to do I've got to get it done, just in case [F2:p.11].

Even having survived for seventeen years following mastectomy, Gwen is still confronted by the knowledge that cancer could reappear in her body and she could die with it, at any time.

Sharon had her mastectomy three and a half years ago. She has a familial history of cancer, and had a craniotomy for development of cerebral metastases (secondary lesions). She had always dreaded cancer, and fear was evident in her facial expressions and voice. She expresses her experience of surgery with great pluck, as she was so aware of the need to eradicate the diseased tissue from her breast- "I've never cried over losing a breast. In fact, if I had to lose another one, I'd front up tomorrow if it meant I lived" [F3:p.2]. Sharon's pluckiness relating to her surgery appears to be driven by her fear of cancer and the need to eradicate it. She experienced her first operation for cancer 'as chance for life'. She did not view it as a tragedy. However, she felt overwhelmed by her diagnosis of cerebral cancer. Prior to arranging immediate surgery, her doctor told her to go home and "make sure your will is in order and you tell your family" [F3:p.14]. At this time she said she was ...

“absolutely shattered! I just couldn’t think if I was alive or dead or what !”[F3:p.14]. Following her successful brain surgery, Sharon said she lives from ... “day to day. I’ve got to be honest about that. Every time I wake up in the morning I think ‘Good, everything’s fine!’ and, umm, because of my family history I’m always a bit fearful that something else will go wrong” [F3:p.14].

Sharon is faced with constant reminders of her body’s mortality, which in her present circumstances she can probably do without. It is not surprising then, that her expression of fearfulness extended to her reluctance to undertake her own breast self-examination, but to seek a monthly medical appointment:

[The doctor said], “Oh you should be doing it yourself!” and I said, “Well I do when I have a shower, because thats when I picked the other one [breast lump].up” ... umm, but the only thing is I’m a bit frightened of it if I found it myself, whereas she gives me a very good examination and I go back [F3:p.2].

I was inadvertently involved in the aftermath of Sharon’s discovery of another lump in her remaining breast, as she and her husband tentatively told me during their couple interview three weeks later. They informed me with quiet gravity that she was to attend the doctor the same day (as our interview) to have a breast (needle) biopsy. At this time they were ‘off tape’ and David said “will you tell her or will I?” as they held hands. I was aware of feeling sad and felt some particular tenderness throughout the following interview, which they were happy to proceed with. I was aware as we spoke of their trust in one another and even in me, a relative stranger. Sharon’s vulnerability in relation to her recent surgical history was heightened by the disclosure of her newly discovered breast lesion, and gave me an insight into her existential anxiety as a person who has undergone two major diagnoses of cancer in two years. Though her familial and surgical biography gave overwhelming evidence to justify her ongoing fear of cancer, the great worry of the possibility of further malignancy involved in this incident (or other deviations from health) served as a grim reminder to me that this situation is part of the experience of many women following mastectomy.

Lauren was aware of the statistical probabilities of developing a further secondary outbreak of cancer, as she asked a rhetorical question:

How do you deal with it? You can't! So you've got to come back and say to yourself "Basically, I'm cured!"- But you know in the back of your mind you're not from the point of view that there is a twenty percent chance [which means that] twenty of us women, twenty of us first stage cancer victims [out of one hundred] are going to have secondaries. ...So then you have to be realistic about that ... I'm not worried about

secondaries as much as I was worried about a primary, another primary [lesion developing] in this [remaining cystic] breast [F7:p.27].

Lauren's words underline the 'Catch-22' situation in which these women find themselves. They all recognise the necessity of maintaining a positive mental attitude to help combat the illness. But there is always the fear of primary or secondary lesions developing, and the fear which may attend other undiagnosed bodily aches and pains. Lauren didn't believe she thought ".... about death more, as much as you think about your health more".

Lucinda was thirty years of age when she was told by her oncologist she may have only three months to live. Her mastectomy involved the diagnosis and excision of a lump reportedly larger than a man's spread hand, six years ago [F4:p.m.11]. "I had some lumps in my neck identified earlier this year, and that was pretty scary, that was pretty terrifying [F4:p.32]". Lucinda hastened to assure me that:

You see I, I've never dwelt on it [her cancer] and I've never gone around, I have not gone around saying "Poor me! I've had cancer!" You know people that I know now have no idea! They wouldn't have a clue. They don't know. [However], I mean - I [still] have my dark days, everybody does, umm they don't feel happy with everything that's going on in their life, and you think, Gee whiz, it could be a lot worse [F4: p.32].

A rich course of pragmatism emerges in Lucinda's words. She does have occasional doubts as to her future, but for the most part she 'gets on with life'. Lucinda sought medical advice about the lumps in her neck, and they resolved without any surgical or medicinal treatment.

Tamara is one of five women in this study who have had more than one lump isolated, and is the second woman who had another malignant lump removed four years following her mastectomy. She said that:

When my oncologist found the lump I was nearly getting to the five years, you know like a lot of people go -"Oh! after five years you're pretty well clear and everything.".... I suppose I was eight months off the five years, and when he found that lump I just wasn't even bothered about it, because I thought oh you know, I'd had six months of chemo so it wouldn't be anything [F5:p.6].

So that's when I got that other little lump and I thought "That's the end of me now!"[chuckle] I thought it had sort of 'taken off' again. But I think I did sort, I wasn't ahh, once I'd had it [the chemotherapy], I felt really good, like I was rid of it. Like a lot of people say, "Well aren't you scared of every little ache and pain that you get, (you know) [maybe] it's positive?"- and I do now. I just sort of live from day to day. I don't really get suspicious of every little thing, although I sort of was having dizzy spells a few months back there, but umm, I think I had like a , I was getting headaches and feeling a bit off balance, and I started to think "Oh no! Don't tell me something's happening to my brain and that, but it never ever happened again but it's only little things like that I sort of think "Oh, I wonder if it means anything - a sharp headache or something like that, but other than that I just sort of think positively [F5:p.13/14].

The anxieties caused by possibly harmless symptoms signals what Gates (1988) refers to as the fears of an uncertain future, in which every ailment is magnified into a potential cancer-related incident until proven otherwise. Tamara's language indicates some ambivalence about her uncertain future, that is, she recognises the need to remain positive about her life, but implies she may be living on borrowed time when she says she is living her life from day to day. This implied meaning is ratified when she mentions her recent feelings during a period when she was plagued by headaches and vertigo. It is important to recognise this ambivalence (which has been demonstrated by all the women in this research- to a greater or lesser extent) is essentially healthy. If the women were not cautious and vigilant about their health,

and disregarded physical signs and symptoms indicating a possible problem, it may have grave consequences.

Of the former consequence, Sharon was able to shed light. One of the oldest women in the study, she quickly returned to her secretarial work in a doctor's surgery following her mastectomy:

I was working and ... at the end of the night we added across our figures for the night. ... Anyhow, I was noticing I couldn't kind of follow across the [ruled] line properly. So I was using a ruler to do it and then I said to Joan ... "Are my figures right?" - and she said, "Oh, just out a bit", and I said "You don't 'get out' a bit!" I was office trained, and I mean - I can remember spending hours looking for a threepence you know in a big budget, and I said, "I'll have to be more careful" Then I came home and go to the letter box and as I there was this piercing thing in the back of my head. It was like somebody had poked something in the back of my head, a sharp pain [F3:p.16].

A week later she began to see stars, which persisted for another week at which time she sought medical help, recognising that something was "radically wrong" with her. The day she reported this, a two centimetre lesion was detected in her brain via computerised tomography, and she was admitted to hospital for surgery. This self awareness and realistic attitude is crucial to women's survival. (This is so for the women prior to their initial diagnoses too, although they may often present "asymptomatically", and are diagnosed via mammographic studies). Tamara, whose concern about her feelings of vertigo and headaches has already been mentioned, also sought medical advice. While these women's health concerns are intimately linked to their feelings of mortality or life expectancy concerns, this is an essential part of their coping strategies to try and extend their longevity.

Reflections

From the experience of these women, it is clear all are understandably concerned about their futures, and that they do experience feelings of anticipatory grief, even when they survive the five year statistical 'window' as three of them have already done. In addition, their frank and open disclosures of their concerns about their

When a woman consents to a mastectomy and any subsequent treatment deemed necessary, the diagnosis of cancer and the local and systemic treatments become contingent on diagnosis, so that the impact of cancer diagnosis tends to mesh into the domain of treatment, and vice versa. For this reason, it was sometimes a difficult process sorting out the data and isolating the different themes. Generally, men were much more comfortable in speaking about the impact their wives' diagnosis of cancer had upon them, than they were about the physical or possible psychological wounding involved in the mastectomy. This possibly related to the men being able to conceive of the cancer in a more abstract way, while simultaneously pursuing a feeling narrative about 'the way it all happened' which they intuited to have less to do with their 'private', intimate lives. Klien (1971) reported that husbands of mastectomy patients experience a great deal of uncertainty and conflicting emotions, and have needs equal to their wives in communicating their concerns. One of the clear themes which emerged from Graham and James transcripts, was that the diagnostic phase of the disease involved considerable emotional distress. The stressful events of the lump discovery and hospitalisation were described at considerable length, by five of the men. Only James, Graham and Gus directly voiced their concern about the cancer diagnosis. Gus said he was devastated by the diagnosis, and he focused angrily on the lack of support, information and congruent initial treatment his mate received. This participant was more reticent about expressing his own vulnerability, but these feelings emerged in the context of his awareness of Tamara's uncertain future. Gus' feelings of anger will be analysed in Chapter Eleven under the theme of anger.

Graham was the only partner who volunteered to speak before his wife, and he did so on account of feeling so nervous about the interview. Notwithstanding this, his verbal responses were delivered in a contained, affable and sometimes jolly tone of voice, from which I intuited he wished to defuse the often emotional content of his language. He also had the difficulties of speaking to a researcher who he hardly knew. He said he had no difficulty in expressing his feelings "as [he] came from a very emotional family", however, it was clear from Graham's syntax and nervous rushes of speech that he found it difficult to talk so openly about his, and his partners' intimate life with a relative stranger.

Notwithstanding these points, this participant, whose wife's mastectomy occurred a little over a year before our interview, spoke with enormous clarity about the meaning this experience had for him. One has a strong impression of his/their life/lives, being shifted onto a different trajectory than the normal:

How it feels like as a man with the trauma of the breast surgery. 'Spouse know you go along from day to day just making plans of what you want to do, and um all of a sudden there's this thing happening You know it will be ok then all of a sudden it hits you. You know, you find out that it is a malignant tumour.[and you think] Oh my god! [M1:p.18].

Graham was aware of Jill's previous breast biopsy/excision (ten years ago), and had lulled himself into the notion that this lump would be just the same. She had recently finished lactating, a period in which she had occasional bouts of mastitis, and he said that:

It wasn't very long after I noticed the lump, and I said God! you know. She didn't even know she had it, and [Jill thought] it was just quite a lot of thickening. And I said "God you had better go and check this out". And yes, yeah it was scary but you .. you... because it happened ten years ago and it was benign... you sort of tend, I tended to think that um... may be it was [going to be benign again][M1:p.18].

Graham described the brief hospitalisation for lumpectomy, and how positively the surgeon interacted with them. They were to be phoned in a week with the (expected negative) histological report. Graham was at home alone when he took a call from the medical receptionist, who requested they come to visit the doctor as soon as possible. Graham immediately realised the importance of this message:

It really hit me! I was stunned, [I said] "it obviously doesn't sound too good, he said "No, I don't know the full details of the pathologist [s report, and he] doesn't think it's normal, doesn't think it's ok." So um I'm off the phone and Jill's off shopping and I rang up Sydney to my parents and bawled my eyes out ! [M1:p.14].

Graham experienced this news as a huge emotional let down or shock, which in the context of our interview he gave every indication of still working through and making sense of. Two weeks following this, Jill had a radical mastectomy. As we spoke, Graham focused on the diverse difficulties of living with a partner who has a diagnosis of cancer. Firstly, he implied that the diagnosis was the start of a chain of psychic or feeling events which are scarcely imagined at the time of diagnosis:

You don't know what is happening, you don't know what the consequences of it are [M1:p.14].

This partner didn't ever refer to the hypothetical death of his wife, but his fear of death seemed to underpin his narrative. He referred obliquely to the risk every one has 'of falling under a bus', but this seemed cold comfort to a partner who, in the same week as our interview, had discovered another lump in his mate's remaining breast. (This lump was found to be caused by hormonal thickening). Graham suggested, that the threat of cancer loomed large in his imagination at certain key points in their lives:

With Jill having a bit of a problem with the other breast, it, it sort of all comes rushing back again. But you tend to sort of you know, go through the chemotherapy and well at least the um operation and the chemotherapy and, once all of that's over you sort of tend to go ahead with life you know. Not sort of think about it constantly, it's only, only when the periodical tests come along [M1:p.14].

The tests and appointments are somewhat double-edged swords for Graham, who wants Jill to be given every chance for survival, but the technologies remind him of his/her mortality and that of their relationship. Graham reiterates, that the statistical risk of death seems so much higher to him at these times, when it feels that his partner may as well be "lying on the road waiting for the accident to happen". Graham's pessimism at these times is suggestive of a deep fear of losing his wife. He implies a feeling of loss of control over a life that had previously more or less moved along according to plan. His uncertainty has great poignancy when he reveals his insecurity following the cessation of Jill's chemotherapy. Even though she continued the use of Tamoxifen therapy, he felt vulnerable by her not receiving further treatment.

Soon as the chemo was over, both of us felt it ..”Oh dear! We’re out in the open!” almost now the treatments stopped and we’ve just got to wait and see what happens [M1:p.14].

It was a scary, scary thing. [I thought] “Oh dear in a months time is something going to show up? [In] Two months time is something going to show up?” you felt that while you were on the chemo you were killing any sort of cells, or any cells that had gone through the system that Jill had two of her lymph nodes infected and it had gone through the system somewhere and waiting to start up again you know. You felt safe that it was killing any of those but did it miss any [?] you know, you don’t know, is there one sitting there somewhere. Now the chemo’s over, what is it [?] What’s it going to do [?] [M1:p.14].

I think the worst, the worst part about it all (I spose) is the not knowing [M1:p.15].

Graham interspersed his discourse with frequent qualifying statements, indicating that the commonsense reality of existence allowed him to think more objectively about the threat of cancer. “You start to look at it more objectively rather than sort of really freaking out over it”. This statement seems to indicate that he conceives experience is multi-dimensional, and can be viewed from within different perspectives, be they emotional or logical..

James situation was slightly analgous to that of Graham’s, because he had also through his partner’s recent hospitalisation and surgery. Like Graham, he had been relatively unconcerned about the outcome of the biopsy which preceeded the mastectomy. James had supported Lauren through the many years of unilateral lumpectomies, and, as they were all benign recurrences, he assumed that it would be another ‘normal lumpectomy’. James said:

I had no idea! none what so ever! Because, no one but we never thought she was going to be cancerous, as ridiculous as it is which is just how you think. “Oh! It’s only a lump! Take it out and it’s finished! You never think of that, and I never ever thought that she was ever going to get cancer, ever. You know it’s like a man going to drive a car and never thinking of an accident. But it happens just like that [snap of fingers] [M7:p.8].

This man experienced great distress and revealed he and his partner sought to overcome their fear of cancer by doing private research. James unconsciously reveals that he has absorbed a lot of information, but it hasn't helped to allay his fear. Indeed his narrative is one of fear and confusion, and implies an almost agonising sense of two conflicting points of view.

Very, very frightened, because, you know cancer is the big C and you think, well when she got it we didn't know much about it. Well you think cancer, that's it! you know? But when we sort of learnt about it after then, we, well they told us that it was just in the breast it wasn't in the nodes, so it was just in the duct in the breast tissue and it hadn't spread. Well, I wasn't happy them taking the breast off after we've learnt that. If it had gone through to the nodes or somewhere else, I don't think we would have made the same decision, because it, would have been too late, well not too late, but if it happens to go through the body and is dormant for who knows how long, and then they take the breast off would have been pointless really [M7:p.8].

He knew her lump had to be excised, but he was unable to give his unflinching support. This is a situation that he has been unable to control, and he was unclear about the need to take the whole breast anyway, because the cancer had not invaded the lymph nodes. Lauren was offered a lumpectomy and radiotherapy, but insisted upon a mastectomy in order to rid herself of recurrent lumps in the remaining breast tissue. In another part of our conversation, James remarked that he and Lauren had eschewed the option of lumpectomy and radiotherapy, because Lauren had found out from her readings that the latter therapy, “dried out the breast like a bit of cardboard”. (Lauren had her own reason to opt for mastectomy). It is clear that James is casting around for a safe anchor to attach himself to. He fluctuates between a reality that supports his own feelings as a sexual partner and a conflicting reality that supports his wife.

In regard to her prognosis, he also considers both sides of the argument, in a realistic way.

Well at this stage she's cured, but as far as I'm concerned she's got no cancer because nodes show it, the breast has been taken off and, and to me she's cured, but that does not, like the

books the research says that it's five years before you can say I'm cured right?

Like I said, the boobs not everything I rather her and no boob than dead, (you know ?) - that's the way that I look at it

You pay the price that's right, and this way you pay it with two breasts. And life will not [necessarily] be any different, like I think you're still going to worry about secondaries, (you know?), Will she get it in the bone? Will she get it somewhere else?(Right?). You've got to face it when it comes, it's no use worrying about it when it hasn't happened yet.

She's got no cancer at the moment, but, what else is going to turn up? She's had it once, you are susceptible to it, (right?) - and it does worry me, but I try not to think about it. Take it as it comes if it happens - it happens. At the moment she's clear you know, like she's had this scan done last month or whatever it is, and at his stage she is clear, but who knows? [M7:p.8].

James' incredible candour reveals an even deeper fear, that the cancer may simply present in another area of Lauren's body. Although he doesn't say so explicitly, James implies that his partner's lumpy breast may be safer than a prophylactic mastectomy. While James has wrestled with weighty and confusing moral dilemmas, he reveals a clear understanding of the potential mortal dimensions of Lauren's situation.

Gus' wife had undergone two bouts of cancer related surgery, a mastectomy six years earlier, followed four and a half years later, by an axillary lumpectomy. The overall analysis of Gus' transcript revealed a man with a largely 'get on with our lives' approach to Tamara's diagnosis. He tended to mock himself as a sensitively feeling individual, but was nonetheless extremely candid about his feelings about Tamara's diagnosis. When I asked him about the impact of the mastectomy he said, 'It hasn't done anything to me at all, sexually or physically'. He considered the impact of the diagnosis, as being "Um, devastating [M5:p.1]", and angrily described the protracted time period which elapsed between the breast lump discovery and diagnosis. Feelings other than those directed to external causes (that is, anger at the medical profession) were more subtly expressed, as they were meshed into his concern for his partner. He almost seems to cast himself in the role of her director, and all but makes her the

mouthpiece of his own/their joint concerns. At this point in his narrative, he was referring to the period in which Tamara underwent chemotherapy;

I think that might have been the worst period, where she felt down and out, and uncertain about her own life. Created a lot of trouble, a lot of, of, I think uncertainty would be it. What was her future going to be? How long is this going to hold off? Is she going to see her kids grow up and get married? Which was the main concern in her life, ah, so you've got all that going through your own mind. Whether it's going to be successful, whether she's going through it for shit, whether it's better off just leaving it alone. Are we really on the right path.

I think. Now I think with Tamara there's a lot of uncertainty in her own mind. Ah there's times where she just wanted to pack it in and say you know enough's enough, I'm not having any more and I'm sick of this, and her hair falling out ripped her apart a lot. Um, that was a lot of ... lot of consoling over the two of us I s'pose you know [M5:p.12].

Gus reveals his own experience of the chronic aspect of his partner's illness and their shared uncertainty of the future, and the efficacy and/or desirability of the surgery as well as the debilitating physical and emotional affects of the chemotherapy. There is the sense that the mastectomy experience of some couples is the beginning of many inter-related events which have the potential to span a time frame which far exceeds one to two years. Gus has witnessed /experienced his partner's second bout of cancer-related surgery, and her systemic treatment with Tamoxifen. He is sensitive to the fact that they may be living on borrowed time.

Reflections

The fear of death and loss of control of one's life as a result of the diagnosis of cancer is of course not unique to breast cancer patients. Because of its very inseparability from the mastectomy, (it is the rationale for the mutilating surgery), the issue of diagnosis of cancer and potential mortality cannot be viewed in isolation from mastectomy nor from the experience of intimacy. Thus, these men's meditations on the theme of mortality and loss of predictability of their shared lives with their partners have had significant repercussions on their intimate lives. We only need to cast back to latin etiology of the word 'intimacy' - "Intus meaning within, which is

related to intimare which means to make known (Weingarten, 1991, p. 287) to realise that the inner realisation of their individual 'potential provisional status as partners' must have affects on them as partners, as well as the individual dimensions of their lives.

Viewed from Weingarten's (1991) perspective of 'shared meanings within intimacy', all women voiced existential concerns regarding their mortality. Apart from Jill and Gemma, they did not reveal discussing or sharing their existential insecurity with their partners. James, Gus and Graham implied that even if they had not discussed their fears of an uncertain future directly with their wives, they certainly felt it keenly, and 'shared' it in non-verbal dimensions of their lives. Using Lang-Takac and Osterweil's (1992) conceptual framework of 'connectedness' or 'disconnectedness' as a guide, it is clear that men were generally uncomfortable about expressing their feelings, and were somewhat emotionally 'disconnected'. Women felt more open about talking about death and were more 'connected' to their families. All the women expressed anxious thoughts about the possibility of their children's motherless future. This is not to suggest that the verbal reticence evident in the partners means that they do not feel. Worden and Weisman (1976-77, p. 1), speaking of patients' existential concerns stated that "What [they] observed, was that patients can be distressed without showing overt signs, and considerable skill may be required before candid information emerges". From the verbal and non-verbal presentation of the male participants in this study, Weiman and Worden's words could just as easily be applied to partners as to patients.

Even though four of the men found emotional expression difficult, three of the women's partners were very articulate about how fearful the cancer diagnosis made them. Ivan (Gemma's husband), David (Sharon's husband), and Joseph (Gwen's husband) chose not to reflect on these matters. Of these three men, only Joseph appeared genuinely disaffected by the cancer diagnosis, and this may have reflected the fact that his wife has survived her breast cancer for seventeen years. As we will see in subsequent chapters, David and Ivan were deeply affected by the mastectomy experience, but could not seem to endure contemplating the negative contingencies implied in the cancer diagnosis. Imran, the remaining male participant, was not

Lucy's partner at the diagnostic point (five years before he met her) and, even though he realised there were risks attached to their aspirations of beginning their own family, his vision of their current and future life was very positive.

In conclusion, while all seven women indicated directly or implicitly that they had concerns about mortality, only three men reflected these concerns. It became obvious through the observational data collection as much as the oral history, that men were frequently unaware of the depth of their own feelings, about the mastectomy and the cancer diagnosis - and vehemently declared being disaffected. In some sense, there are 'shared meanings' within these similar themes. I believe that there may be day to day, unspoken, unreflected, shared actions within the life experiences which connote meaning, rather than formally discussed fears of existential angst.

CHAPTER SIX

Shared Meanings within Themes:

Women's Concern about their Husband's Reaction to the Breast

Amputation:

and,

Men's Focus on the Sexual Effect of the Mastectomy

yeah, not so much a fear as a threat I suppose it's the same type of a thing, in as much as you're not, I don't really like my breast being fondled because.... it's going to cause me problems one day, and a problem I really don't like to have. That's how I feel

(Lauren, wife of James; p. 130.

In, in a way, but once both of us made up our minds that it's [her remaining breast is] not there in a way (you know?) - because of the operation that she's going to have, with the other one (right?) and sort of both of us have made up our mind that it's not there (James, husband of Lauren; p.4).

Women's Concern about their Husband's Reaction to the Breast Amputation

One theme which emerged from the data analysis was that some women had early and continuing concerns that the mastectomy would effect their intimate, sexual relationships with their partners. Jill, Gemma, Tamara, Gwen and Lauren all indicated diverse concerns about their husbands' reactions, and of these, Lauren and Jill appeared to be moving through an active, relationship adjustment, and this reflected the fact that their surgery occurred just a year earlier than our interviews. Lauren was the only woman who directly stated that the mastectomy had any effect on her intimate relationship. Women did share aspects of their intimate lives which had been impacted by the mastectomy, but seemed to downplay their significance on their lives with partners. Analysing the transcripts, it almost seemed as if they believed 'things had returned to normal', as there was a distinct 'we've put it all behind us' feeling evoked from the surface narrative. Thus, in an overall sense, the women's explicit attitude to their surgery was that it made little difference to their lives with their partners, but a close examination of the transcripts revealed that the women implicitly had an underlying anxiety extending far beyond the immediate post-surgical period.

In response to my question concerning the impact that mastectomy surgery had on the woman's intimate relationship with her husband, Jill indicated her earliest concerns were with how her husband would feel about her changed body and whether he would still find her sexually attractive. She said.

It has in some ways, only because ..(not .. not that we don't want to carry on the same, um - Luckily). I did go through [a stage] in the early days [when] I used to think, "Oh how can he be attracted to me?". I was getting used to having one breast and I'd wear a little camisole to bed and things.

I mean now don't think twice about him seeing me naked.
He's been so fantastic about that - so reassuring [F1:p.10].

As we will see, Jill also indicates that the actual physical pain or discomfort that is often a corollary of mastectomy surgery is a major contributing factor in inhibiting intimate contact between herself and her partner. This was an intimacy which she felt he really enjoyed, and, while Jill does not make much of this, her words reveal a change in the way their physical/emotional life together has been altered in the wake of her surgery. In response to my question about whether she misses these affectionate bear hugs Jill said:

I do miss them. I do. Sometimes, he, [pause] occasionally he might really squeeze me tight and I'll, I'll let him, but it does hurt - and I wish it didn't.

And our position [in bed]. Our sides of the bed - we had to change our sides of the bed that we slept on and , and um, because he was frightened and I was frightened that he would roll over - (initially, when the wound hadn't healed and so we just stayed on the other side. ...Yes I suppose I don't really enjoy him - he's quite happy to touch me on my scar and that, but I hate the sensation, It's sort of numb - along my arm is numb. I don't even like touching it, it just is a funny sensation, it's not a pleasant sensation at all [F1:p.10].

Jill has drawn an extraordinary picture of the subtle behavioural changes that have occurred as a result of her surgery. She speaks of her husband's sensitivity to her tender chest wound. Her husband's concern is also evident in her account of their mutual attempts to protect her wound from being bumped. The mastectomy has interrupted the playful dimension of their intimate life.

Jill maintains that her husband has been very supportive. She has been unrestrained about walking without her clothes in his company (which she infers are non sexual situations) but indicates she is troubled by having him see her unclothed body while love-making.

I prefer the light off where lovemaking's concerned I'm not that comfortable. I'm quite happy to be naked in bed, initially I had to wear a little top and stuff, like a nightie, but now I'm quite happy to be naked, for Graham to even rub his hands

over me or whatever, (although I don't like the sensation on that [mastectomy] side. But, um, as far as walking around the house and that's concerned I'm comfortable, but where love-making's concerned I'm not that comfortable [F1:p12].

Although Jill never declares any sexual difficulties within their marriage, she implies that her own physical responses to her loss of her breast in her sexual relationship may be problematic, so that she does not have the same enjoyment of sex as previously.

The fact that they now make love with the light off (when prior to the mastectomy it didn't matter if it was on or off) indicates that she (or maybe they both) feel insecure about her altered body dimension. Jill's insecurity concerning Graham's feelings was expressed clearly in her response to a question I posed concerning the role her breasts played in their sexual foreplay. She said that her breasts were a source of pleasure in their previous relationship before she breast fed her son:

... until I had Jack [her infant] and then Graham always said they were never quite the same after I had Jack and breast fed [him]. They just didn't have the same feel. They were like a couple of milk bottles. He never had the same feeling afterwards [Laughter]. It became very functional. So I suppose, yes, they didn't have the same appeal that they had prior to having my child [F1:p.11].

Jill's mastectomy alone is not responsible for their diminished pleasure in her remaining breast. However, if having breastfed their child has in some way interrupted this couple's sensuous enjoyment of her breasts, then it is reasonable to hypothesise that her mastectomy may have had an impact on their sexual communication too. The very subject of intimacy suggests an underlying trust and loyalty. Each party would endeavour to tell their own story without jeopardising their feelings of loyalty to their partner, particularly not with a relative stranger, who they may be at pains to impress.

Gwen (59 years) experienced the mastectomy operation seventeen years ago. She recalled her feelings of insecurity following her return home from hospital, and

inferred that she thought there may have been a need to camouflage her wound in some fashion in order to maintain her attractiveness to her husband. She said:

Um, He was sympathetic, and I was too damned sore anyway until I got over all that infection bit ... but um, and of course by the time we did get round to actually being able to enjoy each other again um, he'd got used to seeing me like that. [F2:p.9] ...But I suppose we were still fairly awkward with each other in certain ways. He was rather frightened of hurting me and I felt, perhaps I wasn't sexy enough [F2:p.10].

The ambivalence within these two statements, revealed by the phenomenological research process highlights the strengths of this research method, for such statements offer the researcher a vicarious entry into the world of another person's experience. Although Gwen has been circumspect in telling her story, she has managed to convey a wealth of meaning concerning her feelings about her mastectomy, as well as convey her perceptions of her husband's feelings. She feels she will not be sexually alluring enough, and believes that he is fearful of hurting her. This fear she perceives he has, is probably a dual fear of hurting her body unintentionally - during lovemaking or sleeping beside her at night, or a psychological injury to his already wounded spouse's self-esteem.

Lauren recollected being very concerned about whether her husband would accept her surgically wounded body following her mastectomy:

I guess umm ... I didn't have a problem with my body image. Um ... I had maybe, I did have more of a problem of whether my husband would accept my body image. Myself, [Pause] I would look at myself in the mirror and say this is me, and it would hurt [F7:p.15].

She later said she had changed her negative image of her body,

[and I had visualized myself one way (you know?) and I had accepted the visual concept I had of myself, and as I see my husband accepting that and reassuring me about that [and] that was good, that was very, very good [F7:p.15].

Lauren's ambivalence about her own body image was certainly mirrored in the feelings her husband described concerning her surgery, and may have led to her constructing an idealised self-image to counter her husband's feelings.

Of the women participating in this research, Lauren revealed the most complex issues relating to her perceptions of how her husband responded to her. Her dialogue reveals much intra and inter-personal conflict concerning her remaining (cystic or "lumpy") breast. As I will discuss in the following Chapter, Lauren, anticipating (a self-arranged rather than medically imposed) second mastectomy had disowned her remaining breast, and didn't want it touched by her husband. She didn't like him touching her on her remaining breast because of lumpiness. Any touch served to remind her of the threat of cancer. She was able to cast more light on this feeling of threat in her coupled interview than she did in her solo interview. In the latter session, Lauren was much more emotionally warm, and seemed particularly vulnerable. This may have been directly connected to the fact that her desired second mastectomy had been scheduled for a week hence, and the enormity of the second operation seemed to have impacted on her. As she explained:

not so much a fear as a threat I suppose it's the same type of a thing, in as much as you're not, I don't really like my breast being fondled because.... it's going to cause me problems one day, and a problem I really don't like to have. That's how I feel. Not necessarily is it going to, but because of what all the doctors have said to me, with the the history of the right breast, and the history of this breast to what it is now, more than likely I'm going to get another primary, if I keep the breast. So it's always there, it's always that,... like and while you're nursing that, so it's all, .. like when, when the breast is being touched you sort of straight away, you're not thinking about.. the sexual connotation of that breast then, your mind reverts back to the.... what it's going to do to you later on .. perhaps. and you have that fear, and you just don't want to know about it. You just don't want it to be there. So therefore you don't want it to be touched, you know [C7:p13].

that's the situation. The way it will always be, because women have been made that way and men like it that way. If it wasn't meant to be that way we wouldn't of been made that way. It's an intimate part of the women's body for the man. It's an

acceptable thing, I mean even the Bible describes it, the breast as being an ecstasy for a man. So it's obviously that way. So then you are trying to... do the right thing by yourself, by your family, by your mate in the long run, saving yourself all this trauma and everything else. So of course you don't want to acknowledge it [very upset] because if you acknowledge it then you don't want to get rid of it. But you know it's best to because the doctors won't do nothing else [The doctors wouldn't needle biopsy all her breast lumps to assure her of their benign status] [crying] [C7:p16].

The psychological conflict that Lauren experienced is never more obvious than at this point in her narrative. She acknowledges that the universal pleasure that men have in women's breasts, but because of the ceaseless trouble she and her family have endured over her recurring breast lumps (with the incipient threat of cancer), she feels the most acceptable thing for her to do is to remove this threat via a second mastectomy. She is unable to acknowledge her husband's (or indeed her own) sensual delight in her breast, for if she "acknowledges it [she] won't want to get rid of it".

She was aware of her husband's pain, in the light of her reluctance to have her breast touched by James. She described how this had affected their relationship:

Mm.... not a great deal really, I mean umm - then I say that from my own point of view, not sort of truly knowing the other side [James side of 'the story']. I mean, once James said to me, "Well, once you have this operation done, um - I'm never going to be able to touch your boob again." And that touched me, and if I think about him, Think about that [statement], and I think about it for him. But then I think "Well, better not to touch your [her 'husband's'] boob for a while than not to be able to touch your woman at all in five or six years!"[F7:p23].

Lauren's language reveals her psychological distress, as she is caught between the fact that she knows her husband does not wholeheartedly accept her decision to undergo a second mastectomy. At the time of our interview, she told me that she and her female general practitioner had been trying to convince him that this was the best future course for Lauren:

Well that was when my G.P. ...wanted me to (she thinks it would be simpler for me to go and have it off, for all reasons

...- but primarily medical reasons, for the future) So um. But it's my decision. Now my husband has to join in on that decision, now he's never really been keen, but by the same token as he said to me, if it's what I want then he will support it. ... To my husband, the only reason you have a breast off, is for medical reasons, if there's a need to. So he's lining up with all these other males that he's heard say this, and that's fine from his point of view. So we [Lauren and her G.P] I'm trying to furnish him something, right? [F7;p.16].

Lauren is referring to her need to 'furnish' her husband James with convincing reasons for her mastectomy. Whilst she seems sure it is her decision, she is still troubled by trying to convince James [with her G.P] that this is the right decision. Some of Lauren's inner turmoil may be explained in part by her religious beliefs, as she had mentioned -in relation to her intention to miss a mammography screening some years earlier- that:

And I said, "Oh forget it, don't worry about it, it's OK. And he said to me "Well, if you don't make the appointment, I will and I'll take you there"

Now our religious teaching tells to, we are to be in subjection to our husbands, to the extent that we take note of what they want for us you see. Not to the extent that we are doormats but we listen to what they say to us. So I thought about that and I thought "Yes I s'pose I'd better do what he tells me to do." [F7:p.3]

It is obviously important to Lauren for her husband to be convinced of the necessity for her further surgery. She is often so consumed by her own need to be rid of the emotional turmoil that her recurrent breast lumps have caused, that she understandably seems to 'leave James behind' or at the periphery of her consciousness. Her whole physical and emotional demeanour put the lie to any notion of her being in subjection to her husband, as she had a slightly rebellious tone, and was frankly iconoclastic when referring to the male members of the medical profession. This notion of subjection to her husband she refuted by saying that female members are not expected to be doormats, however, she is obviously torn between what she perceives as the right course of action and the need to please her husband.

When this suffering woman is able to focus on her husband's awareness of their situation she does so with extraordinarily clarity.

Quite obviously, Lauren is looking at her long-term prospects for a healthy life, free of the threat of breast cancer, and whilst she recognises that this is a painful process for her husband, she implies that these events have been and continue to be much more traumatic for her.

As a participant researcher, it was somewhat perplexing to me when Lauren made these observations, for while her words were full of the most delicate meaning, her verbal delivery was fast, and only softened slightly from the unvarying, (almost) angry intonation in her voice.

I asked Lauren if she thought that her life would return to normal following her anticipated second mastectomy, and if she thought she would be able to give more of herself emotionally to her husband when her mastectomy was complete. She replied:

That can only happen, I'm hoping that will happen - but that can only happen in accord with the way that James looks at things. To me, that's real. We both know that . And so, at the moment (I mean) there are still some difficulties there, although *we made the decision that in himself it's gone* [That is, her remaining breast] [My italics] [F7:p.23].

Lauren's own words reveal how aware she is of the difficulties she and her husband are facing together, and also how much she wants him to agree to her breastlessness. She says that they made the decision that her [remaining] breast was already amputated in his mind. Parts of Lauren recognise the difficulty her husband is having in accepting her surgery, but other parts seem to need to deny this reality and quell his concern. Perhaps this is the only way she is able to order her world in order to endure as little anguish as she can.

Reflections

This unusual situation provides a unique opportunity for us to attempt to understand the complex emotional responses that some women face. All women who have mastectomy operations experience unique events, however, Lauren was actively seeking a second mastectomy which her husband is unsure about. The fact that she had been unable [at the time of the interview] to find a surgeon willing to undertake her surgery, which makes her story an unusual one. Her relationship she acknowledges was troubled prior to her breast problems, but it is certainly true that her chronic breast lumps and cancer have proved to exacerbate this relationship. Lauren's accounts highlight the extreme ambivalence which may confront women contemplating mastectomy, in their need to appease their husband's needs, in elective total mastectomy. This point begs the question about whether women are offered segmental breast excision (or lumpectomy) versus a mastectomy. At major hospitals in Perth, Western Australia, women are being offered lumpectomy by surgeons in increasing numbers, as research has shown that women's survival rate is not increased by total mastectomy [National Health & Medical Research Council, 1995]. A lumpectomy is viewed as a more palatable, less traumatic option, and is considered more appealing from a cosmetic point of view.

Before her mastectomy, Lauren was asked if she wanted a lumpectomy, but chose mastectomy because she feared that the surgeon would not have been able to remove all the cancer, and she feared the radiotherapy treatment they advised. Four of the women in this study refused lumpectomy, choosing a total mastectomy for the same reason as Lauren. This suggests that the research findings are not being appropriately understood by women or not presented well by physicians, who may themselves not actually believe that lumpectomy is as 'good' as a mastectomy.

The nature of the female breast is so overlaid with symbol and myth, it is so brazenly objectified by the media, so representative of a male sexual plaything that it is little wonder women have misgivings about their husbands emotional/sexual responses following their surgery, even though this intervention is seen as essentially healthy and life-saving. Extending the analysis already discussed in the theoretical literature concerning the body, Ussher (1993, p. 23), writes that:

The promotion of these images of 'perfect' breasts makes the average woman feel imperfect, and makes her conceptualize her visible breasts - rather than her less visible vulva- as her main erogenous zone. This can result in the need for psycho-sexual counselling for women who have undergone breast surgery, and as a result of it see their sexual life as having ended.

Some women who have experienced mastectomy may feel threatened by the fear of their husband's rejection or indeed abandonment of them. The women's accounts we have reviewed in this chapter imply the fear of their husband's rejection in the early post-operative stage, but they have adapted, or are still in the process of adapting their relationship as a result of the mastectomy. Women in my research responded in a similar fashion to those in Hilton's (1993, p. 95), who stated that post-operatively "although they had pretty well no sex life for three months following mastectomy, most felt that they were still intimate as people."

Some of the women in this study have revealed that their husband's response to their changed body and indeed the deep seated psychological changes that they and their husbands underwent in the aftermath of surgery were of significance to them. The narratives of the women are quite different and shed some light on the varied effects that this surgery may have on the intimate lives of women undergoing mastectomy, their sexual partners and their families. The fact that these women focused on their partners responses to them is itself indicative of the fact that the sexual partner is a crucial person in the ultimate rehabilitation of the woman. Three of the seven women who participated in this research had major concerns about their husbands following their surgery. Gwen, who had her surgery seventeen years ago - was very settled in her relationship, while Jill and Lauren who were only a little over a year post surgery at the time of their interviews, were still I believe, actively moving through an adjustment continuum with their partners.

My analysis has highlighted that these couples' narratives have the potential to assist other women and men living in the aftermath of mastectomy. These experiential accounts could also act as meaningful and direct means by which to sensitise health-care workers to the complex needs of women undergoing mastectomy, and their lovers.

Men's Focus on the Sexual Effect of the Mastectomy

All seven men in this study stated that the mastectomy had not affected the intimate, sexual side of their relationships but, in the light of the overall analysis (perhaps characteristically) most channelled their insights concerning sexuality within the partnership to how their wives had been affected. From the stories of the women and the themes highlighted by the men, this one-sided perspective is possibly a simplification of a much more complex interpersonal renegotiation of the intimate relationship in terms of physical limits (congruent with physical or emotional distress) involving both partners. Toughill (198, p. 416) suggested that "The sexual partner needs time to adjust, just as the patient does." All the male participants except James were unconscious of the fact that they too were making, or had made adjustments to the mastectomy event. Fogel and Woods (1978) found that the quality of the marital relationship pre-operatively influences the marital relationship afterward. This finding had good fit with this study also, as couples who expressed their premarital connectedness tended to articulate even stronger bonds as a result of the mastectomy. However, this 'strengthening of bonds' did not mean that the sexual relationship had been unchanged, even while individuals or couples were at pains to deny it. The male participants' propensity to deny the physical/sexual and emotional impact on themselves may reflect their need to confirm to a traditional strong male role identity. Role theory and how it applies to the men in this study will be discussed in a subsequent Chapter.

Graham said there had been no change in response to my question regarding the effect of the mastectomy on his intimate relationship with Jill. When I probed for clarification, he responded: "No, um, libido wise, no [change] [M1:p .11]". However, he went on to explain that the effects of the chemotherapy and a relapse of an old depressive illness had affected Jill's libido.

Though Jill's part of the depression that was nothing to do with the cancer or was... had, had a problem with, with her

libido, she's since. since had some treatment, and it's improved, yeah, so um.

The cancer and the operation hasn't had anything to it's sort of um lulled and improved after the chemotherapy and that, mm, no problem [M1:p.30].

As has been inferred in prior dialogue, the mastectomy had multi-factorial effects on Jill and Graham's family, particularly in regard to their little son's routine. Their child's disrupted sleep patterns, which both attributed to the trauma of the hospitalisation and mastectomy, restricted their sexual opportunities. Graham put it succinctly when he said:

As I say we've got a three- year -old around so it's really difficult [Chuckle]

It's been as one can expect with a three year old [Chuckle]]
They're the greatest contraception out, aren't they? [Chuckle
]][M1:p.30]

While this disruption in child rearing may appear as no insurmountable problem, this difficulty, with its effect on their own sleeping arrangements, implies that this couple may have endured a protracted adjustment in the light of these reduced opportunities for physical and emotional sharing of intimate moments. Of his actual sexual interplay with Jill, Graham revealed his fear of harming his partner was a central concern,:

You find, if I embrace her, squeeze her, I wonder if I'm going to hurt her, hurt her scar or something. But she lets me know if it hurts or something. No, not at all, I sort of ..One of the things that I've had in my mind that I'm not to be afraid of being intimate um with touching that part of her [M1:p.31].

His words imply that although he knows he shouldn't be afraid of touching Jill around the site of surgery, he still is. Certainly, his descriptive account of her wound in Chapter Seven concerning men's feelings about their wives' mastectomy revealed that he had adjustment difficulties in relation to Jill's altered body.

Schain (1988), suggests that mastectomy threatens mortality and may trigger the man's fear of losing his woman, (which has certainly been one of Graham's greatest

concerns). These fears, she claims, may elicit feelings of powerlessness that may seem intolerable.

Paradoxically, instead of dealing with the reality and spending more time with the compromised immortality of the spouse, the husband may withdraw affection and sexual energy as a form of self-protection.

Issues touching upon men's reactions to mastectomy are complex, revealing ambivalent feelings partly obscured in the participant's language. Men who commit themselves to caring relationships could be faced with a classic double bind. They probably realise, in a purely visceral response, the visual and tactile aberration that the physical reality of mastectomy entails, but block out the outrage and pain of this insult in an effort not to hurt the feelings of their partner. This probably means that he tells his partner everything is alright for him when it is not. She possibly intuits that everything is not OK, but maintains the status quo in order to appease her mate. Such blocked communication possibly harbours distrust, and may have been a part of the difficulty Jill and Graham encountered in their own (apparently resolving) communication breakdown.

Ivan shared common experience with Graham in so far as he supported his wife through her mastectomy within two months of the time Graham had. So. It may be that these men mentioned their sexual lives on account of the fact that they remained at twelve to fourteen months, so relatively close to the time of surgery. Ivan said that Gemma's mastectomy had made no difference to their sexual life together, and that their physical expression of intimacy proceeded along familiar ground:

.. as Gem said um, we both like Gem to be on top, or dominate as you call it, and ah it just means I've only got one breast to play with rather than two, but no, it sort of, that side of it hasn't made any difference [M6:p15].

m,.. well I used to caress her breasts, you know, I suppose quite a bit, but um maybe a bit more sensitive now to being over caressed. Um,.. she still likes to have her breast kissed and titillated I suppose you could say. but um,.. it tends to get

too sensitive if I do it for too long um, I suppose before I could share it between both breasts and now it's sort of, but ah ... yeah, I make sure she tells me if anything is upsetting her or hurting her or if she likes it or doesn't like it, sort of we just go from there [M6:p15].

Ivan is refreshingly candid about his sexual life, and, he reveals that the adjustments he has made are grounded within a shared, sexual context. He shares the fact that he has only one sexual plaything instead of two, and, in response to a question I posed to him in the light of his wife's account of his fondling her false and remaining breasts - he said;

Yeah I do it deliberately, I um, I was determined not to, to make it obvious that I was touching her left side more than her right side, so if

I ... if she's washing the dishes I come up and grab both sides of her. And I think it has definitely helped, makes her feel more normal than anything different [M6:p.6].

Of the men's narratives, Ivan's was the most open concerning sexual intimacy. Like Graham, he feels that the treatment events around the mastectomy have impacted on Gemma's libido rather than his own. Ivan revealed that her Tamoxifen therapy had created menopausal effects, which he attributed to a diminution in her libido.

No I don't think the mastectomy has, no. Um,.. I think it's sort of, I think Gem probably told you about [vaginal] dryness and a few things like that but, and um, she probably ah, doesn't want to make love quite as often, but it sort of hasn't been a problem, as such [M6:p.13].

Ivan expressed no difficulty in touching his wife's mastectomy wound , and even said he regularly massaged it. He seemed to have a total sensual enjoyment of his wife, revealing that:

She likes, likes to be kissed all over so, and um, it [her taste] sort of has changed, but it, it didn't change straight away, so I think it's more the effect of the Tamoxifen rather than the

operation. I think that's one of the effects of, of menopause I think is, not that I know that much about it [M6:p.13].

Of the men who shared intimate aspects of their sexual lives, Ivan appeared to have made creative adaptations to the physical, corporeal changes the mastectomy brought to their lives as lovers. Krumm (1982), posited that sexual validation from a partner may signify acceptance, allay fears and provide encouragement to endure the disease process. Ivan seems to be opting for life-sustaining sexual expression rather than consciously thinking about his partner's mortality.

Although on the surface Ivan's narrative suggests there's little been little difference in their intimate lives, other aspects of his narrative (already explored in the above themes) indicate that this adjustment has been fraught with the deepest of feelings, both for his partner and by himself. I suggest that Ivan's own testimony infers that these emotional aspects of his adjustment process are inseparable from the shared reality of loving and making love. Of the couples in the study, Ivan and Gemma were the only participants who mentioned love within the framework of their conversations with me.

Gus also mentioned his sexual life, asserting that - "It hasn't really done anything to me, sexually, physically, any way at all[M5:p1]". He is unable to closely examine his own feelings in relation to making love, apart from speaking empathically of Tamara's (unconfirmed) reaction to him touching her scarred chest:

Oh, I get the feeling that she really doesn't want to be touched there, (you know). Ah, she's never said anything, ah, she still comes to bed with no top on. No. (You know) I'd say it's, I'd say if you rub your hand over it, she doesn't push you away or anything, she more or less.... it's probably nothing, it's probably a normal feeling every woman has, I don't know, (you know?) [M5:p6].

This begs the question, is Gus afraid to touch his partner's wound. Is his intuition correct or does he use this hypothesis as form of self protection? These questions raise the issue of just how much more difficult it may be for partners to be sexually open and honest following mastectomy than couples not affected by this surgery. This

vignette casts a sliver of light on the myriad, complex non-verbal, 'intuited', interactions which comprise the lived sexual experience of couples. Whether his intuitions are valid, and represent the truth within their shared experience of intimacy is the sort of detail that requires 'checking out' within partnered situations. Gus said he 'didn't know' if he was correct about this, but his hunch was correct, as Tamara told me she didn't enjoy being touched across her wound. Gus also revealed that he was careful to resume sexual activity soon after Tamara's return from hospital, as he didn't want her to believe his sexual desire for her had waned, which he believed could have had disastrous consequences for their relationship.

As already highlighted, James' narrative describes a husband with many unresolved conflicts concerning intimacy, his inability to understand or feel intimacy with his mate, together with marked feelings of ambivalence relating to Lauren's first mastectomy, (just twelve months ago), and her yet to be scheduled (second) elective mastectomy. James referred obliquely to his sexual life many times, but also revealed that he and Lauren had a long-standing marital problem.

And we've had difficulties, like ah ... in our sex lives, but not because of the operation. Other things come up, but that [mastectomy] helps to [make the relationship worse], if you let it, it could compound it, (you know what I mean?) ... ah ... her having a mastectomy [M7:p.3].

As already posited in the discussion about the impact of the breast amputation on husbands, in James' case it was clear that he placed a high value on the female breast as he faced the fact that her remaining breast would soon be gone forever:

It's fact's a fact. It's still there, you know. And I guess, well I (the way I look at it), is while it's still there, I may as well enjoy it, (you know?) - for like the rest of my life..... I'm not going to have that anymore, you know what I mean [M7:p.4].

His tenuous emotional and sexual needs were further confounded by Lauren's insistence her remaining lumpy breast was non-existent:

In, in a way, but once both of us made up our minds that it's not there in a way (you know?) - because of the operation that she's going to have, with the other one (right?) and sort of both of us have made up our mind that it's not there [M7:p.4].

While these quotes have been cited in discussions above, they reflect so fulsomely the sexual torment of a man put in a seemingly untenable position. Emotionally, James wants and needs to touch his wife's remaining breast but, in the appeasement of his wife - has colluded against his own desires by symbolically, almost amputating an object of his desire.

Reflections

Of all the men's definitions of intimacy, James' indicated that although he remained confused about the meaning of intimacy, he viewed it in essentially sexual ways. He said that men want sex, but women want love. It appears that Lauren is putting her husband to the "ultimate test of love". In the light of the cultural ascriptions of the female breast, the extenuating circumstances of this man, and the acknowledged marital/sexual difficulties he had already experienced, it is perhaps not surprising that he had few emotional props to fall back upon when the quality of his sex life was diminished. The sexual implication of the female breast as a principal determinant of attractiveness, gender and desirability is nowhere more obvious than in James' brutally honest words;

I've always found, yeah,... you know I mean to me it's like going to bed with a bloke if a woman's got no breasts, now that's what it looks like. But you've got to learn to adapt is all, you've just got to learn to overcome that ... that feeling [C7: p.11].

James and Lauren's experience of intimacy and mastectomy appeared to have the most 'phenomenological rigour' insofar as their dialogue seemed almost entirely free of 'pre-reflection'. Both were more anxious to talk, and mercurial in their speech patterns, which made considered reflection almost impossible. This meant that the meanings they attributed to the phenomenon of intimacy following mastectomy were

'multi layered' 'overlapping' and 'sedimented' into the transcripts. This 'overlapping' or indissoluble quality of some of the thematic threads of intimacy is nowhere more evident than in James' dense, subjective accounts of his traumatic response to mastectomy.

James had other aspects of his sexual life which he shared, but these dimensions of his intimate life could not be directly attributed to the mastectomy, and had greater congruence as illuminating a 'disconnected' emotional life.

While the remaining male participants made passing comments on the non-existent impact of the mastectomy on their sex lives, apart from Joseph, they all revealed in subtle ways that there had been adjustments in other areas of their lives that impacted on the intimate, shared experience. Sexuality is as broad and slippery a concept as intimacy, and for this reason I have concentrated on the directly given descriptions of sexual intimacy. Other chapters explore different aspects of intimacy. Sexual intimacy is implied in subtle behaviouristic ways, and in these passages, I assist the reader to explore the hermeneutic meanings of language in an effort to glimpse 'phenomenological moments' of intimacy following mastectomy.

CHAPTER SEVEN

Shared Meanings within Themes:

Women's Sense of Loss in Relation to their Body Image and Men's Feelings of Grief and Loss

"..every now and again I notice women's breasts now, (you know) , you notice um, in movies you see these big voluptuous women and I never used to notice that before, not consciously notice it , so I guess really deep down, (I'm not saying I'm kidding myself), I just know that deep down it has made an effect, it has , I am aware of it".

[Gemma, wife of Ivan p. 18].

I think the only time when I sort of regretted it I think was, actually in the ... in the um specialist's rooms, when the decision to take the breast completely was made. For I, think it would have been for about five minutes. I.. thought, oh what a waste, and then I thought, Oh that's a selfish way of looking at it. But yeah, I did have that thought

[Ivan, husband of Gemma: p. 18].

Women's Sense of Loss in Relation to their Body Image

According to the literature, any surgery, accidental injury or disease which effects the integrity of a person's skin, appearance, or bodily dimension can have profound affects on the individual's view of her/himself. Fischer and Cleveland (1968) defined body image as a psychological experience which focuses on the individual's attitudes and feelings toward her/his own body. A simpler definition is found in Schilder's earlier (1950, p. 21) work on body image; "The picture of our body which we form in our mind, that is to say the way in which our body appears to ourselves". Schilder's landmark work of body-image disturbance in people affected by amputations (published a decade after his death) prefigured Merleau-Ponty's later formulation of a phenomenological understanding of the body-image. I will return to both writers later in this chapter, most particularly Merleau-Ponty, for his theories on body-image expand upon the philosophical and methodological premises developed in earlier chapters.

Carroll (1981, p. 29) referred to body image as "... an interrelated phenomena including the surface, depth, internal and postural picture of the body as well as the attitudes emotions and personality reactions of the individual in relation to her body as an object in space, apart from all others". Price (1990) also described body-image as a dynamic construct involving a triad of concepts - these being: i) the person's feelings of bodily reality; 2) the person's ideal body; and 3) the person's bodily presentation.

It became clear as I analysed the data, that elements of Price and Carroll's constructs of body image were evident in the participant's stories. These constructs emerged as significant statements as the women frequently described their bodily reality in relation to ideal images of femininity, as images of feminine presentation (meaning feminine apparel) or of their emotional responses to their altered body shape. Even though these women who have undergone surgical amputation of a breast are able to be publicly representative of 'normal womanhood' with regard to their physical shape (with the use of breast prostheses) this, (as we will see) didn't appear to safeguard

them against a private feeling of longing to be whole again. Although none of the women spoke of a wish to be whole in an explicit way, from the language used and the tone of the women's voices they expressed an underlying desire to be whole. Thus, these women's accounts of others' breasts or inanimate objects associated with "normal" - (that is double-breasted physiognamies) served to highlight their sense of loss, while at the same instant relating very much to their bodily reality, and has emerged as a theme in the data.

Gwen, who was one of the two older women participating in this project, revealed her feelings about her breasts before and after her mastectomy in these words:

There was never enough of them. I mean now I've got half the bosom I've always wanted - [Laughter], because all your hormones go to the other side [remaining breast] and it swells up most beautifully. [Laughter] I never had as much as I wanted, but it did affect me afterwards, because, although I'd never been one for black lingerie, the sex bit like that, I would suddenly find myself in front of black lingerie in [a department store] or something and I'd be looking at these sexy nighties and I'd think "Christ, what the hell am I doing here.!"but it was the .. um .. sort of deep sadness I think that I'd never be able to flaunt myself again. Yeah, its a shame because I think you need to feel that you can [Flaunt yourself if you want to [F2: p.8].

Although Gwen's longings are triggered by external cues, she is obviously reliving a deeply internalised yearning for the breast she no longer has, and these feelings are connected to her sexual being and intimate life as she says she won't be able to play the temptress again. Even though Gwen made light of these feelings, her language reveals how sensuously connected she is to her remaining breast when she said "...it swelled up most beautifully", implying that the flatness, and possible puckering of her own skin-grafted wound would not have been easy for her to adjust to. Gwen tells us a little about her feelings in a jocular manner. Gwen did not describe the appearance of her wound other than to talk of the surgeon performing a wide excision of tissue which entailed grafting of skin from her thigh, and a subsequent wound infection. However, she described constantly visualising the word mutilation on the hospital walls, but the last "T" was missing [mutila-ion]:

[Laughter] But of course, about the emotional bit in hospital, all the way on the walls I could see this word mutilation with that last T lopped. You know ? That was the way I could sort of see the whole lot.Yes, so very vividly I saw it like that. Yes, very visually. Sort of theoretically visually. Not physically visually [F2:p.7].

What is interesting about this and other aspects of Gwen's dialogue is how her spoken narrative, seems to conceal and reveal meanings about her perceptions of herself. Her chipper tone suggests superficially that her mastectomy had relatively little impact on her body image. She described her complicated surgery matter-of-factly, and then drops a broadside in the form of her symbolic (externalised/depersonalised) representation of her mastectomy in the form of the startling word 'mutila-ion'. Although she initially described this as 'the emotional bit', her form of poetic description may have helped protect her wounded self-image. Her culling of the second T from the image of the word may have been easier than visualising herself as mutilated. This interpretation has good fit also with the 'externalisation' of her inner feelings concerning her changed body shape and changed patterns in sexual play, by focusing on intimate apparel for females.

Jill (37 years), who was one of the youngest participants when she had her mastectomy, was very aware of her altered body shape, and her mental self-image of her body was largely negative. The first words of her interview revealed a male/female dialectic between her remaining breast and the mastectomy site:

Right, well - I have two poses in front of the mirror. One side of me is a little masculine and the other sides my feminine side. [Laughter] If you don't mind me saying, that's the way I look at it. [Laughter]. Its actually fooling myself to think of them [as normal] it looks quite normal if you stand on one side and look in the mirror. Nice. But no, as a woman its just been [pause] I've been grateful I suppose that things got caught when they did and then coming to terms with it as a woman. Its... [Pause] It is hard when you see women with flimsy tops on or maybe no bra and I feel like running up to them and saying " Enjoy your breasts [Laughter], you mightn't always have them" and that sort of [Pause] but I manage [F1:p.1].

These two examples give a clear sense that these women are confronted by the visual reality of their unilateral breastlessness every time they look in the mirror or look at other women's breasts. Jill's dialogue is particularly poignant when she hesitantly suggests, just how difficult it has been for her as a woman coming to terms with her mastectomy, "It's just been It is hard when you see other women I feel like running up to them in the street and saying enjoy your breasts!" Like Gwen, it seemed important for Jill to see herself and be perceived as strong and 'not be a whinger', so it is not surprising then that she says, "I've been grateful I suppose that things got caught when they did, and then coming to terms with it as a woman - but I manage [F1:p.1]".

Jill's apparent need to perceive herself as strong and in control was subsequently borne out when I telephoned her to enquire about her feelings and thoughts after reading her interview transcript. She revealed that she felt disgusted at the degree to which she had indulged herself in what she thought was abject self-pity during her interview, and she'd had to put it (the transcript) aside for a few days. My own perceptions of the conversation were in marked contrast to Jill's. She revealed herself to me as a vulnerable woman who was still in the process of coming to terms with a major life event, but whose responsibilities in life allowed her little opportunity to reveal her own inner feelings. The depth of Jill's feelings was evident on numerous occasions throughout her interview, most particularly in her facial expressions and voice intonation, which were sad and very soft.

Jill revealed that before her mastectomy she had always wished for larger breasts, or at least large enough breasts to show some cleavage :

I used to enjoy not wearing a bra too sometimes because I was small enough to be able to get away with it without looking too vulgar or ... but now I know I just can't have that breast [F1:p.2].

Like Gwen, Jill's experience of mastectomy has altered her perception of herself. She no longer sees herself as the same as other women, her image of her torso is that she is half woman, half boy. This break in self perception is compounded by her present

experience as a woman with one breast when historically she has enjoyed both her breasts as sensual organs:

It just takes, its, definitely sensuality there - having two breasts compared to one, it's just [There's no getting away from that] .. as much as you would try to, or try to convince yourself that they're not, but they are, they are a sensual part of living [F1:p.12].

Jill's feelings of strangeness with her new appearance and somatic feelings are echoed in Girgis and Foot (1995, p. 47), citing research undertaken in Europe by Muti, Triacca, Varetto, Balocco and Nicoli, who revealed that in:

88% of [50] patients, their own body image was felt as impaired by the fundamentally aesthetic and functional attribute and that they also admitted to a certain unease on looking at or touching their own bodies, especially when they were naked.

Now that Jill has only one breast, her feelings of sensuality have diminished, and, although she maintains she is able to be open concerning her own nudity with her partner, her sexual self confidence has been undermined. She now : “.. prefer[s] the light off, where lovemaking is concerned I'm not that comfortable”. It is scarcely surprising that this woman has difficulty making love to her husband with the light on when she feels herself to be half woman half boy. There is some implied similarity in Jill's timidity to Gwen's experience of feeling she would never be able to flaunt herself again.

Furthermore, Jill explained that there had been major adjustments to her sexual life on account of her altered self image:

There have [Been adjustments] I wouldn't feel comfortable, um.. I suppose in a lot of positions [coital positions] that we may have had in the past because it's just too much of a reminder - it's there! [the mastectomy]. I don't want to be reminded of it [F1:p.12].

Even though she did not elaborate on this point, the implication is that the capacity for mutual spontaneity and joy within her intimate relationship would probably be diminished because of her sexual self-image.

Jill also described her loss in the sense of being disturbed by the flatness of her chest, the linearity of her mastectomy scar, and her lack of nipple:

If you could still have the nipple and not even the breast you'd feel like you had something, but to just have a line on your chest where everything used to be, it's very severe. ...one side of my chest is just completely gone. I look like a man [F1:p.3].

Again, she refers to herself visually, as looking masculine, and seems to infer that even men have nipples. When previously breasts were an important part of her sense of being a woman, and an integral part of her sensuous life.

Jill had also breast fed her child, and she said that this role was very important to her:

I felt that I'd breast fed my baby for sixteen months and it was really special to me - and he absolutely [Pause] we used to say he's always been in love with my breasts - [her baby] , so losing the breast was really quiet devastating for Joe [her babe] [F1:p.12].

Jill was obviously proud of her son's sensuous delight in her breasts, and is now constantly reminded of her status as a single breasted woman. Even though she stopped lactating six months prior to her mastectomy, eighteen months later, her son is still seeking comfort and reassurance (that her remaining breast is still there). She laughed as she said, "I suppose one day Joe will decide he doesn't want to put his hand up my jumper any more" [F1;p.11].

Tamara relived her experience of her newly witnessed breast wound:

And I can remember just looking in the mirror and saying how gross it looked.I think it was just a look side on at the side I had, ... and it was just so flat and no flesh or anything ,compared to the other side. I did sort of think how horrible it

looked, and I thought that (you know) it wasn't a very pretty sight for even Gus to have to look at ...[F5:p1].

Tamara only twice described her mastectomy scar in these negative terms, and thereafter she spoke of it in terms of her sense of loss on behalf of her husband as a man living in a marriage with a wife with one breast. This is not to suggest I wish to diminish Tamara's subsequent comments in any way, as it was patently clear that her self-image was intimately associated with her husband's view of her, her use of the 'second person commentary' my window into her world. Tamara said her mastectomy had forced her to change the way in which she dressed, and revealed that her womanly appearance was an important part of her enjoyment of her relationship with her lover. She found that this change was:

... really frustrating, because, not so much in winter when you can 'rug-up' and everything, and I mean this, I suppose that this is where I feel sorry for Gus, because I know he sort of likes low-cut dresses and you know, especially if you're going out dressing up and things like that. Whereas now [as a mastectomate], if I get something sort of cut down a little lower, I have to always wear a high camisole or something like that. Not that Gus minds that but um, I don't know I still sort of wear little teddies and things to bed [chuckle] and things like that sort of- but it is frustrating. Like with summer, you can't really wear anything cut away, because you're sort of flat and you've got no flesh on that side, and even bending over (because you've got the prosthesis on that side) -it sort of gapes - and if you've got any tops that gape, [others] can see straight down there! [F5:p.2].

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This change in Tamara's clothing style has obviously affected her feelings of femininity and she inferred that since her mastectomy she misses having what I have called 'glamorous confidence' of being whole and able to fill her bodice and entice her man as she did before. Tamara describes this nebulous yearning thus:

Yeah I suppose really ...you can get gorgeous little teddies [lingerie] and things like that, and I feel that when I put them on they just look terrible 'cause it's really flat on one side. ... I suppose I think [about it] more for Gus - you know what it's like [and] he doesn't seem to bother or mind or anything but I just think it would be nice [F5:p.5].

In spite of her initial feelings of revulsion when she saw her mastectomy scar in the hospital, she was open about showing her wound to her husband and three children when she went home, and the family members acceptance of her changed body was a large part of her recovery.

That's why I feel for women when their husbands can't handle [the woman's wounded body] or when they don't even want to look at them or anything, cause I think it would be just so terrible, because I think it's a big part of the woman's recovery really. So, [in Tamara's case] it's been really good in that respect. [F5: p.17].

Lauren is the same age as Tamara, but was forty-one when she underwent her mastectomy surgery a year prior to our interview. Prior to her mastectomy she said that breast stimulation had been a large part of her sexual life with her husband. Indeed, as well as losing the sensuality of the amputated breast Lauren has also lost her sense of pleasure (and even ownership) in her remaining [now lumpy] breast.

I've already been like that for twelve months. Since I don't like it, I don't want it, so my reaction to it is, (as regards the sexual side) - is, don't touch it, don't caress it, don't do nothing because I really don't want it. I really don't want it to be part of me. And I really don't want you [her husband] to want it to be part of me [F7:p.22].

Lauren's words effectively dissociate her from her unwanted breast by depersonalising it. She always refers to her breast in third person language. An integral part of her is now known as a impersonal, externalised 'it'. Moss (1978) cites Struass (1967) who, in critiquing everyday understandings of body-image, emphasised that the human 'lived body' (a concept I will expand upon later) is never experienced anonymously as the body but rather as mine, as my own body far more intimately acknowledged than objects known as mine:

What must be remembered however, is the extent to which in pathology this owning or affirmation of the body and its parts as my own is to a greater or lesser extent disrupted. In standard psychiatric terminology, this pathological phenomenon is called depersonalisation (Moss 1978, page 87).

Moss (1978) in work with obese people, revealed a commonly manifest depersonalisation phenomena, and observed on his research subjects a process of differentiation (the body/body-part is different from "me"). He asserts their position is untenable for the process of differentiation is a psychic attempt to ward off 'external' [not integrated] reality, because the "not me" body/body-part continues to be dragged around by the inhospitable host. Moss considers this to be a,:

....sign of a serious disorder in self-world relations since, as we have said, when part of the body is depersonalised and disowned, the same happens to functionally related regions of the world (1978, p. 87).

My deliberations infer that Lauren's objectification of her remaining breast may have far wider ramifications than her body, that it touches on her intimate relations with her husband, her doctors, indeed her whole world.

Keeping in mind Moss' insights into depersonalised body-image helps in understanding Lauren's narrative, which reveals a body-cathexis to validate extrapolating his concepts to her experience. Further biographical information shows that Lauren has endured multiple excisions of many (one sided) lumps over thirteen years leading to her recent mastectomy, and, almost as soon as she was discharged

from hospital she discovered lumps developing on her remaining breast. This has led her to perceive her remaining breast as a threat, and she doesn't like to be touched there, even though she is aware her husband wants to touch her. When I asked her if her mastectomy had any effect on her feelings of responsiveness in her remaining breast she replied, "Well yes. For one reason - not because um, not because I don't have a breast to offer, but because the breast I have is a threat to me". She said that "I don't want it to be touched [and] I prefer it not to be there, so I act like I don't have it".

Lauren declared that she has disowned her remaining breast already in the lead-up to her second radical surgery (not medically sanctioned mastectomy). Although there is a wealth of psychological complexity in Lauren's last account I intend to focus on Lauren's disturbed body image- and to a lesser degree examine her perceptions of her husband's reactions to her disturbed feelings. Lauren described the deleterious affect of her perception of her remaining (lumpy) breast as a threat on her intimate relationship with her husband:

But you know it's strange how you come to the intimate side of things, because it comes back to the way you perceive yourself really - you know., and if I don't like this breast, then really I don't like part of myself. So if I don't like part of myself then I can't give all of myself [F7:p.23].

Lauren has lost one of her breasts via a surgical excision and has been so alienated by the medical treatment she hasn't received for her remaining lumpy breast that she has conceptually amputated it as well. It is little surprise that her sexual relationship is suffering in the wake of her admission that she doesn't want her husband to touch or recognise the existence of her remaining breast, which will soon disappear.

Notwithstanding the immediacy of Lauren's words, it remains unclear to what degree the mastectomy related events prior to and following Lauren's mastectomy were responsible for the difficulties within their relationship, as they were both open about having had quite a long-standing difficulty in their sexual relationship. The literature suggests that couples who have marital difficulties prior to their mastectomy

experience are more likely to experience serious adjustment difficulties following the surgery.

Lauren claimed to have been relatively unaffected by her mastectomy in terms of her image of her own body. She was clear that she was able to be open and walk about naked in her husband's presence, and that she was even able to undress in the public baths. It is clear from some of the incongruities of her accounts that she has some conflict with her deeply internalised image of herself, and what or how others perceive her.

I didn't have a problem with my body image, um I had maybe. I did have more of a problem of whether my husband would accept my body image. I would look in the mirror and say "This is me" [and] it would hurt -um but slowly I have been able to accept that. before I had even had the operation I would even do things like visualise ahhh myself without my breast. I really prepared myself well for that.

I tell you there was this picture in the paper about six months ago, and there was this woman sitting there, and they portrayed her with her one breast. That was the most horrific thing for me to look at. That really said to me "That's you", and I .. I didn't like that. Where before I looked at myself as being "This is me, I can accept this" - and I had visualised myself one way (you know?) and I had accepted the visual concept I had of myself, and as I see my husband accepting that and reassuring me about that [and] that was good, that was very, very good. Ummm .. but when I saw this I thought "But that's how other people see me"! [F7:p.20].

This passage is an extraordinarily candid revelation of the complex (psychic) 're-imagining' that this woman undertook in order (perhaps) to make sense of her experience or simply to heal her wounded body image. Her shock and alarm as she described her memory of the offending photo was quite apparent to me in our interview as well. She suggested that the photographic image she saw must have in no way resembled her image of herself as a woman who'd had a mastectomy. Wabrek and Wabrek (1976) maintain that while the woman may not express it, she may be convinced that a deformed or mutilated person is held in very low regard by society, and she may expect her husband and family to pity or reject her. I saw the photo, and

even as a nurse used to caring for women in a similar position, I found it a disturbing image for a large front-page spread on a major (Saturday) metropolitan newspaper. However, as a person without personal involvement in mastectomy surgery, I did not have the same *distaste* for the image as Lauren, which made me aware of her extreme sensitivity to the issue of her body image.

Lauren felt at ease about disrobing with her friends at the public gymnasium, but her husband didn't want her to continue this practice:

Well I used to get dressed in front of them. (I say that) I used to because my husband explained to me that when I had this [mastectomy], he doesn't want me to dress in front of other people. So for him, out of respect for him (as he said), as he said to me and explained to me that there are some things that he wants for himself, and I understand that. So I say used to in the sense that it has happened, but I won't be doing that anymore. But I won't be doing it for a good reason, not a bad reason [sic] [f7:p.21].

She infers that her husband is a proud man who doesn't want her (or by implication himself) to be the object of other people's scrutiny or pity. Lauren's unresolved feelings in this regard are not surprising considering that it is less than a year since her first mastectomy and she is wanting/waiting for her remaining breast to be amputated. Her desire for a second mastectomy has been triggered by what Lauren perceives as medical miss-management of her remaining breast lumps. She sees no other way to free herself from the constant worry of lumps (which she claims were not all biopsied), than to have a mastectomy. The psychological stress endured by Lauren, has been compounded by her husband's long-standing resistance to her proposal for a second mastectomy. However, although her GP has recently 'brought him around to the idea' he remains somewhat ambivalent about her mastectomy and is adamant that it is her [Lauren's] decision. Lauren spoke about her husband's attitude to her planned surgery:

So that's why I say in that respect I only really thought about myself, and I never really thought about his reasons, but his reasons basically came through to me as being, "It's not my

body, I can't make that decision, but I don't want to be responsible in helping you to make that decision in case you regret it later"

Lauren's complex, fluctuating feelings related to her altered body dimension, and her own body image are understandable.

Gemma, as Lauren and Tamara, is forty-two years of age and like Lauren, had her mastectomy just a year earlier than the time of her interviews. Gemma was far more positive about her experience. Her dialogue implied she was undergoing an adjustment to her altered body dimension and ".. is still able to stand in front of her mirror and still go to bed without anything on" However,

"..every now and again I notice women's breasts now, (you know) , you notice um, in movies you see this big voluptuous women and I never used to notice that before. Not consciously notice it , so I guess really deep down, (I'm not saying I'm kidding myself), I just know that deep down it has made an effect, it has. I am aware of it [F6;p.18].

Gemma's words reveal a lot about her human need to fantasize and idealise, and this was implied in her focus on wearing her prosthesis and still wearing attractive, body-hugging clothes. Schilder (1950) says that when clothing is worn, it instantaneously becomes a part of the body-image and is filled with narcissistic libido. He believed that women especially reveal this in their attitude to adornment and clothing. This gives a sound theoretical basis to explain why women who've had mastectomies gain so much self-confidence following being fitted with prostheses.

Gemma's conscious awareness of other women's breasts since her mastectomy touches on the dynamic effect that cultural influences of beauty have on the body-image. On this subject Schilder (1950, p. 285-286) argued:

We should not underrate the importance of actual beauty and ugliness in human life. Our own beauty or ugliness will not only figure in the image we get about ourselves, but will also figure in the images others build up about us and which we take back again into ourselves. The body-image is the

result of social life. Beauty and ugliness are certainly not phenomena in the single individual, but are social phenomena of the utmost importance. They regulate the sex activities in human relations Our own body-image and the body-images of others, their beauty and ugliness, thus become a basis for our sexual and social activities.

This perspective widens our understanding of the implications that our perceptions about beauty and ugliness have on our body-images, and just what changes Gemma is having to acclimatise to in her body-mapping. Her focus is on the “voluptuousness” of other women’s breasts in which she implies beauty, but her awareness of this soft female protuberance was engendered by her certain awareness of its ‘opposite state’ of concavity/ mastectomy evident on one side of her chest.

Lucinda, a thirty-six year old woman didn’t recall any alteration in her self-image or womanly perception of her body because at the time of her mastectomy six years earlier, she was unhappy in her marriage. Her perception of herself was so poor that she inferred her mastectomy hardly made any difference to her body image. In response to my question about her body image following her mastectomy she replied, “I just didn’t think about it. I just completely blocked it out. As though it was absolutely and totally unimportant. Um, It was just not a part of my thinking and that was it [F4:p]”, and when I asked her if he had ever seen her naked since the mastectomy she replied forcefully - “Oh good heavens no! He’s, he wouldn’t know what I looked like. He’s never seen me without a shirt - ever! [F4:p]”. I asked her if she was open concerning her nakedness with her husband prior to her mastectomy, and she said “Yeah, and the children yeah. It’s no big deal, yeah it wasn’t a problem. Afterwards [after the mastectomy] yes, very much so, because I didn’t want him to feel humiliated - I didn’t want him [to see the mastectomy wound] ‘cause I knew he would be [humiliated][F4:P]”. Given the dismal picture Lucy had painted of her marriage throughout our interview, I thought it possible that her husband’s response to seeing her wound would cause her humiliation and, going with this ‘hunch’ I asked her if he had wanted to see her mastectomy wound:

Yeah, probably did but I rejected [him]. I can remember, the next day or the day after. ‘Cause the next day [after her

mastectomy] I was really out of my tree, [from the effects of narcotics] um ... and he pulled my shirt forward as though, [to say] 'Oh you know! Give us a look' and I said 'Don't do that! You know you can't do that to me! [F4:p].

I believe this assumption was vindicated by her recollection of her husband's curious though (as Lucy described it) insensitive attempt to see her wound.

Lucy recently met another man, who she is living with, and claims to be very open with him about her mastectomy from the time that she met him. She inferred that she had integrated her changed body dimension into her life insofar as her lack of a breast was just a part of her. She referred to this obliquely when I asked her if her fondness for ballroom dancing ever caused her to miss wearing certain styles of glamorous dresses. She said "I can't wear sleeveless ... or something that's low cut ... I also have to remember that I am sort of getting older" [C4: p3]. Later she remarked of her mastectomy status, "I don't even think about it [chuckle] I'm going to be like this for a long time"[C4:p5].

Sharon, the remaining female participant in the study, is a fifty-eight old, who, following a mastectomy three and a half years earlier, had further surgery to excise cerebral metastases, ten months following her mastectomy. Sharon's last surgery occurred two and a half years prior to our interviews. During the interview process, while Sharon appeared very nervous about being interviewed, she was able to talk about her mastectomy scar, and her ease with being naked with her husband and their continued sexual relationship. She remained somewhat unclear about performing her own breast self examination techniques because of her fear of isolating another lump.

Reflections

It appears that women have different perspectives about themselves in different situations: Jill was able to walk about naked in her husband's presence, but was unable to face the idea of making love to him with the light on, and, while Lauren was

unperturbed if people saw her unclad at the public change rooms, she was horrified when she saw the photograph of a mastectomate in a newspaper. In a paradoxical way, the body-image is never static, it is always an incomplete structure, for as physiological conditions, or life situations alter, internal structuralisations of body-image occur. This fluid property of the body-image is evident in this study. This is particularly clear in Gwen's case, as her 'phantom breast feelings disappeared some months following surgery. This suggests that the human psyche is in a constant process of making sense of the boundaries of our lived existence (our bodies), and our relationship to the outside world.

Women may have difficulty in acquiring a realistic body image, or in acknowledging their breastlessness within a newly integrated body consciousness that is still interpreted as, 'me as I am,' rather than 'me as I wish to be.' These difficulties may be underpinned by complex personal and psycho-social influences.

The accounts of the women in this study reinforce the idea that our image in the mirror is coloured and shaped by our past experience, our present expectations and our awareness about what others think about the way we look. The selection of details concerning our bodies then, is subject to much more than simply what is so-called "objective evidence" as seen in a mirror.

The picture we have of our own body then, is not based on a passive visual perception of "what is there". Rather, the picture is built up around those parts of our body which have a special relation to the world of things and of other people (Moss, 1978, p. 77).

In the context of the women's descriptors of body image, this observation takes on special significance, for most were aware and very concerned about the effects the mastectomy had on intimate partners.

According to the phenomenologists viewpoint concerning body image (indeed the phenomena of being alive and sensate), it is a dynamic concept of being which involves the pre-reflective interiority of the self, the exteriority of other 'selves' or

objects and the disposition for human action within space and time. This means that body-image changes within human developmental processes, indeed, one may even speculate - from minute to minute. Young (1985, p. 27-28) infers the subversive, capriciousness of the sensuous embodied life :

The writings of Lacan, Derrida, and Kristeva show subjectivity as multiple and shifting, and always outrun by the sociolinguistic world. For Kristeva, the unity of the self, its self-referring consciousness and identity as the self-same origin of meaning, rests precisely on its cleavage, on the slitting of the process of subjectivity that enacts language into two moments: the logical, assertive consciousness and the slippery, desiring,, playful, violent unconscious. *The unitary subject, ... is thus exceeded by the subject in process which spills over into the contradictions, ruptures, and encounters of sensuous experience* [My italics]

Although such philosophical writing borders on the abstruse, it nonetheless provides a theoretical insight into the complicated sensations that the women in this study feel, and how they stand in opposition to the logical, common sense notion of the body as instrument of conscious will. Young argues that the body has a life of its own, even though the conscious mind may try to subvert it. In many ways, the women's accounts evoke the rupture and contradiction of their sensuous lives following mastectomy.

Erna Schilder (1989, p. 30-31) asserted that "The assumption that the lived embodied experience is a mental representation that can be expressed and put into words, is creating a conceptual framework which closes off the access to 'nameless' sensations. *On the other hand, reflections that concentrate directly on the 'Gestalt' of the human body in a given epoch are rather scarce.* [My italics]". I believe that the women's accounts of their feelings about their wounded bodies/selves (and their accounts of somatic disturbances delineated in the following chapter), have in a small way made up for the lack of 'nameless,' or 'Gestalt' sensations relating to the body in the nursing literature.

Jill's testifies to situational differences with her body-image, that is, her uncomfortable feelings when naked with her husband when she first came home from hospital. She is now feeling better about it fourteen months later. However, she still feels bad about her husband seeing her chest during their lovemaking. The body-consciousness of many of the women participants is suggestive of constant re-appraisals and re-definitions, within the context of our interviews and according to the length of time since their surgery. In a sense then, this phenomenological study snatches 'fragments,' or 'moments' of the multi-faceted phenomena of intimacy following mastectomy, rather than uncovers the 'essence of the phenomenon.'

There is a distinct difference in the need to internalise the new body reality, as 'the newly refashioned me', and the public persona, in which, in the name of an (understandable) aesthetic need for symmetry (and hence normality), the woman wears a breast prosthesis. In part, this desire for aesthetic appeal may undermine the woman's ability to ever imagine herself as a mastectomate, even though when naked, her mirror assures her of this. The dichotomy between the public and the private image may obstruct a self imaging which reflects a form of 'dual reality' in women who've undergone mastectomy. The need for most mastectomates to be fitted with prostheses is self evident, but the socio-sexual necessity for it may undermine a healthy psychic integration of the newly acquired bodily dimension. To explain this further, the woman avoids social stigmatising by wearing a prosthesis, but this 'falsey' may hinder her ability to incorporate her new body image in her psyche. This theory may partly explain Lauren's complicated body consciousness following her mastectomy experience.

In summary, five of the seven women in this study gave clear indication of experiencing difficulty in relation to their body image following their mastectomies. Of the two women who seemed to have been most unaffected by their mastectomy Lucy was apparently non-committal about her changed body. She inferred her poor marital relationship and poor self-esteem (pre-mastectomy) had a deadening affect on her sense of body-image, while Sharon was able to cope well with her changed body-shape in her sexual relationship because of the love and support she has from her husband. Both these women exhibited some difficulties with their body-image. Lucy

implied that she actively depersonalised her body in an effort to push her mastectomy reality away, and Sharon was unable to touch her chest because she was afraid of discovering another lump.

Of the five women who indicated that they had some difficulties in adjusting to their altered body dimension, Jill (who'd undergone her surgery fourteen months earlier) inferred that this was one of her major problems. The remaining participants were reticent about these concerns, choosing to focus on their altered breast dimension by using external cues - such as intimate apparel, their husband's reactions or appraisal of other women's bodies. This lack of emphasis in highlighting their own concerns may be partly explained by the fact that body-image is an abstract, poorly understood concept, and much of the emphasis in the treatment of cancer lies in the surgical, radiological and chemotherapeutic domain of care. It may be precisely because this treatment is designed to extend the woman's life cycle, that she may feel guilty for complaining about her surgically mutilated body to the members of the health care team, which she may perceive as 'biting the hand that helped her'. While counselling before and after mastectomy is becoming more widespread in the major metropolitan hospitals, the responses of these women indicate that health care workers need to give their clients permission and time to express their positive and negative responses to the mastectomy experience.

Men's Feelings of Grief and Loss

An implicit theme that has emerged from the data concerning the partners of women who have undergone mastectomy is that the men have all experienced some feelings of loss, grief or change in their response to the visual and tactile reality of their wives since the time of surgery. This theme lay deeply embedded in the data, as the men frequently denied being affected by their wives' mastectomy, and were more at home with 'sandwiching' negative feelings within more of their 'surface' dialogue concerning the welfare of their partners. Even in the case of James, who was adamant -if not vehement in his awareness of loss (both past and forthcoming), he remained loyal - in part- to the notion of the woman being the most central sufferer in the

experience of mastectomy. In the overall analysis of the men's transcripts, it almost seemed as though they tended to devalue themselves as having much right to feel at all.

Of the male partners, only two did not reveal statements indicative of loss. One of these men was Imran, who as Lucinda's lover, had only known her as a person with one breast, and seemed very focused on what their relationship held, rather than did not hold. Secondly, Joseph omitted any reference to his wife's appearance, other than to compare it to other wounds he had seen. Joseph was only comfortable in expressing his feelings of loss by attributing concern for his partner. This husband's suppressed emotions will be analysed in a following chapter.

Delving even deeper into the data then, it appears that denial of feeling, even while men gave plenty of evidence to the contrary, was a concomitant process within the interviews with men. Denial of feeling in men has been the focus of attention in the emergent 'Men's Movement' in Australia, spear-headed by the psychologist Steve Biddulph (1994). Biddulph believes that post-industrialist society has worked to isolate men from one another and their women. This type of society has alienated most men from male mentors, and thus men have become 'horrendously under-fathered'. This under-fathering (Biddulph believes) has had a spiritually and emotionally imprisoning effect. Men remain distant from from their true selves through (1) loneliness; (2) compulsive competition, and (3) lifelong emotional timidity. The third construct of Biddulph's theory - emotional timidity, may be a useful framework through which to analyse the men's feelings and perceptions, even though denial of feelings was not confined to this gender.

David said quite simply that Sharon's excised breast was 'his favourite one'. He expressed this in a jocular way, and laughed at the apparent absurdity of saying such a thing. Nonetheless, this was a big thing for him to divulge, as by his own admission, he found it hard to express his feelings.

It didn't affect me at all. Ah, we always have a bit of a joke, she should have lost the other boob 'cause that one was my favourite, so that was the way we looked at it sort of thing

... you know. So we got, you know. But no, its never effected us in any way at all. I never looked at her and said Ugh! God [M3:p.5].

The interesting thing about David's feelings are how little he finds it necessary to devalue his own feelings, even though he said he favoured her breast taken by the mastectomy. David has obviously experienced the mastectomy as a traumatic event, even though his practical mind tends to concentrate on the job of getting on with his life. He told me that he was with Sharon at the hospital following her surgery:

Oh yeah I was there, yeah just hours after them and had a bit of a gander, you know. Thought what a marvellous job this bloke's done kind of thing, you know um, 'n from then its never No, no, it was a bit of an oddity for a while, you know [but it's] Just the lack of one boob, you know, [it] looks queer, but to me now, I don't even notice it, (you know)?. But for, probably the first couple of months, you know, course I kept watching the scar! Yeah, [it] just had me in this big scar! I kept looking at it ...No, it didn't effect us in any way, no [M3:p.8].

David has taken the opportunity to 'get to know' the new shape and appearance of Sharon, and reveals 'having a gander' [look] at her wound in the hospital and feeling the 'queerness' of it, even in the same breath as he says it hasn't had any impact on their intimate life. This kind of response was common in the women and the men, and it seemed as though they were acknowledging two different realities. Their overlying consciousness and feeling was that of the essential health and continuity of their relationship, and, with this in mind they didn't feel that the mastectomy had an impact on their intimacy. However, the conflicting reality which is implied in many of the narratives is that the mastectomy, has affected parts of their being in meaningful ways. David implies this conflicting reality within himself (in his speech above), and that it also exists within other men:

Well, as I said, you know, I'm fairly practical and I, its gone, what can you do about it? Um, you make light of what you've got left kind of thing, you know, and that's it. Nothing I can do about it. So I accept her for the way she is, plus I've heard all

sorts of stories about men being ah, upset and everything and marriages breaking up over women losing one breast and all this sort of stuff. True or false I don't know, but you do hear these stories [M3:p.5].

It is clear that David has strong feelings of loss about his wife having had mastectomy surgery, even though he doesn't believe that he has been negatively affected by it.

Graham spoke clearly about the impact of Jill's mastectomy on his life as a husband, and was frank about the negative affects on their intimate relationship. Although he never expressed his feelings directly as a loss, or that he was conscious of grieving for the radical alterations in their life as a couple, his perceptions concerning her bodily reality imply his deep sense of sadness and bewilderment. Graham infers that the surgery is the beginning of a chain of events which they were ill-prepared for:

you don't particularly know, don't know what's happening, don't know what the consequences of it are.

And as it goes back to - going back to how it is as a man, I 'spose it goes back to, to the relationship and how one values that relationship, and um other than the physical sort of differences which to me I found... or initially sort of found a bit of a shock. But ah you know tend to transcend that and it comes back to what, what the relationship [means] [M1:p.2].

Graham acknowledges that there are larger considerations than the loss of his wife's breast, and that she and their life as a couple are more important than this one part of their life, but later in his interview is able to ventilate how Jill's surgical trauma has become his trauma too. His faltering syntax indicates his difficulty in describing complex emotions, in which he speaks of his natural feelings of withdrawal from the visual insult of Jill's wound, against his feelings of obligation to support his sexual mate.

You look at it in the shower and there's a bit of a shock. There's ribs and skin and everything, but there's just no breast. But I never sort of not wanted to look at it. You do feel as though um... it's different, and maybe sort of not...um.. not sort of [nice] to look at it. But I forced myself to get used

to it. But it doesn't, it's never revolted me as such, or anything like that, it's [M1: p.23].

Graham's ambivalence emerged within the couple interview:

I don't, I don't think of it as such. I think of it as a blessing. And so does Jill but ... yeah, yeah they're the most difficult attributes you know. You can't help but think of women with two breasts cause you see them all around [M1: p.23].

Graham finds it difficult to comprehend the reality of Jill's body changes, and her deviancy from the normal has constituted a loss for them both. Both Jill and Graham indicated that their sexual relationship had been affected by the mastectomy. Graham seemed most disturbed by the visual affect of this surgery, since his wife's lactation period, her breasts had not possessed the same appeal for him as before her pregnancy, and he didn't say he missed her breast as a tactile phenomenon. This was not the case with other men in the study, who, while having similar feelings towards their wives' wounds, seemed to miss the tactile reality of the excised bosom, as much as the visual dimension of it.

Ivan said he really missed his wife's breast, as breast stimulation was and remains an important part of their sexual play together. He was proud of Gemma's shape, and enjoyed seeing her cleavage and touching her, as she enjoyed wearing certain garments which displayed some bosom. Ian's keen sense of loss was experienced even prior to his wife's mastectomy, when he was aware of the feelings of shock he encountered when in the pre-operative period between the needle biopsy and the surgeon's consultation, Gemma decided to have a mastectomy rather than a lumpectomy:

we sort of talked it over um,... before we actually went back to the specialist ... um ..that if it ... if it was positive that Gem was going to have ... have it treated. We had sort of almost come to the decision that if it was as bad as Gem thought it was, that she'd have the breast off. Even before we spoke to

the specialist. And um, .. I sort of was a bit shocked by that in so much as I didn't think that she'd want to take such a big step [M6: p.1].

Ivan and Gemma were presented with an option of lumpectomy or mastectomy, and were informed of the fact that as much tissue is excised on either side of the tumour as the tumour's depth. Gemma decided that the wide excision involved in a total mastectomy was more liable to eradicate her cancer risk, whereas Ivan says that this decision was shocking, even though it was based on advice given by the surgeon. Towards the closure of our interview, Ivan acknowledged his feelings about Gemma's mastectomy. With moist eyes and his face almost mobile with emotion he said:

I think the only time when I sort of regretted it I think was, actually in the ... in the um specialists rooms, when the decision to take the breast completely was made. For I, think it would have been for about five minutes. I sort of thought, oh what a waste, and then I thought, Oh that's a selfish way of looking at it. But yeah, I did have that thought [M6:p.19].

This is similar to what one of the men in the study by Zahlis and Shands (1991, p. 83,) experienced:

The most difficult part was just accepting the fact that the breast had to be removed! To know that something you truly enjoyed for these years was no longer going to be there. It's just accepting and grieving for the loss.

Ivan doesn't appear aware he is grieving, even as he feels far more comfortable in concentrating on the care-giving role than in focusing on his own 'neediness'.

After that I thought, that's not the way to think about it, I've got to block that out, and um, I've had no trouble with saying well, rather than it's a waste having the breast gone, I've thought about it on the positive side of it. Than goodness it's gone because now she's going to live forever. And that's about the only [M6:p.19].

Ivan related his first reactions to Gemma's mastectomy wound, and, like Joseph, found it useful to compare it with other serious wounds he had seen as a sort of reference point from where to begin:

Um ... Well I, I wanted to be there when they, they took the dressing off. Um, just to give Gem some moral support, and um...- that it was neat and clean and tidy. It wasn't unattractive, and it wasn't repulsive or anything like that um ...I saw a mates hand when he got hit with a chain saw and that was a very graphic sort of a wound, where this [M6:p.3].

This logical, analytical approach to viewing Gemma's mastectomy wound is helpful to Ivan's practical, logical self, but would not compensate him for his certainty that a sexually significant part of her body has been removed. He understands the mortal imperative of removing his wife's breast:

and a... No it's just for the best. That's the way we've looked at it all, all the way through. Um,... what evers for the best is what we're going to do [M6:p.3].

but his sensitive voice, his syntax and facial expression gave indications of his heart understanding the mastectomy in a different way. Sometime later in the interview, while he explored the theme of his closeness to his wife, he said:

The disfigurement didn't relate to being a bad experience because the good side of it was at least now she'd got rid of the cancer no,.. I think I accepted (you know) the fact of the scar and being disfigured, the scar being the disfigurement, sort of didn't ... didn't put me off or upset me or anything that. I sort of got over that with the scar from the first caesarean, and we had a healthy baby to justify the first caesarean, and another healthy baby to justify the dog leg in the second caesarean. And now increased life span to justify the third [mastectomy] scar so. So no, the disfigurement didn't oh enter into [it] [M6:p7].

Now, while Ivan maintained a positive, rational framework from which to understand his wife's and his own experience of mastectomy, he also had a sentient part of

himself which was obvious in his emotional delivery of the facts. Of all the men in the study, Ivan presented as the most emotional, insofar as his concern for his wife and their situation was directly expressed in his eyes, face and voice. While I was interviewing him, he communicated the sense of reigning in on some powerful emotions, and on many occasions his eyes were moist. The discrepancy between what was related by Ivan as 'reasonable' and what he felt (most obvious in body language, vocal timbre and facial expression), is what Goleman (1996) calls two fundamentally different ways of knowing. "The way of knowing most prominent in reflection and awareness involves the rational mind, whereas the pre-reflective, intuitive, impulsive way of knowing involves the emotional mind. In a very real sense, we have two minds, one that thinks and one that feels"(Goleman, 1996, p. 8).

Viewed from this perspective, Ivan's experience of his wife's mastectomy can be analysed from within an holistic framework. Within such a framework, discrepancies between *what he says* and *what his feelings tell us about him* can be understood when Ivan uses the word disfigurement frequently within a passage in which he is telling us he has accepted Gemma's surgery. Disfigurement is a strong word to use in the context of acceptance, and seems contrary to his 'thesis.' However, from the "two mind" context, Ivan is accounting for two experiences, even though he is probably only aware of telling his 'rational experience'.

Ivan's use of the apt descriptor 'disfigure' indicates he is ambivalent about Gemma's scar, although he feels insecure about talking about his feelings about it. His ambivalence is healthy, and reflects the reality of his wife's altered body, but he seems to feel it would be disloyal and hurtful to Gemma to reflect any negative feelings concerning his response to her body changes. These points inferentially indicate that Ivan is still grieving /processing his feelings of loss following Gemma's mastectomy.

Furthermore, I was assured of my hunch that Ivan had been sensitised to his wife's breast amputation by the concern and importance that Ivan held Gemma's bodily aesthetics. Both Gemma and Ivan mentioned that breast stimulation formed a large part of their sexual play together, so Ivan must keenly miss this normal part of their

former life. The emphasis he placed on the aesthetic contour of Gemma's chest around her prosthetic device, also reveals by implication the psychological and physical impact her surgery must have had/be having on Ivan. To elaborate, he said that the surgeon had "hollowed out" her chest a little towards the line of her neck, so they had some trouble obtaining clothes to fit her, as the prosthesis was not bulky enough. He had especially made her a small lambswool pouch to 'fill in' this deformity:

Probably to a person that didn't know that she'd had a mastectomy they probably couldn't tell the difference. But I can sort of see the difference between left and right, and um... it appears just as a slight hollow on the right hand side. Normally where a, a blouse or whatever, the 'V' part comes, it just seems a little bit hollow [M6:p.19].

Ivan seems to see and know the geography of his wife's body in a very intimate way, and her appearance is important to him, as he has noticed that her mastectomy has impacted on her silhouette, in spite of having a professionally fitted prosthesis. If he was concerned enough to manufacture an additional 'prosthesis', he is quite obviously deeply concerned about her surgical mutilation. While Ivan's concern for Gemma's 'outward appearance' may infer some difficulty with his ability to communicate with her on a sexual level, this was not so, as he said he is able to be as open (and she with him) as they were pre-mastectomy. Ivan's account gives testimony to the fact that even while the 'reasoning/ reasonable' man may believe that he has adjusted to the surgical mutilation of his mate, his feelings may tell a very different story.

Gus, who was almost the same age as Ivan, was in some ways similar in his emotional distancing (from himself) on certain points. For example, he frankly recounted missing his wife's second breast as a sexual toy, but then seems perplexed by naming it his plaything, and is at pains to qualify his statement in terms of his wife's' rather than his loss:

Oh, I miss having something to play with. I wouldn't say it was a big miss. You know it doesn't really matter, I, I think ah, perhaps her feeling on the other side would be more

important, you know ah, what she feels if I'm missing, would probably hurt her, more than what I miss. I don't really miss it that much, to tell you the truth [M5:p.9].

While he has been sensitive to Tamara's feelings about his own loss, that is, - it is sad for her to feel sad about not being a 'whole woman' for him, but it's not legitimate for him to feel sad or angry on his own account.

Gus certainly presented as a man with a very no-nonsense gruffness, which was belied by his twinkling-eyed heart- of-gold approach. This earthy approach enhanced by his deep voice and occasional colloquialisms, which he aptly used to illustrate his hands-on approach to Tamara's breasts:

Maybe, maybe because she use to have a good pair of knockers, and wear her tops down you know, I used to pull her bras down and give them a good shake. Oh,..I'd say nothing really bothers you. It really doesn't bother me now, I don't give a rats [arse] you know [M5:p.9].

It was six years since Tamara's mastectomy and she has had chemotherapy, suffered early menopause and had further lumpectomy surgery. Tamara's own account of their life paints a somewhat different picture regarding her breast loss. One has the impression that her partner misses it more deeply than he is aware . Tamara said he liked her to wear low cut bodices, and pretty lingerie to bed, and, he also mentioned the importance of reassuring her self-image via his feedback on her appearance. Throughout our interview, I had the intuition that Gus was a very contained person, who wasn't comfortable to be open with many people. Indeed, his whole transcript gave the impression that it was a difficult period for them both, and the mastectomy was only the start of the story.

In contrast to Ivan, James had little difficulty expressing his powerful feelings in a verbal way, but was less expressive of his feelings in his face and body. He presented as a big man, with a deep voice and gruff but not unkind manner. Through the

interview process, I sensed he used his voice unconsciously as a protective, emotionally distancing tool. His narrative constantly returned to the physical reality of Lauren's mastectomy.

In analysing James' tape, his story involved almost a bewildered merging of the reality of the present mastectomy and his appalled recognition that there was another to come, which he had to adjust to. This bewildered non-acceptance by his 'feeling mind' is juxtaposed against his 'rational mind', which recognises that Lauren desperately wanted the surgery. This past/present amalgam is evident in the following passage, in which he examines his reaction to her surgery:

She had a week in hospital of course, ah, she took it very well. Me personally, I supported her, I mean it doesn't really worry me, cause I had already made up my mind before she had the operation, that (you know that I am the sort of person that will adapt) ... But if I have to do it, there's no other way, I'll do anything, you know and then accept it. And I have accepted it
![M7:p.2]!

James said he accepted her first operation, (though there is very little time for couples to 'accept' mastectomy pre-operatively, even though they consent to the surgery). However, he is at pains to convince himself that he wants his wife's second mastectomy, and this seems clear in his ambivalence concerning his adaptation and acceptance. He says futuristically that "he has to do it!" and then says "I have accepted it!" This husband speaks very openly about his own feelings of frustration and suppressed grief as he lives through a painful period in which he is anticipating the complete obliteration of (yet another) attractive, erotically significant part of his wife.

The following passage contains a clear statement regarding his response to his wife's appearance following surgery:

I've got to look at Laurens side of things, not my own really. But it doesn't come easy for a man to look at a wife with no breasts. You know ... but you've got to adapt and you've got to learn to adjust you know You know - 'a scar is a scar' - like,

but ah ... it does... Yeah, well I didn't know what to expect so, it doesn't look very nice ... and it looks strange [M7:p.13].

In the midst of this monologue, he sadly reflected on his current feelings about Lauren's remaining breast:

A fact's a fact. It's still there, you know. And I guess, well I (the way I look at it), is while it's still there, I may as well enjoy it, (you know?) - for like the rest of my life..... I'm not going to have that anymore, you know what I mean

and it's, ... [SIGH]. well to be honest with you, you're going to miss it because it's not natural ... and it's hard - but you've got to learn to adapt and that's all there is to it [M7:p.12].

James is uncompromising in his perception of the mastectomy as having a profound affect on him, and his speech infers that the visual anomaly and tactile impoverishment caused by the unilateral mastectomy will be magnified significantly for him, when Lauren undergoes her second mastectomy:

Yeah, I'm sad alright, don't worry about that. I mean. I say to myself, why me? Why my life? [sigh] I got married to have a married life, put it that way, with ... with normal circumstance you sort of learn, gradually and slowly you've got to make the decisions to actually cut it off, cut both of them off, you know it's not easy, I can tell you, it's sad ... and I feel sad, I do feel sad. I feel angry and sad you know. But theres nothing I can do about it. there's just something you've got to accept, no good fighting about it, or even with yourself, and Lauren [M7:p.21].

James acknowledges that it is enormously difficult for a sexual partner to sacrifice a part of his wife that he implies was a large part of his attraction and sexual arousal and stimulation, indeed, a part of his marriage.

I mean I didn't make the decision - she did, but ... I've got to live up to her, because it's her body, and I've got to support her, that's all it is to it. So that's what I've done. Sometimes I think she's going a bit too radical you know, with this other

one, but I keep thinking about it. I think for the day, it might be wrong, but for the next month, week, year, years (you know?) we're going to always be living on the edge [M7:p.2].

In the above dialogue James reveals he hasn't ever been able to fully support his wife in her bid for a prophylactic mastectomy, and in other parts of his transcript infers he was gently coerced into 'agreeing' by Lauren and her G.P. His position, versus the psychological health of his wife and family (and indeed himself) made him see the long-term sense in capitulating to her desire:

Like I could handle one [mastectomy] but then I thought "Oh no they're not going to do two" (you know)? - but then thinking about it, (when I put myself in Laurens shoes), what is worse? living on the edge for the next twenty years or having no breasts. So I really thought about it, and then I thought, no for Lauren, it's best for Lauren and best for the family

I don't know how this [next mastectomy] is going to [affect me], one's not so bad, but like I said with both of them gone. It could affect her but it all depends on me I think. But if I will accept it, I think she will accept it [M7:p.21].

James intuits that Lauren's acceptance of herself after her bilateral mastectomy will have a lot to do with his own response, but he seems clear that it is not and will not be will not be easy for him. Later, in the coupled interview with Lauren and James, he thought that the surgeons were ethically correct to not agree to her second mastectomy:

I think that [it would be] an ethical thing for them not to do [the mastectomy, because] they can't do it because of the way they feel.... as a man, and I can understand that. But it wouldn't be easy to cut the breast off a woman, lets face it !.[M7:p.24].

James puts across his point that it must be almost unconscionable for surgeon, particularly a man to be able to do 'cut off' a female breast, particularly when there is no (immediately) life-threatening reason.

James discourse demonstrates a candid, 'egocentric' perspective. Analysed from within the psychoanalytic framework, his 'egocentricity' means that he loves her breast, and he wants it to stay, or, to put it another way, he wants to keep it. Other husbands in the study were more guarded in their responses, and their narratives appeared to have been censored internally by their 'alter- ego', or moral self, and they tended to defer to the needs of their partners as having for more importance than their own. If men actively suppress their true feelings, (and these are likely to be those feelings/perceptions of negative import), and are unable to speak of them or acknowledge their reality, they are more likely to have unresolved grief about the mastectomy. This gives rise to the hypothesis, if it is reasonable to expect men to have negative feelings about their mates' body changes following mastectomy, do men who are unable to ventilate these negative feelings ever resolve their personal sense of loss? James was one of only two partners in this study who was relatively comfortable in exploring the negative aspect of the mastectomy, but this may be explained in part perhaps by the fact that this man's problems were magnified by the exigencies of the double mastectomy situation.

There would be very few men and women unfortunate enough to be in James and Lauren's position. This testimony affords a invaluable insight into the protracted and anticipatory grieving experienced. James' experience allows us a window through which we can try and understand the process of choosing mastectomy, even while he implies that the second mastectomy is no more a choice for him than the first one.

Reflections

Men and women who experience mastectomy consent to it under onerous circumstances, typified by psychological distress engendered by the cancer diagnosis and time constraints surrounding the assumed urgent need for surgery. Couples frequently feel the emotional pressure of having to choose quickly what type of surgery is performed, because surgeons usually wish to operate within days of diagnosis. Gemma, Tamara and Lauren all had mastectomy surgery, even though they were offered lumpectomy. They did so because they believed there would be less likelihood of the cancer returning. Their surgeons would have been aware of the many

recent studies which have demonstrated that lumpectomy/radiotherapy and/or adjuvant therapy is just as effective in long-term prognosis as mastectomy. How do husbands feel about the total removal of their wives' breasts, when they have been offered the less mutilating surgery? There is some logic in the assumption that they could feel angry because of the wife's choice of more mutilating surgery, even though he may have agreed to this in the first instance.

From the compelling narratives of these five men, it is not unreasonable to assume that many men may feel similar things, but are afraid to ventilate them. They may be less able to open because their wives' lives have been saved or extended because of the surgery, and they feel callous or uncaring in ventilating negative, (and what are perceived as) self-interested thoughts. They may also feel that because she has had the surgery, she is the only one who can legitimately feel any loss. Inferences drawn from the analysis of the transcripts of Ivan, Joseph, Gus, and David appear to have good fit with this hypothesis.

In conclusion, my use of a phenomenological research process, using an open ended interview technique has been a vital tool in elucidating 'phenomenological moments' within these men's lives. Just because the partner doesn't ventilate his loss, or may be only dimly aware of change in his life does not diminish the fact that very significant losses have occurred in both people's lives, and these changes would reverberate into the fabric of their intimate partnership.

Even though this is a very small sample of partners, their testimonies suggest that there is a need for group and/or individual counselling opportunities for men. However, even if this service were to be made available, it is not certain that it would be used by men. The escalating violence in Western society has made psychological counselling an increasingly familiar service to the public, but whether men who have experienced a wife's mastectomy will deem it a significant personal event worthy of professional assistance is a question which suggests a need for further education and research.

CHAPTER EIGHT

Shared Meanings Within Themes:

Women's Feelings of Somatic Strangeness

and

Men's Denial of being Affected by the Mastectomy

Somatic: Of the body, corporeal, physical (opp. mental spiritual, psychic)

[The Concise Oxford Dictionary, (1976), p.191].

Yes, I suppose I don't really enjoy him [touching my wound]. He's quite happy to touch me on my scar and that , but I just hate the sensation. It's sort of numb - along my arm's numb, I don't even like touching it, it's just a funny sensation, it's not a pleasant sensation at all.

[Jill, wife of James, p. 10-11].

I get the feeling that she really doesn't want to be touched there, (you know). Ah, she's never said anything, ah, she still comes to bed with no top on. No. (You know) I'd say it's, I'd say if you rub your hand over it, she doesn't push you away or anything, she more or less it's probably nothing, it's probably a normal feeling every woman has, I don't know. [Gus, wife of Tamara, p. 6].

Women's Feelings of Somatic Strangeness

In the previous chapter, I discussed how the women in this study revealed a sense of loss in regard to their body-image, and how these disturbances were manifest in diverse, abstract ways - which highlighted the process of emotional adaptation to a very significant surgical mutilation. According to Oberst and James (1985, p. 47), "the body undergoes major physiological adjustments to an altered state and the individual must learn about the partially unfamiliar body that results". In this chapter, women's narratives are explored to illustrate how these women were affected by the mastectomy physically, and how these physical feelings have a bearing on the women's body-image, and their intimate relationships. It is clear that physical sensations play a large part in the formation of body-image and that in most instances the women's stories imply that there are strong links between these 'altered sensations' and subtle emotional changes.

The theme of residual post-mastectomy sensations at or around the surgical site arose from my question concerning the healing of the wound and the presence or absence of comfort in wearing a prosthesis. Participants tended to 'downplay' these physical (or somatic) feelings, but it clearly emerged that these feelings were of some concern to them. This hesitancy may be attributable to their surgery being perceived as life-extending, if not life-saving, and for the women to perceive themselves as 'whingeing' to the researcher concerning the end product of the surgery make them appear ungrateful. Certainly, none of the women concerned had any complaint about the actual quality of the surgical operation, so their expression of feeling was unconnected to any sense of surgical mismanagement. All the women except one discussed their physical sensations at the surgery site, and while there was a wide range of comments concerning a lack or alteration in feeling around their wounds, they often implied some disturbance of sensation in relation to the wearing of a prosthesis.

The literature on mastectomy, refers to the pain and discomfort that is part of wound healing following surgery. Axillary numbness is to be expected if the woman has undergone an axillary clearance - that is, surgical 'clearance' or dissection of lymph

nodes (National Health & Medical Research Council, 1995). There is a dearth of information however, on the effect that these somatic changes – (at or in the environs of the surgical site), have on the emotional life of women. That is, how do these changes in sensation affect their physical experiences, self-esteem and sexual partnerships. The psychosocial and sexual difficulties following mastectomy, have been recognised (Renneker & Cutler, 1952; Quint, 1963; Wellisch, Jamison & Pasnau, 1978; Northouse, 1988, and Sturesteps & Darroch, 1987), but the physical sensations of women following mastectomy have not been described in detail. Thus, to gain a greater understanding of women's intimate experiences and feelings following mastectomy, seven women's exhaustive descriptions of their somatic disturbances are discussed.

In the immediate days and weeks following surgery, Gwen clearly recounted that her husband was afraid he might bump against her in the night and exacerbate her wound discomfort. In the context of speaking about her sexual relationship, Gwen gives a clear account of the physical difficulties she experienced having had a mastectomy:

You can't sleep on the right side. It's always your favourite side for sleeping, and of course, if you're big-busted you'd tend to fall flat on your face if you're on that side - because you've got nothing to prop yourself up with.. And of course, yes, it feels awkward [F2:p. 9].

Gwen makes light of her difficulties, but it is clear that the disturbance in her bodily dimension was very clearly experienced. Her sense of the 'symmetricality' of her body shape has been lost with the void left following her right mastectomy. As well as her initial pain, which was exacerbated by a wound infection, the 'voided body space' and the subsequent wound previously occupied by her breast accounts for her inability to settle on her favourite side. Gwen's account gives the reader an idea of the 'strangeness' she must have felt while lying in bed and indeed, how she felt she might roll over without her breast to support her. Her words imply that these somatic difficulties had implications for her psychological and sexual functioning as well, and she is comfortable to elaborate upon her feelings of being felt physically awkward.

Gwen could feel her mastectomy area when she had something up against it, she recalled experiencing a phantom breast phenomenon for quite a few months following her surgery. She said of this:

... the extraordinary thing is you don't understand at the time, because, it's like amputation, you still feel the limb, and I could still have the op and come round after it and I could still feel the breast. And you do - and of course the dressings, you don't look that bad either because the dressings, you know the padding and all that [gives a breast like shape]. And it took, I suppose a couple or four months or so before the feeling that the breast was there gradually faded and so reality sort of set in about six months after the op and then I knew ... um, I'd handled it terribly well too. I was so proud of myself. But then it came at a time whereas, "OK, I've been terribly good, now can I have my breast back?" And that's when the reality hits you that, (you know), "This is it!" - you're never going to get [the breast] back ! [F2:p. 5].

Gwen hints at the ambivalent feelings she had to deal with in she knowing on a cognitive level that she'd had a mastectomy, but for some time following her surgery her 'emotional/sensorial self' felt the presence of a phantom breast. Schilder (1950, p. 67) reports that "... one of Bettheim's patients felt his right arm was preserved somewhere and would be given back to him.". This curious account is not dissimilar to what Gwen described. Schilder (1950, p. 66) postulated that,

"the real significance of an experience is due to the emotional attitudes, or, in other words, to the life situation. Our own body and the image of our own body is, of course the object of the strongest emotions,"

and that these phantom emotions are the so- called 'externally felt' and internalised result of trauma to an important part of the body.

Gwen's first few months following her surgery were characterised by feelings that her amputated breast was still with her in her feeling state. However, even knowing this feeling as a phantom phenomenon, she still feels that her breast exists somewhere, and if only she is "good", it will be given back to her. It is worthwhile to note that Gwen's description of her experience pertaining to these phantom feelings and

paraesthesias are very brief and undermined by her playful, ironic tone. Nonetheless, her words give us a brief entree into the complex domain of her emotional experience following her mastectomy.

Schilder (1950) also tackles the problem of pain (or, as I would prefer to call it *altered sensation* when applied to feelings such as numbness) from a psychoanalytic framework, and how these feelings impact upon the psychic body image of the person. He says that:

When we suffer from organic pain, the model of the body changes immediately in its libidinous structure. All energies now flow to the diseased organ, as Freud and Ferenczi have emphasised. The postural model of the body is overloaded with narcissistic libido in the aching part. Paraesthesias and bodily discomfort have of course an effect very similar to that of pain. With the erotic, a change in the perception goes on The aching organ becomes a centre of renewed experimentation with the body. It takes a part [a focus] usually taken by the erotogenic zones (p. 126).

This interpretation of the psychological effects resulting from deleterious changes in bodily sensation will have obvious implications when we examine the narratives of the women in this study. Gwen said she felt awkward in bed, and inferred this was not only to do with her inability to find a supportive posture lying on her 'breastless' side, but that this awkwardness extended into her feelings with her husband too. While the psychoanalytic approach seems persuasive, it is interesting to note that none of the women described their wounds as being invested with any positive attributes of eroticism or sensuality. Perhaps if Freud and Ferenczi mean a state of erotogenic tension/agitation, then the analogy is valid. In contrast to Schilder, Gyllenskold's (1981), large qualitative study was also based on a psychoanalytic framework, but she found that six of the thirty women in her longitudinal study described phantom phenomena. She concluded that these feelings of a remaining organ were linked to successful adjustment, and were a congruent affective grief response.

Gwen describes other somatic experiences in response to a question regarding her wound sensations following her mastectomy:

...You get very numb down here. it's like a slab of meat [her arm] because they had to cut the major nerves, its hard to scratch [because of the numbness] and certainly over the years now a certain amount of sensation has come back, but it still feels different from the other side, it never sort of regains that [F2:p. 7].

When I asked Gwen if her chest wall felt ok now, she said:

Oh yes, yes, I still have to be careful though because of the skin grafts, um, like the prosthesis - I had to be careful, especially in the summer, that it [the prosthesis] doesn't get too hot against that [her wound] . Some of the prostheses you see are flat to the wall, or they were, and I always had to have a little hollow in mine so it took away off the skin graft [F2:p. 6].

Gwen said that they didn't make her prosthesis to order, but revealed that:

... there were just different varieties and I never liked putting it into a cover because I felt detached from it . That is, I'd prefer to feel that its part of me, and by not having it in the bag, it sort of clings more to the chest wall and I feel more natural, yes [F2:p. 6].

Gwen is very particular about her need to have her prosthesis actually touching her skin, so that she feels more natural and responds like her remaining breast. Her need for the close proximity of the 'lifelike-feeling' false breast on her chest wall obviously afforded her some physical as well as psychological comfort to her.

Gwen was quick in assuring me that her mastectomy hasn't precluded her from life's pleasures, as she still enjoys swimming, and in fact she says there is nothing she hasn't done that she would've wanted to, but that:

Its just that, my arm tends to get a bit um, tired there - the left arm. I can't carry as much as I used to on it because you can always tell because you get a certain amount of strained

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feeling up in the armpit and then you sort of take it down because the last thing you want is lymphodema [F2:p. 8].

Gwen was confident that her mastectomy had not affected her intimate life with her husband, but her somatic disturbances following this surgery infer that her intimate feelings about her body have been radically affected. She had a lumpectomy, followed a week later by a radical mastectomy (which required the surgical ‘harvesting’ of skin from her thigh for implantation and filling of a very widely excised area of her chest wall); and secondly, she developed a post operative infection. Possibly due to the fact that seventeen years have elapsed since the time of her surgery, Gwen has underplayed any pain she experienced during her wound healing phase, but what has clearly emerged from her dialogue is a short and long term, intimate account of her body feelings and experiences in the wake of her surgery.

Jill was articulate about how her body had changed since her mastectomy some four months earlier. Jill’s words evoked a clear sense of a quality of what I have chosen to call a ‘sense of otherness’ about her newly defined chest shape:

I have, I have um, because of the operation, I’ve had some strange sensations, like the nerves I suppose have all been cut, and he used to love picking me up, sort of under the arms and giving me a real big bear hug - and he can’t do that now. It always hurt, that’s painful and I find, well, he doesn’t do it any more because I used to say, “Oh be careful!” and things like that,

So, I do miss that. I do. Sometimes he occasionally he might really squeeze me tight and I’ll let him, but it does hurt -and I wish it didn’t.

And our position, our sides of the bed; we had to change our sides of the that we slept on and, and um, because he was frightened that he would roll over initially when the wound wasn’t healed Yes, I suppose I don’t really enjoy him [touching my wound]. He’s quite happy to touch me on my scar and that, but I just hate the sensation. It’s sort of numb-along my arm’s numb, I don’t even like touching it, it’s just a funny sensation, it’s not a pleasant sensation at all [F1:p.10].

Jill describes with great clarity the impact of her physical sensations on her intimate life with her husband. In response to my question about how her feelings about her body affected her active sexual relationship with him she said that her arm and mastectomy wound:

.. doesn't have any place in our love making really, because I don't feel anything [in that area]. At least if I don't touch it I, [PAUSE] it doesn't remind me that it's numb, I just feel a bit of a sensation, It's not nice [F1:p.11].

Jill revealed that her marked somatic disturbance has much wider implications than her sensitivity to and consideration of her wound area alone. In describing how her lovemaking with her husband has had to be adjusted following her mastectomy she said:

Well, I would never be comfortable with Graham above me because he'd be too frightened of pressing on my, where my breast was, and even lying in bed, and I used to often just, - (even apart from lovemaking) I'd often just lie on top of him. I'd just about go to sleep sometimes. But things like that, I don't really enjoy doing anymore because of the sensations. I miss those [UNFINISHED SENTENCE] [F1:p.11]

There have [been quite a few adjustments in their sexual relationship] I wouldn't feel comfortable, um I suppose in a lot of positions that we have had in the past because it's just too much of a reminder its there! I don't want to be reminded of it.

I prefer the light off where love-making's concerned I'm not that comfortable. I'm quite happy to be naked in bed.For Graham to even rub his arms over me or whatever, although I

don't like the sensation on that side, but um, as far as just walking around the house [naked] and that is concerned, I'm comfortable, but where lovemaking's concerned, I'm not that comfortable [F1:p10-11].

Jill's corporeal feelings about her 'incised, wounded' body are affecting her ability to communicate as freely as she used to with him, because of the limitations her feelings of strange numbness (and sometimes, outright pain), which certain activities evoke

in her. Again, the implications of these feelings encompass a far wider human dimension than her body. Although they are exquisitely personal body sensations, in the context of Jill's intimate sexual relationship, they have obvious interpersonal implications.

She is loathe to be reminded of 'it' - (meaning her mastectomy) and all the associations that go with it. Her physical sensations and her attitude to a changed body appear to remind her of loss, and this is accentuated by certain sexual situations. Perhaps this is not surprising, as intimate sexual contact with another heightens sensorial awareness, and Jill implies that she is living through a period of grief for losses of their pre-mastectomy intimacy, as well as for the loss of her breast. These feelings persist even though she reveals that her partner is not averse to caressing her wound, which suggests that he is very supportive and accepting of their changed circumstances.

Jill also remarked in a light-hearted manner that she is concerned to maintain her body silhouette, as breast prosthetics can move in an apparently capricious manner. She said:

I haven't bothered gluing mine [my prosthesis] to my body.[although] I did when I first got it and when I was pegging out the clothes and bending down it slipped off- that was in the summer time. So. I thought that was quite hilarious so I've gotten used to just wearing it in my bra, but I tend to forget sometimes and get out of the car and bend down and depending on whatever. it'll fall out or something [LAUGHTER]. I tend to laugh it off, but it is annoying.

It gets irritating and by the end of the day I just want to get it off, I just - I mean I'm not a large breasted woman, but even being a 34c or whatever I am, there's enough weight by the end of the day to be carried around, and it does get uncomfortable [F1:p. 2].

These matters may seem trifling or inconsequential, but relay a rich source of meaning as to the actual day to day experience of some women following mastectomy. This allows us to gain insight into how their physical concerns may at least partly inform the changes in their intimate responses to their partners.

Gemma, who had a mastectomy thirteen months earlier than our interviews, reported her wound as having ‘... a strange feeling’ [F6:p. 29]. Although she was anxious not to ‘make complaint’, and construct the most positive implications out of her mastectomy experience, I believe her response to my question was largely negative:

No, it’s, I’ve rubbed cream on it all the time and, um, [even though] the specialist was very pleased with it. It’s still, it’s hard, it’s sort of a strange feeling (you sort of), I guess because you’ve always had a soft part there and it’s sort of hard, and ah.... it has actually - it has it’s advantages in some ways. I was playing badminton the other night, and having had all the glands um cut out, I actually hurt this arm a little while I was playing, and I said to Ivan, I said in some ways I said It’s good I said “I can feel the pain!” I said “and that’s all numb!” And I could feel a bit of pain and I said, “Imagine what it would’ve been like if it wasn’t numb [Chuckle]” I said it would’ve been really, really sore!” [F6:p. 29-30].

Gemma was one of the most candid participants in the study when talking about how she, her husband and family coped with her illness and surgery, and her sexual adjustment. But she skittered around the topic of her own innermost feelings, and her physical concerns in regard to her mastectomy. She never described her wound as numb, as did Jill and Gwen, and yet she says it feels ‘strange’.

This sense of corporeal strangeness is implied when Gemma openly speaks of her sexual relationship:

And I guess sometimes, when I take longer to become aroused, I feel that if I had another breast maybe, it wouldn’t, wouldn’t take as long or something. So I guess in that way, there’s always that feeling, well maybe I wouldn’t be going (if I was only going through menopause), maybe I wouldn’t be having this trouble if I had two breasts. [F6:p. 18].

Gemma reports that she is possibly taking longer to arouse sexually. She attributes this to her mastectomy but only infers that the ‘strange feelings’ of her scarred body

may be a contributing factor. Gemma's dialogue reveals similar themes as described in Jill and Gwen's experience following their mastectomy, and, even though she finds it difficult to reveal her feelings, she recognises that, even while her husband and two teenage boys are:

.. doing everything they can to basically make me feel that I'm just the same sort of person that I was before - but you can't be, you can never be that same person [and] I know I've changed a lot[F6:p. 23].

Unlike Jill, Gemma did not notice any change in her relationship with her husband apart from a feeling of closeness. Gemma said that their already close intimate relationship had not changed other than her perception of her difficulty with sexual arousal, which she was unsure of whether was attributable to her mastectomy or her early (Tamoxifen induced) menopause.

Similar to the other women, forty-two year old Tamara also experienced numbness at her mastectomy site. Even though her breast surgery occurred six years ago, she gave a very clear account of the strangeness of feeling only partly, or 'not feeling' certain tactile sensations:

Actually I have, under my arm sort of at the end I've still got like pins and needles, it's very numb there because it's sort of affected the nerve endings, and I still, when I shave under my arm and everything, I can't feel it. I've got no feeling there at all.

The surgery is, I've got that, is it lymph ade [sic] [lymphodema] I could feel my arm was aching every time I used it. And then doctor mentioned I had Lymphodema, he said that is what I've got. ... My hand and my arm really puffed up, but I got a massager and I had to have one of those skin tight gloves [F5:p. 15].

Tamara said she had difficulty playing tennis, and she had to be careful not to play too long. She could no longer serve the tennis ball in the overarm style. She found that she has to be particularly vigilant in the care of her arm in the summer time, when it swells more readily, and is aware of it being swollen most of the time, as it is her

'dominant limb'. The extra physical activity involved in the use of her affected dominant arm is a burden, but she finds she can't change her habits as easily as she knows she should. Tamara is always aware of her right arm being bigger than the left:

that's the only other thing that really bugs me, sort of my arm is, (even when it goes down) it's still sort of a little bit bigger than that left one, it sort of gets puffy [F5:p. 15].

Tamara provides us with much intimate detail about how her altered sensation and circulation effected her busy lifestyle. While Tamara is the only woman in this research who reported lymphodema, she is adamant about carrying on as normal, and continues to carry heavy objects with her effected arm - as her right arm feels stronger. Even so, she appears to be badly affected by poor lymphatic drainage of her arm in the summer months. How these somatic changes had (and are having) on Tamara's body-image, and her sexual relationship with Gus she doesn't divulge, but it is reasonable to assume that these 'symptoms' had and are having an ongoing impact. What emerges from Tamara's story is that she has less opportunity to become unaware of her mastectomy because of her strange body feelings and particularly her arm swelling. Because her arm is also involved in so many of all her daily activities, and not often hidden from view, there is less chance of forgetting it. It is reasonable to suggest that Tamara's 'central attitudes' have been affected by these changes, even though she is coping well.

Lauren's narrative concerning her body-image has been discussed in the preceding chapter, and you will recall her story involved the 'objectification' of her remaining breast following a long history of surgical lumpectomies and a mastectomy. While Lauren spoke at length about her revulsion at being touched on her remaining 'lumpy' or cystic breast, she was unable to say much about her mastectomy scar, or the feelings she had about it. She was talking about the pros and cons of wearing her prosthesis or not when she went into the public spa, when I asked her if her if it was comfortable, she responded:

No, it feels good actually. At times only because of the scar and sometimes when I get tired, it feels ah ... it's more the scar.. Oh I don't know. Just aggravates it, oh I can't really explain it [F7:p. 23].

Lauren is unable to clearly describe her sensations at her wound site, but her answer suggests that her wound may be numb, and the feelings she has are aggravated by tiredness. Lauren has appeared to have put her operation behind her as she anxiously awaits news of a surgeon willing to perform her second mastectomy. Her physical and emotional preoccupation is clearly with her remaining, unwanted breast, and her perceptions of her wound are rather inchoate.

I do not wish to cover the same ground as I did in the previous chapter, but I think it is important to recapitulate on the feelings of revulsion Lauren had towards her remaining cystic breast, in the wake of her lengthy and unusual history of multiple breast lumps and mastectomy. The mental anguish that this woman has endured has made her disown and marginalise her breast, prior to its removal. Schilder (1950, p. 301) believed that "Mental suffering finds its way into a somatic expression, and somatic disease leads to mental suffering", and, while it is clear that Lauren has endured the latter, what is not so clear is whether her mental suffering is connected in some way to the development of her disease. Certainly, disowning her breast must have some physical (somatic) ramifications.

Lucinda, like Tamara had her mastectomy six years previously. She said less about her localised mastectomy sensations than Tamara or Lauren, but her words have good fit with those of the other women. She said "... even though I don't have a lot of feeling there. There are two sides to everyone". Her response was woven into her perceptions about her first meetings with her fiance, and reflect her view that she is much more than the sum of her parts. Her brief reflection about her mastectomy wound reveal she has diminished sensation, but it seemed to bother her less than any of the other women, and she had nothing to say about her prosthesis causing any irritation.

Reflections

Sharon, Lucinda, Tamara, Gemma and Lauren share their experiences of mastectomy, and all possess a surgical wound, which has had a mutilating rather than cosmetic effect. The term amputation most fittingly describes mastectomy surgery, as it involves the removal of the whole mammary gland, with the same crude cosmetic and potentially devastating psychological effect that the surgical or accidental pruning of limbs has on its victims.

The numbed amputation site then, most usually nippleless, hard and linear, is effectively surgically de-sexed. Jill gives a good indication of how de-sexualised her breast amputation site felt when she said she didn't like her partner touching her there. She describes her scar with a sort of 'otherness' quality. All of the women are actual 'amputees' which is an even more brutal term than "mastectomee". As a whole external organ has been excised, it naturally interrupts the normal physiognomy of the body, the nerves are cut, skin, muscle lymphatic glands and tissue are dissected. The numbness which, for most women in this study was a corollary to their surgery, may be the most difficult bridge for health care workers to cross in terms of understanding the affect that the woman's wounded status has on her immediate life. The mastectomy surgery is lifesaving and necessary, regardless of the cosmetic damage such wounding entails. However, the view of wound healing shared by the medical and nursing professions, and if not the wider community, is, that once the initial acute pain and later discomfort have subsided, life should return to 'normal', even if there are feelings of paraesthesia (or numbness) experienced.

This attitude reflects the practical world of logical problem solving. If the 'patient' has pain or discomfort, then it can be treated, whereas if the client has numbness or tingling around his/her wounds then this is viewed clinically as an unfortunate corollary of surgery which is often deep and in which damage to surface nerves is unavoidable. To expand on this, nurses and physicians caring for the woman following mastectomy are primarily occupied with maintaining physical and emotional support, reducing pain, and monitoring closely for any evidence of change in wound status. Quint's (1963, p. 92) words remain applicable (or perhaps even

more so in this era), because the pace of surgical ward life and 'patient turnover' has increased:

After mastectomy, most women are not yet ready to talk while still in the hospital. Even if they were, they have little access to nursing personnel except for brief contacts centered on procedures and physical tasks. That nurses do not openly initiate discussion about mastectomy, and its personal meanings is the rule, not the exception.

Thus, women may not express any concern about any somatic disturbance (other than frank pain) at the wound site. The quality of numbness seems to develop as form of resolution of wound healing, which follows at some point much later than the acute pain phase of pain (which all women don't experience) in the immediate period following surgery. When Gwen read through these finished chapters, she pointed out to me that I was wrong, that she experienced numbness from the very time of the operation.

This means that from a nursing standpoint, the issue of numbness (if indeed it is an issue), is not likely to be addressed by the nurse, because the patient has long been discharged from hospital. It may not be addressed by the surgeon, or thought of as any problem of significance. Likewise, the general practitioner may have a similar response and label it as a 'surgical problem.' If the woman sees a counsellor, he/she may also be likely to dismiss it as a 'physical' problem, which the counsellor may feel uncomfortable, unwilling or unqualified to discuss.

People who have had diverse forms of surgery are able to describe these residual sensations, many years following their surgery. However, while many people after major operations involving deep dissection of their body tissues may describe numbness over their wounds, what separates women who have had cancer-related breast surgery from this larger group is their emotional investment in their breasts. The female breast symbolises much more to women (and men), than simply a

biologically necessary, erogenous organ which nurtures infants. Viewed in this way then, it is not surprising that the women in this study have difficulties in adjusting themselves to their fractured body sensations. Can it be possible to assimilate the real

(wounded/scarred) body image into the bodily sense of self when from these few women's accounts, their 'post-mastectomy bodies' feel strange?

This 'otherness quality' lies at the heart of the 'existentialism conundrum' involved in the study of disease affecting humans. This is a study of people who have been affected by a disease. Too often in the study and practice of medicine and nursing, the person is transformed into a disease, and this disease process becomes the principal focus of clinical interest and observation.

As we have already seen in the review of the philosophical literature relating to the body (Gadow, 1980; Lawler, 1994 and Moss, 1978), the object body is familiar to all clinicians, who, examine the human body (as opposed to the essential person) categorise physical phenomena and assign medical 'labels' to signs and symptoms. A nursing philosopher, Sally Gadow (1980), theorises that the patient's perspective is vastly different than that of the systems model, even though he/she too (like the systems model), 'objectifies' the sick body part:

The immediacy of the lived body is only partly mediated by illness, injury, or pain. With the appearance of incapacity, one experiences the body as something which opposes his purposes, a weighted mass, a thing-like other (Gadow, 1980, p. 94-95).

Gadow contends that the lived body is mediated by injury or pain [or numbness I would argue] into feelings of "otherness" while that incapacity 'shatters the lived body.' This suggests an evanescent, unmeasurable component of human feeling about 'dis-ease'. It is this variety of evanescent, hard to define feelings that the women in this study describe, and it seems that the somatic feelings of women seem to be poorly understood by clinical personnel and by the people experiencing them. This is partly reflective of the fact that such feelings are highly subjective, hard to qualify and quantify, and also because clinical staff are not taught to treat non-acute physical feelings (as opposed to symptoms). I believe that these women's stories imply a link exists between their physical sensations, and their sense of wholeness.

Throughout the literature concerning mastectomy, authors have tended to categorise 'client problems' into physical and/or psychological difficulties. This reflects the objective *modus operandi* of the physical scientist whose philosophical roots are embedded historically in Cartesian dualism, which encourages dichotomous, mind/body differentiation. The lack of focus on the lived experience of women following their mastectomies, of how their whole selves have been affected by mastectomy is partly reflective of the dominance of the physical sciences, and the pursuit of quantitative research methodology - versus qualitative methodology.

There has been much intellectual discussion about the impact of mastectomy on women's body-image. Only Carroll (1981) and Mantell and Green (1978) have clearly indicated that body sensations at the surgery site may be of significance. Carroll (p. 31) believes that:

Complaints by the patient of strange bodily sensations, loss of feeling or contact, detachment or depersonalisation, as if one is observing what is happening to themselves instead of experiencing it, all are signs worthy of careful scrutiny by the health care team,

while Mantell and Green (1978, p. 215) take a very positive stance by suggesting that:

When the post operative site is stimulated, [massaged] many women experience a strange tactile sensation owing to various degrees of numbness in the area. If viewed positively rather than fearfully, this unfamiliar feeling can be recognised as creating a new erogenous zone. As a woman becomes aware of herself as a viable sexual being, she will begin to appreciate this new sensual pleasure.

This suggestion is novel, and seem to posit a holistic hypothesis towards affecting a combined somatic/psychic integration of the wounded body/self. Certainly, none of the women participating in this study suggested or inferred they liked touching or being touched across their operative sites. Even while Gemma's husband said that he sometimes massaged her wound when he was giving her body massages, she did not indicate she perceived any sensual pleasure in this. I suspect that these (apparently '

small') somatic concerns are far more significant within the sexual dynamics of the relationships than most realise, although Schain (1988, p. 156), discussing the benefits of reconstructive breast surgery (cancer-related), suggests crucial linkages may exist between somatic disturbances and negative orgasmic potential, in mastectomates and their partners:

It appears that a woman who feels more like herself (and is not pre-occupied with her "differentness") is somehow more able to give herself up to the sexual act and abandon herself to the experience of the moment. Feeling lopsided, defective, or even just different from one's pre-surgical state may be sufficient enough to distract her from feeling sexual pleasure.

Thus, if women who have mastectomies feel numb over a formerly erogenous zone, one may wonder how it could be possible to 'feel physically normal', or that is, how they did prior to their mastectomy. In the corporeal sense, because of the radical nature of the surgery, it is impossible for these women to replicate their pre-surgical sensual map, particularly as mastectomy is synonymous with the removal of the highly sensitive, erogenous nipple. It is hoped that over time, women can incorporate their new body topography into a personal context that they feel comfortable with. The experiences of the women in this very small sample suggest that their feelings or physical sensations in the wake of mastectomy could form the basis of a much larger study, in which women's needs in this area could be determined.

It may be impossible for women to overcome their strange feelings around their operative site, but it is possible for doctors, nurses or allied health workers to initiate research into supportive ways in which the physical (and implied psychic wound) could be healed beyond the traditional observed/objectified (versus felt) criteria of cellular reformation and tissue repair. Faulkner (1985), stated that the emphasis on physical recovery after mastectomy means that emotional and social adjustments are frequently overlooked. While there has been an increasing awareness of the need for psychosocial support of the woman in the 1980s, to my knowledge, there has been no holistic research investigating the possible restorative benefits of traditional modalities of therapy. Therapies such as, wound/chest and/or body massage,

therapeutic touch and hydrotherapy, could possibly promote the partial restoration of sensation by women who have undergone mastectomy.

In conclusion, these women's accounts of the physical sequelae associated with mastectomy reveal that their 'strange corporeal sensations' around the scar may be subtle, but have significant ramifications on different aspects of the women's experiences. Some women have diverse affects following the mastectomy; ranging from self esteem problems, self-image difficulties, emotional and/or sexual changes and alterations in the sartorial, sporting and working dimensions of their lives. Women in this study tended to accept the physical sensations as a part of the overall experience of mastectomy; to 'cop it sweet' in the wake of being saved from death, or because they realised the enormity of the surgical dissection. However, this shouldn't blunt our awareness of the fact that such subtle affects may have the most lasting effects, and if not understood could lead to poor psychic and/or sexual adjustment following mastectomy. The implications for health care workers are that they should become more astute at 'allowing', or 'permission giving' with women to enable them to articulate their (assumed) 'small somatic concerns' in order to integrate more fully their altered body shape into their sense of self.

These deeply personal accounts corroborate the inferential evidence gleaned in the prior chapters of this thesis. The experience of mastectomy has deeply and lastingly affected the intimate lives of the women involved in the study.

Men's Denial of being Affected by the Mastectomy

All the men in this study remarked that the mastectomy had no affect on their intimacy, or their lives. They did reveal that just the opposite was true. I did not have to deeply probe the hermeneutic meanings embedded in their words, for the meanings were often 'unhidden'. The surface content of these men's accounts tells us of their keen sensitivity to the feelings of their wounded partners, rather than their own, and, as noted in previous chapters, they tended to undervalue their own feelings. However, the evidence presented by these men suggests that they have keen feelings, and are thus more deeply affected by the event of mastectomy than they admit. I have linked

this theme back-to-back with the women's theme of somatic strangeness at the mastectomy site, as many of the men sensitively featured their partners' wounds as they unknowingly described their individual, and complex responses to the mastectomy experience.

Of the three men whose experience features in the first part of this analysis, Gus seemed the most relaxed, while Ivan and Imran appeared more emotional. This may be explained in part by the fact that the latter two men were making early adjustments to their partners' wounds, whereas Gus had lived with this reality over a six year period. At times during our interviews, all men struggled with the effort of speaking about their intimate relationships (in the company of a relative stranger), but still managed to convey stories rich in content and meaning.

In spite of his 'laid-back' delivery of information, Gus still revealed his sensitivity by his adamant support of his wife by using every opportunity to bolster her self-esteem. He referred to this encouragement as a 'pick-up':

There's times when you want to go out and she wants to put a dress on, you got to say ah, that's alright, don't worry about that and you've got to convince her that somebody looking down the top of her dress is neither here nor there. Doesn't matter a rats, [arse] to me, apart from that life's normal, it's just maybe that little bit of 'pick up' you know. You, you got to ah, convince her that she looks nice on the night, and she might be ah... if she wants to wear a particular dress, you know it doesn't really matter, or you put a camisole (is it?), across the [decolletage of the] dress, and you've got to convince her that, that looks fine, you know, that's [the mastectomy is] neither here nor there, so that's a little bit of pick up, you know? [M6:p. 11].

These behaviours indicate that he gives a lot more than 'a rats' when it comes to protecting Tamara from her own feelings of inadequacy, and this sensitivity to his partner continued into the whole domain of intimacy in their life:

My main concern was for her. Ah,... I don't know really. Openness I suppose, I tried to convince her that it didn't

matter and things had to be open and straight forward, you know?[M6:p. 11].

Gus believed that the mastectomy should not be made to impact on their marital relationship and that they should remain as open on a physical and emotional level as they had prior to the mastectomy. Referring to their sexual expression following the mastectomy (and the chemotherapy):

It was important to me to get back into it straight away, to kind of get her confidence back up. Might be right, might be wrong, a lot of people might think you're a pig but not to me, you know. Yeah, ah, it's kind of ah, ah, little things, as I said it never ever bothered me, my main purpose was to try to instil into her, that it didn't matter so .. life just carried on [M6:p. 11].

Gus infers that if he did not need her sexually, in the same way as he had before the surgery, then this could further undermine her self confidence. While he said that he/they “probably made concessions [sexually]” following the mastectomy, he was at pains to be totally honest in regard to emotional openness, physical nudity and sexual activity as he was prior to Tamara’s surgery. His main concern was to let Tamara know that her surgery and her scar didn’t worry him. He said that seeing her immediately after her surgery, he felt:

Relieved, happy ...Visually I don't give a rats, so long as she was going to be well and up and 'trackin' again. Ah. my main concern was for her. Ah,... I don't know really. Openness I suppose, I tried to convince her that it didn't matter and things had to be open and straight forward, you know.[M5:p. 6].

Gus inferred an intuitive sensitivity to his partner’s altered sensations around her wound in the following words:

I get the feeling that she really doesn't want to be touched there, (you know). Ah, she's never said anything, ah, she still comes to bed with no top on. No. (You know) I'd say it's, I'd say if you rub your hand over it, she doesn't push you away or anything, she more or less it's probably nothing,

it's probably a normal feeling every woman has, I don't know.
[M5:p. 6].

It may be possible that touching of the mastectomy scar is difficult for both partners, as it may accentuate their feelings of loss, or draw attention to the 'abnormality'. Gus' intuition concerning this point was validated in Tamara's interview, but it appears to have been a subject they haven't pursued in a verbal way. In response to my question about his perceptions of their intimacy changing since the mastectomy, Gus revealed that he was a bit of a 'larrikin', who liked 'taking the mickey' out of his wife occasionally. He did stress however, that he was always careful not to undermine her womanly confidence in regard to her mastectomy-related body changes:

No, [it hasn't affected our intimacy], perhaps [except] ah, probably as I say, propping her up, getting her confidence up, that might have a little bit to do with it, and be[ing]] a little bit more careful [in] what you say. Ah, you still have your fights, you still have your blues, but I'd never sling shit in that area. You know you might sling shit in another area, you know you might say, you've got a fat arse or something like that. But I make a special point not to put shit in that area. Um, to me that's very important. [M5:p. 11].

While Gus is rough and ready in his expression, he indicates that he is not insensitive to his partner's emotional need for support in relation to her body-image and feelings of being desirable as a woman.

Like Gus, Ivan was aware of his wife's altered sensations across her mastectomy scar as well, but was able to describe his wife's feelings with more clarity:

You can touch the wound and she can't feel it. I think [she can feel it] to an extent, but the pins and needles type feeling, that was only the immediate post operative healing. Ah, but mainly the muscles under the back of the arm, they were all pins and needles [M6:p.11].

Ivan has an intimate knowledge, interest and commitment to helping his wife move through the sensation changes he knows she is experiencing, He has no timidity in touching her wound, and they have both negotiated a form of sensual exploration of the scar. He implies that this touching therapy is helping to heal his wife. Of his physical ease with and sensitivity to Gemma's physical change Ivan said:

I did a massage course, I don't know, a couple of years ago I think it [was]] and Gem's always enjoyed a massage ... and um ... and when, after the op, I did a lot of massage on her, on her shoulder., and even, even on the scar Ah, but yes, she still enjoys you know a rub and a massage ... [and] it was still doing [her]] good even though she couldn't feel it [M6:p.11].

Perhaps he is also healing some part of himself that is suffering as a result of what he referred to as her 'disfigurement'. Ivan's discourse revealed him as a very sensual person, devoted to Gemma in a very romantic, erotically charged way, and it is possible that he felt he was 'feeling himself into' his mate's scarred chest in order to expiate his own sense of powerlessness and hurt. Ivan's sensitivity to Gemma's changed circumstances since her diagnosis with cancer were also manifest in his intuitive sense of when Gemma was feeling downcast, and being able to be there for her as a shoulder to cry on when she was ready to express her fears and sadness:

Gem tends to try and hold onto things by herself, instead of sharing them with me when they first happen. It's only when they start getting a bit much for her that, ... then I can sense that there's something wrong. At two o'clock in the morning [Chuckle] Maybe it's the best time. I sort of go to sleep with the feeling that something is upsetting her, but when I ask her what it is she says nothing, and two o'clock in the morning she'll decide that there is something and she'll tell me about it - and um... just have a nice cuddle and that, at that hour of the night or whatever, is fairly reassuring I imagine [M6:p.11].

Imran, the only participant who had known his partner since her mastectomy (performed five years earlier), was very sensitive to his new partner when she informed him of having surgery. He spoke candidly concerning the delicate period of navigating a path towards emotional and physical intimacy at this time. The picture he

pains is one of tenderness and respect for what he assumed may have been a very difficult interpersonal journey for not only Lucy, but also himself.

[Since her mastectomy], No one else had really seen her with her blouse off, [even her former husband] except for her doctor and so on and so forth [so] It meant that I just took things very slowly, and I suppose that.. that specific [intimate] experience. You could almost say that I checked. Not necessarily verbally but certainly checked almost with each button that I might of undone, so to speak. Um because if I felt that she reacted, or didn't want me to progress any further, that I wouldn't have. I would have stopped.[M4:p. 2].

Imran also had an expectation that complete physical honesty and emotional exposure was necessary for the long-term health of the relationship:

I suppose that if, if the relationship was going to continue in an honest manner and so forth that I wasn't sort of looking to test her, or anything like that. But I thought that this [physical openness to the erotic experience] was really necessary I suppose. But I did I was very, very careful with the progression of that [M4:p. 2].

Twelve months into the relationship, Imran has a similar sensitivity as Gus, when he intuits that Lucy may be negatively affected by his touching her across her mastectomy scar. He believes it will remind her of her loss:

I suspect that Lucinda is probably a little more self conscious but not really, um I tend to think that it's more ... sometimes she might suddenly be aware of it more than other times or um, but in general (as in intimacy) in my definition of a closeness um... of um... where I might put my hand, that sort of thing. I guess I'm a little more conscious and careful um.. and that's probably all [M4: p. 2].

This partner infers she has had a radical mastectomy which, having excised her breast tissue and muscle layer means that her skin is stretched close to her ribs, which puts another dimension of potential pain into interaction with his partner.

But I mean there are sort of other things in that .. in that area, because it's straight on to bone, it's obviously more sensitive. I mean in a, in a.. more subject to pain, rather than sensitive in a ticklish way - more subject to pain. Ah so a... um, there's that care in inverted commas needed. Um but as far as the feeling side of it I suppose um.. um... [M4:p.3].

While his sensitivities are with his partner, the mastectomy quite obviously has an impact on him, as he has to acclimatise or adjust to her physical and emotional needs:

It doesn't really make a lot of difference I just am careful there because of that I suppose. I guess that's the main reason. Because I suppose I tend to think if ... if I put my hand there [on Lucy's mastectomy scar] for arguments sake, um it might make her conscious of it that's something is missing, more so than it makes me conscious that something is missing. That's all [M4:p. 3].

In conclusion, of the three men who featured in this chapter, Gus and Imran seemed slightly less aware than Ivan of the impact that the physical reality of their partners mastectomy had on their intimate lives as lovers. In synopsis, their concerns revolved around : 1) the self-image of the partner; 2) fear of touching as reminder to the woman of her wound/mastectomy/cancer; 3) maintaining 'normality in their sexual lives; and 4) fear of hurting the partner. Although these men felt that they hadn't been greatly affected by the mastectomy, they have implied numerous physical and emotional clues within the transcripts, which suggest the opposite.

Joseph, the oldest participant in the study felt that Gwen's mastectomy had little impact on his life:

I don't think it really made a great deal of difference. It had to be, and I just accepted it as such.

The mastectomy was very sudden you know. Well you're going back [seventeen years], but I don't really remember

being put out or anything like that um.. but the kids would of been at home so I would of had to do some cooking or something like that.

I don't think there was any great drama [M2:p.1].

Joseph's philosophical approach to this disfiguring surgery made me recall Gwen's remarks concerning numerous hospitalisations and surgical procedures she had experienced prior to her mastectomy, which she said had prepared her for hospitalisation. I asked Joseph if this prior experience had been helpful at all, and he responded humorously:

No, we were fairly well used to the routine...So well, the a standing joke is that we had to leave England and then Kenya, because she had been to all the hospitals.[Laughter][M2: p. 1].

This was the beginning of our taped interview, and I had the feeling that Joseph was uncomfortable in speaking about his feelings in this unusual encounter. I wanted to give him the opportunity to say more and asked how the surgery affected them as a couple. While he had not been worried, he felt that 'Gwen might have been concerned about it'. Joseph was remembering events which occurred many years ago, and his commonsense approach to life is evoked in his narrative, in which he seems to 'roll with the punches' that have been involved with his own existence. He is not comfortable in acknowledging his feelings:

No, it certainly wasn't a shock, ah... I don't know quite how to put it. You know I, .. I,.. expected, you see I have a certain amount of time in hospitals anyway, and ah ..I've seen some pretty badly mangled people, and so on like that, so wounds and things like that don't worry me and um.. um so when I saw the scar, and so on like that, It didn't ah, you know turn me off or anything like that. It's just that, you know, as I say it's just another thing that you accept

Well this is going back to the war, and I was in the Airforce and I got burnt, and , and um.. you know spent a lot of time, like nine months in hospital. You see people coming in and out all the time. So um you know you just get used to it. Being young you know it's just part of the game. But ah ..It's

nothing unusual, I've seen the odd accident if you know during work [M2: p.4].

Joseph draws on his own traumatic wartime experiences, implying that physical wounding is a much more acceptable option than death, rationalises the mastectomy wound as being much less traumatic than death:

Well personally I don't think it, it hasn't worried me, you know I haven't been repulsed or anything like that. Um I think it would be quite normal, um I think Gwen might have been a bit worried about it, you know, what the affect might have been, but a.. you know, as far as I was concerned, you know as I have said before, it had to be so, that was it, it didn't worry me but still appreciate the impact that it may have had on Gwen [M2: p.3].

He was not concerned about the cancer diagnosis, or the possibility of cancer returning. His story indicated a belief that all the cancer was excised during the mastectomy when he said "For sure, for sure, yes, I mean if it hadn't been [for the mastectomy] then she would of been and gone.". He was not concerned about the mastectomy in regard to its visual or sexual impact, relating no 'feelings' other than concern for how Gwen may have been feeling:

As far as the physical side of things were concerned I don't know, didn't worry me. I think that the only thing that would of worried me was how Gwen felt about it, um which was something which I couldn't do anything about. I mean I suppose I could have patted her on the back and say there, there or something like that but, It is as I say physically, that's it.

I'm not making it easy for you am I? [Chuckle] [M2: p. 6].

Joseph infers that while he was aware of Gwen's feelings, he didn't feel comfortable in offering emotional support. Immediately following his reflective comment on the interview process, Joseph went on to explain his ability to remain unemotional about life events related to his early socialisation:

I think maybe in part, we, we've always been at boarding school, and so on like that from the [the time when] we were kids, so um, crises were never sort of ah spoken about, or ah, no one went dashing around crying for mum or anything like that. You just stood on your own two feet and accepted what was coming from age six in boarding school, and so on like that. I also think that as a family, we were not particularly demonstrative. You know, with all that silly nonsense about British stiff upper lip. ...[Chuckle]. That may be the reason why you know I sort of felt ... well I didn't feel the need to sort of particularly upset about the thing [M2: p. 6].

Joseph's story gives an invaluable insight into how some men may find themselves unable to respond as empathically as they wish because they have not had these sort of behaviours modelled in their earlier lives. In her own interview, Gwen remarked that her partner had been frightened of hurting her accidentally in bed. They hadn't resumed sexual activities for some weeks on account of her post operative pain and infection. In relation to seeing her wound for the first time, Joseph said:

yes I thought very brave of her actually, I think she was very wise to do so. I can still sort of picture her in Royal Perth Hospital there with the kids coming in and having a look, and so on.[M2:p.4].

Joseph hints at the enormity of his wife's surgery, and of his regret only once, when he says:

If there had been another method where by it didn't have to be so drastic, um it might have made a difference but um that was the way it had to be, so [My italics] [M2: p. 6] .

Joseph described himself as a poor communicator, yet he was quite insightful about his inability to express any feelings about Gwen's mastectomy, and inferred his deep regrets on the loss of her breast within the context of the inevitability of the surgery required to obliterate the cancer. Joseph says "If Gwen hadn't needed such drastic surgery, it may have been different" which indicates that on a perhaps deeper level, he is aware of the magnitude of her mastectomy, (which involved such a wide excision of tissue that the surgeon had to harvest and graft skin from her thigh to her breast in

order to effectively close the wound). There is a world of meaning implied in these words, which suggest that Joseph has experienced a great loss.

David, who is eight years younger than Joseph, had a similar way of dealing with the stressful events of his wife's mastectomy and subsequent surgery. He didn't feel that Sharon's surgery had affected him in any way, but was able to speak with considerable detail about how breast cancer had affected his wife:

Well, I, it never affected me in any way. That's the thing. I accepted it and she rang me up on the phone and said she had it and I said "Well, okay, so we get it fixed." And, (laugh) but I, I, I tend to look at everything realistically. You've got a cancer, lets get it fixed, lets get it over and done with and we'll see how it goes from there. But emotionally, no it doesn't effect me. I sit back and watch things realistically. I don't let... tears get involved you know ? [M3: p.1].

David's straightforward vision of Sharon's breast cancer was that she would obtain treatment, and work things out one step at a time. His stalwart spirit was obvious in his remark

I said to her "You're never dead 'til they shovel the last bit of dirt over you. So, that's the way you go. You fight !"
[Chuckle] [M3: p.1]

His laconic response was amusing, and while the implication of 'beating death', was poignant, it is David's way of dealing with the threat of death. He briefly 'sandwiches' a declaration of his own shock, between exploring feelings of concern for his wife:

Well, I feel for Sharon more than I feel for myself because she's the one that's got to go through the operation and everything, you know, yeah.

It was a shock to her, um, oh it was a shock to me too, I thought, you know, terrible thing, and I feel more for her than I felt for myself, you know, because I knew I had to stand up, or well I had to, ah, kinda handle it. If I didn't handle it,

what's going to happen? No good me collapsing is there [M3: p. 2].

Like Joseph, David had a military background. He inferred that if he collapses [cries] he would be letting down Sharon, who needs much more support than he does. He said he finds it very difficult to express his feelings, and although he is able to talk to Sharon in a spontaneous, intimate way, he inferred that he doesn't explore 'deep' topics'. While these men have their own unique experience of living their lives with a mate who has had a mastectomy, there is a commonality in the way they have approached the dis-'ease' within:

Gem's always, always had the thought she's going to beat it. And I've, I've known she has, she's going to. Because of that it hasn't been hard for me at all. I've, I've in some ways just tagged along, but um, it's probably not really correct to say that, but um, It hasn't been hard for me to give Gem support. I know that she's going to beat it and I know that we're going to live happily ever after sort of thing. Just a matter of knowing that, you know once you know that it sort of doesn't have the same impact - I've always looked at it from her point of view. She doesn't need me, getting ... getting run down or carried away by, by grief, so ah, I've just sort of said, whatever best for Gem is what we're going to do. And it's been very easy actually. I was sort of amazed in some ways myself, but ah... it's surprising what love does. [SAD LOOKING]

I can honestly say that I've never given it any serious thought other than that few minutes after that decision. And now ever time that I think it, it's automatically, you know, thank goodness she hasn't got cancer anymore. And that's the way you have to look at it [M6. p. 23].

All five of these men's descriptions, and those of their wives, are rich in meanings which revoke their principal thesis, that is, that the mastectomy has had no affect on their intimate relationships. From the analysis undertaken in the previous chapters, it is clear that the process of denial is adopted to a greater or a lesser extent by nearly all the participants, possibly as a strategy to cope with the stress of too much change too quickly.

Reflections

Sabo, Brown and Smith (1986) observed the denial in their clinical study of 24 males, and used sex-role theory to explain why the social conditioning of men into inflexible, male roles has the effect of complicating the males' adjustment. As has been evident in this chapter (and those preceding), the men in this study placed a high premium on their wives' rehabilitation, but most kept their own feelings under tight control. Sabo et.al (1986) found that men were most comfortable about expressing concern for their wives, and found that men in this position often adopted a 'protective guardian,' role, with a bright, coping facade during their wives hospitalisation, which fostered the process of denial. That men adopt protective, supportive roles is supported in the research by Sabo:

In order to take on the role of protective guardians, husbands further developed the capacity to deny their feelings - not just publicly, but privately as well. On a conscious level, this denial was designed to allay the wives fears of sexual rejection, disfigurement and further illness.

At a deeper emotional level, however, putting on a brave front" helped the husbands to unconsciously deny their worst fears. Observations of the men's support group made it clear that most husbands had little or no insight into the fact that their own feelings about masculinity, death and illness, and being a husband and lover had been changed by the mastectomy (Sabo, 1991, p. 77).

It is clear that the same phenomenon has been observed within the men in this study who focused on their wives' adjustment and not their own. Denial of both partners had the effect of blocked communication. In a later study, Sabo (1991) analysed a larger cohort of 52 couples within the conceptual framework of critical feminist theory, which holds that it is the power differences between the gender roles which determines the different approaches between the genders, rather than role:

In contrast [to liberal feminism] critical feminist theorists remind us that the husbands denial is more than a psychological process or role orientation. It is also a manifestation of a power struggle to redefine the conjugal agenda in the wake of a life threatening illness and, moreover,

to deal with intimacy issues within the issues within the husband-wife relationship (Sabo, 1991, p. 71).

When Sabo speaks of redefining the conjugal agenda, he means that when the wife is discharged from hospital, the husband tends to be relieved, as it appears that everything is returning to normal, and this is reinforced when she (sometimes immediately) resumed her normal household duties. Husbands expressed relief at the 'return of the status quo'. As they fell back upon the (assumed) position of male strength, tended to use the role of 'protective caretaker' as an adjunct to denial, and, rather than intimacy being increased, there was flight from intimacy. Thus, caretaking became a defence against increasing intimacy. Sabo (1991, p. 82) argues that (viewed from the critical feminist viewpoint) the denial stance reinforces traditional male psychology which "... revolves around dominance striving, status aggrandisement, self-control, emotional inexpressivity, and the devaluation of women and femininity". He suggests that when the sexual dyad is analysed in respect of this political, power relationship, the woman capitulates to the man's insistence on preserving the status quo, thus reinforcing the pattern of denial, and blocking meaningful, intimate communication. This theory is persuasive, and can supply a framework to understanding in this study, as most participants evinced to a greater or lesser degree, aspects of denial within the various themes examined thus far. The female participants did seem far more open and articulate about speaking about themselves and aspects of intimacy, than were the men, and in contrast to their single interview with me seemed more at ease (as did their partners) during the couple interview. None of the couples were as free in eliciting information as they had been in the single interviews. This may suggest that women do collude with their partners in the process of denial in an effort to appease their husbands and preserve a bogus status quo.

In conclusion, couples do share meanings, at least of parts of the multi-faceted aspects of experience of intimacy after mastectomy. While couples did not choose to reveal shared meanings verbally in the paired interviews (that is, they denied being affected by the mastectomy), there is ample evidence in their individual conversations with me to suggest both intimacy-engendering shared meanings and behaviours that imply the opposite.

CHAPTER NINE

Shared Meanings within Themes:

Women's Perceptions of Marital Support and Men's Perceptions of Role Changes

I'd hate to have him to do anything that hurt me, that really hurt me because I don't know that I'd be able to be so positive, you know? I think I would go down the drain then
[Sharon, wife of David: p.13].

.. since the brain surgery she says no, she can't handle it anymore, she can't seem to work it out, so I've had to take that. But there's really no hassle. As I say, I do all the housework. I do all the cooking.
[David husband of Sharon: p. 8].

Women's Perception of Marital Support

Most of the women in the study made direct or indirect references to their husband's support as being a key factor in their recovery. This finding supports other research (Lindsay, Norbeck, Carrieri & Perry, 1981; Wellisch, 1981) which found that that social support is a significant aspect of the woman's successful adaptation to mastectomy surgery.

Gwen, who had her mastectomy seventeen years ago, referred to her husband's gentleness and empathy in the aftermath of surgery. She was too sore to even think of any sexual activity until her wound infection healed and her pain subsided. Gwen spoke of their intimate awkwardness when they first resumed sexual play, inferring that their initial sexual adaptation was the most problematic, but that this difficulty soon sorted itself out.

Gwen and her partner have each experienced significant physical wounding throughout their lives. During their time in Africa, they had shared many dangerous moments in their lives together. Compared to these perhaps more tangible dangers, Gwen feels that her mastectomy has not impacted greatly upon their relationship. Both, have been 'physically flawed'; Gwen via many (other) surgical procedures, and Joseph, from serious burns suffered during the Second World War:

We had never really looked for perfection and the loss of anything like that [her breast], um was very sorrowful, but it wasn't a major issue because we'd all been so flawed over the years we'd barely got anything decent left, you know [Laughter][F2:p. 10].

Gwen indicated that her mastectomy did not have a big impact on her day to day life, as she continued to care for her children and her home, although her surgery was radical - involving a skin graft. She also developed a wound infection, and she was hospitalised for three weeks until her wound had almost healed. Marital support was only inferred rather than made explicit, and then it was implied in a sexual context:

But, it, I suppose we were still rather awkward with each other in certain ways. He was frightened of hurting me and I felt perhaps I wasn't sexy enough or him any more.

Um, until one night we were, the two spoons in the bed you see, and the arm came over, and I said (you know) "What do you think you're doing?", and he said "Just checking the equipment", and I said - (took a chance) - I said "Well I think you should be called upon to show cause, why some of this equipment is missing and maybe to make reparation for it. (like you do in the police if you lose something). There was dead silence and then a little voice said, 'well, I could hardly say it just came off in my hand could I?' And that was it! We were in tucks ! Absolutely ! [long burst of laughter] It just came off in my hand! I mean the vision of it! [laughter] [F2:p.10].

Gwen's mirth seems to act as a catalyst for renewal of her sexual relationship with her husband. Gwen's occasional humour surfaced at other times throughout our interview, and I had the feeling that it was a positive vehicle for subtle forms of communication between Gwen and her husband. Joseph presented as a shy, gentle man of relatively few words - and a twinkling sense of humour. By his demeanour and words, he struck me as being a very, practical, down to earth gentleman, not given to exaggeration or great shows of affection. He even referred to himself as being 'phlegmatic'.

In some ways Gwen resembled her husband, and when I asked them in their paired interview if humour was a source of comfort or support, Joseph replied:

I don't think it was consciously used. It's just the way things turned out. We'd had a fair bit of experience as you know of having to do things. Now we've just got to make a decision one way or another, and so the humour just happened [Cough] All right? [Looking at Gwen]

Gwen: Yes, Absolutely!

Joseph: She agrees with me.

Gwen: You can't ever use humour consciously, can you?

Interviewer: Well no.

Gwen: Otherwise it comes out as some hairy jocularity which is very hurtful. Um. but if it just sort of wells up the way it always does, (well ours sort of seems to), it works out fine

I think it smooths every path, really, and it's certainly helped us [F2:p . 8].

Gwen and her husband chose to “get on with life” explaining that - “well you might as well, it's like going against a brick wall”. Put within such a realistic perspective, this couples' use of laughter demonstrates a healthy attitude and a subtle form of mutual support. The almost tangible sense I had of this couples' devotion to one another, was also inferred in Sharon's dialogue.

Sharon was adamant in her quick response to my question about the possibility of negative effects the mastectomy had on her relationship with her husband. She said [with emphasis], “Oh no! No! [it] Got better if anything”, to which I replied “How lovely. Would you like to tell me a little about that?” she went on:

Oh, I just don't know. Because I mean, you know, David has always been very supportive. When I came out of the hospital with the mastectomy, I said, oh you know I can go to this place and get a prosthesis and a bra and they'll put a pocket in the bra. And we were there more or less straight away and, ah, David waited outside and then, ah, its never worried, as far as I can see, it doesn't worry him and, but then we just thought Oh well, we're together, you know. And well, there's not a lot you can say. We'd always had a good relationship [F2:p. 10].

Sharon's response implies much concerning her husband's commitment to her, by being prompt in taking her to the prosthetist to have her new 'false' bra fitted. Both partners gave every indication of being keenly devoted to one another. David's interview also exhibited his anticipation of Sharon's physical and emotional needs, as she remained somewhat frail following her surgical treatment for cerebral metastatic spread of her primary breast cancer.

Sharon's comments revealed that she had a vision of David as strong, and that she was able to carry on in their intimate association without difficulty. She infers that his

early support of her by his presence at the hospital and witnessing her wound being dressed was a great support in her subsequent home adaptation.

He came up to the hospital, Well, he was always there, and, um, he, I had this drain and all that and he watched me with the dressings and that, and then it was as though I'd had a boil removed off my knee.

You know it was (?) - as far as I could see. David doesn't show his emotions outwardly, um, but you know he was ah, he was, he was marvellous, and when I came home it didn't worry him at all. I used to stand in front of him, put me [sic] nightie on and I wasn't huddled around the corner [F3: p. 6].

Sharon said she was not at all ashamed of her new shape, even though she joked about her awareness of the 'lost' breast being David's favourite because of the way in which he would embrace her in bed at night. Without a hint of her earlier self-consciousness Sharon went on to say how she and her partner had adjusted their patterns of sexual play:

.... you see that was the way he liked, you see he lay there and he used to put his hand across to me, and [now that we still lie the same side of the bed] we kind of wriggle around [laughter] or, often I'll come out here [to the sitting room] and he'll have his chair and I'll come and sit on his lap and he'll put his hand up under my nightie and put it on [her remaining breast] and he's happy. We both sit there watching the tele. But you know we're not sex fiends ! [F3:p. 6].

It was clear from her enthusiastic manner and candour that Sharon's sexual life remained important to her. She clearly indicated pleasure that David has been able to adjust to her changed body shape by simply transferring his affections to her remaining breast. This consideration of her changed physical status and her emotional security is only implied in her speech and intonation, but later revealed directly in feelings about intimacy which were both physical and emotional and that she would:

... hate to [have] him to do anything that hurt me, that really hurt me because I don't know that I'd be able to be so

positive, you know? I think I would go down the drain then
[F3:p. 10].

Sharon sees her husband as her primary support, without him she wouldn't be able to cope. She felt that she drew strength from his strength, and always felt comfortable knowing that:

if something was really wrong I can say something to David.
You know, I don't have to do anything with a girlfriend. I've got a very good girlfriend, she's two years older than me, but, but I don't have to go to her with problems like that
David's the one . You know ? [F3:p. 10].

Sharon does not use the word trust, knowing it is clear that her partner is the person she feels most able to share with, and this aspect of their lives is important to her. Her perception of support appears to have had positive effects on her view of their intimate life, as she said quite unequivocally that her relationship had become even closer since her mastectomy and subsequent craniotomy.

While Sharon needs to share intimate time, physically and emotionally with her husband, her conversation indicated that they are both afraid of talking about death. While she inferred the desire to talk at length with David about death, he felt more secure in pursuing an optimistic stance about her/their future together. This thread in the tapestry of their life was revealed when I asked her about how far into the future they were able to look together:

Well, I look day to day. I've got to be honest about that. Every time I wake up in the morning I think, 'good, everything's fine' and, um, because of my family history I'm always a bit fearful that something else will go wrong.

But ah, I don't know about David, he just says, you know, he doesn't worry about things like that. But he's very supportive in all ways because um, he does all the cleaning in the house, um, the cooking, everything since, mainly the brain operation, that um. I've forgotten what we were talking about.

Interviewer; Just um, how far into the future you

Sharon: Oh! The future! We've had a couple of trips to Singapore and we both liked it very much and he came out the other day and said, 'We can't have a holiday this year, but if you want, we'll go away again next year if you can start saving a bit of money'.

So it's always a "carrot" David gives me, [And I think] 'yes, we'll have a trip to Singapore and I really get going then, 'Cause I think, Oh! I've got to be able to walk!' [Laughter] No. He's very good [F3:p. 11].

It becomes clear in this passage, that each person perceives their lives together as being on borrowed time. David is aware of the seriousness of his wife's condition, and he wants to present her with opportunities to live fully, to travel, rather than focusing on the negative aspects of her recent history. This is not inferring any denial on his part, but rather suggests the need to be practical and get on with their lives, while they are still able. The responses of David and Sharon reveal that people have different approaches to dealing with the prospect of death.

Of the women in this study, Sharon presented as being most in need of physical support, as she was occasionally unsteady on her feet if she moved too quickly. She was pale, with an aura of a person not yet completely recovered, and her frailty was accentuated by her snood on her head, which covered the partial alopecia resulting from chemotherapy.

Sharon's need of support is clear in her words: "I'd go down the drain" without him. Her constant concern about the possibility of her cerebral lesion growing again and impacting on her ability to think and move around spontaneously are evident in the quip she makes about David's 'Singapore carrot' - "...cause I've got to be able to walk". Her fear of the loss of control of her life is at least helped by the presence of such a staunch ally.

Sharon's story is different, in so far as she has endured primary and secondary infiltration of malignant cancer cells in her body. Her narrative gives the reader some indication of the impact the disease has on the couple and the emotional benefits the woman feels with a supportive spouse at her side.

Gemma too was aware of how important her husband's role in her life in the wake of her mastectomy. Gemma and Ivan married twenty-two years ago, and, similar to Sharon and David, had been childhood sweethearts before marrying.

As far as our love for each other, that has never changed, in fact it's got a lot deeper. And we've both found that we appreciate a lot of more everyday sort of things, you know we've gone into a lot more um, we've gone into crystals, we've gone into a lot more meditation and that sort of thing. I, I put it down to that, it may be the operation, but it could of happened anyway [F6:p. 12].

Like Sharon, Gemma feels that the love she and her husband share has become deeper since her mastectomy, but at the same time she avoids any dramatisation of events. Gemma and Ivan have also found it beneficial to seek alternative answers to the traditional medical explanations concerning cancer, and both seek solace and strength in the use of healing crystals while continuing her hormonal therapy.

Gemma is careful to add that, based on an already strong relationship, this may have happened in any event. She is also confident that the supportive framework of her marriage is strong enough to shoulder the burden of a surgical mutilation.

.. it's strange I never felt as though I was robbed. You know some people have said to me, don't you feel as though you have been robbed you know, that it 's all unfair and why did it happen to you. I never seemed to think that. I just feel well it's happened you can't do anything about it. I've never ever thought of myself any less of a woman. um,.. I guess it's got to come down to Ivan and my relationship, because he, we have an extremely strong marriage... and I think in that way I knew that he loved me for myself, and you know sort of just the way we were when we started going out together and things like this. I never sort of thought now is he ever going to think of me any less of a woman [F6:p. 10].

Gemma has the past supportive relationship before the operation (and the strengthening of their bonds in the fourteen months since surgery) to underline her conviction that he feels her no less of a woman. Since her operation, her family's

consistent positive feedback was seen as a powerful tool in healing her wounded self-esteem as she remarked: “They are doing everything they can to basically make me feel that I’m just the same sort of person that I was before” [F6:p.18]. The concept of the strength of the supportive pre-operative relationship having a buttressing effect on the post-operative interaction of the couple is well supported by the literature. This is one of the rare moments when Gemma unconsciously revealed that she has been in some way changed, been ‘made different’ by her experience of mastectomy.

This relationship can be viewed as a dynamic, ‘system’ having physical, emotional, and spiritual qualities. She perceived that her husband’s involvement in her hospital treatment during her immediate post-operative days was very important to her. Like Gwen and Sharon, she knew her husband felt comfortable about her other surgical scars:

And I can remember the sister, [Who said]

“Oh ! I don’t really know about this you know”. I said, “He demands it and so do I”. It is both very important that we both face this scar together at the first time.” And he was, and it was strange because we both sort of looked at it and thought “Oh is that all there is to it! ”[F6:p.10].

You know, you sort of think of a horrible scar and everything and it was so neat and everything and there was nothing nasty about it at all. And so we were there together when they took it off. And that was I think the most important thing that happened because we both shared it, we both excepted it then, he accepted it then, I accepted it then, knowing that and seeing that fact that he took the news as well [My italics] [F6:p. 11].

In sharing this experience of viewing the neat and clean wound area, they were able to (as it were) de-mythologise the previously unseen, ‘imagined’ wound - which they had “... to face together” in order (according to Gemma’s perception) for them to accept it more readily. There is also the implied insistence on both parties to ensure that their partner accepted it. Gemma inferred that this openness was crucial in overcoming the fear of giving offence to either partner. Doubtless this formal, ritualised viewing of her wound would have set the foundation for greater preparedness for openness and intimacy at home. In this way, Ivan’s participation in

this (apparently) simple ritual probably helped them both. Citing Grandstaff (1976), Northouse, Cracchiolo-Caraway and Pappas-Appel (1991) say that if a patient's spouse is positive about seeing his wife's wound, the process of the resumption of physical intimacy is initiated. Conversely, if the husband reacts negatively, she withdraws from her husband emotionally and physically, and he does likewise. More recent studies found that the majority of wives found their husbands positively respond to seeing their mastectomy scars, with the few who didn't respond so well attaching more sexual importance to the loss of the breast (Northouse, 1989).

I deliberately wrote 'apparently simple', because a wound is 'only a wound' on a purely clinical level. But to any woman 'on the inside' of a mastectomy incision, involving the amputation of an organ heavily invested with biological, erotic, emotional, aesthetic and social meanings, it may entail the most inchoate, complex emotions when she is faced with seeing her wound (or breastlessness) for the first time. There is no reason to suppose that her sexual partner may feel any less complex emotions.

Gemma insisted that her husband observe her first wound care, and infers husband inclusion in mastectomy wound dressing was not a common practice in this hospital ward. It is possible that the nurse concerned in this interaction would not have been able to give Gemma any care other than on the 'physical' or clinical level. That is, she probably would have spoken to her about her wound healing, what she was doing and why, and treated her pain, but it is unlikely that she would have been able to talk to Gemma about her emotional concerns. Had she been able to do so, then she would have known the significance Gemma placed on her husband's presence, or would have listened to Gemma and respected her words.

The implication of this example for clinicians is obvious. Doctors and nurses engaged in caring for couples need to be sensitive to their needs on more than just the immediate biophysical level. However, this does not mean that *all* husbands should be involved in seeing their spouse's wound in the hospital, if they, (or their wives') don't want them to, but, if the possibility for inclusion exists, then health care workers need to offer and 'give permission' for this to happen, as people are frequently confused or unsure about their rights within alienating clinical environments.

When the nurse asks the woman; ‘Would you like your husband to be here’? she/he shows awareness of treating the patient as a person, and acknowledges a psychic wound as well as the physical one needing healing in the partnership. If accepted, this invitation also contextualises the person with a healing wound back into the (more) intimate framework of everyday life. This offer of help may be a ‘simple’ intervention which may be a first step in what could be a very difficult psycho-sexual (verbal or non verbal) negotiation between partners. Frank (1981) suggested that if the nurse does not give sexual advice, probably no one will. In one study, 64% of women said they would have liked to discuss intimate sexuality concerns, but that the nurses attitude served as a deterrent (Woods, 1979). Thus with her partner present, mastectomy wound care can become a first shared experience, hopefully setting the scene for further visual, tactile and verbal exchanges. Nurses and surgeons are in key positions to be able to introduce the topic of intimacy concerns to patients, and should not balk at the opportunity to enable couples to share anxieties about sensitive issues. Fortunately for Gemma’s case, she was assertive enough to insist on her own needs being adhered to.

Gemma perceives the mastectomy as not having affected intimacy with her husband. The mastectomy event has added another dimension to their intimate life, of which the woman’s single breast status is maybe only the smallest part. Perhaps the single underlying concern for the couples within this study is their ontological awareness. Gemma had undergone her mastectomy a year prior to our interviews, and even though she strove to maintain positive on a day by day basis, her life had changed since her cancer diagnosis. She found that Ivan’s sensitivity to their circumstances was acute, as he shared her concerns on a plethora of emotional issues. Although Ivan’s way of coping was somewhat analogous to David’s, insofar as he wanted to address the positive rather than focus on the negative possibilities of his wife’s diagnosis, this partner supported his wife’s quest towards a spiritual lifestyle. Gemma appreciated his sharing of challenges with her.

Gemma’s dialogue is intriguing for without using the word support, she is obviously being supported, and this support is reciprocal:

I know I had to be strong. I had to be strong for the boys. I had to be strong to be strong for Ivan, because. And yet on the same way that he had to be strong for me you know [Chuckle] it was, and for our friends [F6: p. 8].

For instance, Gemma claims Ivan doesn't like speaking about death, [which is natural enough, given the circumstances], but she has only recently experienced the death of her mother, and she is not yet sure that she will 'remain cured'. It is almost as if she is striving to make him aware that it could happen, that she is preparing or supporting him against this contingency:

We don't talk a lot about that, because he's, he was brought up in a church, and he sort of rebelled against it. He, we both believe that, well we both like to believe there's an afterlife. That we are going to meet up together and things like that. We don't actually, I know quite often when I do bring up, you know about death, he'll get quite, "you're not going to die". He's not going to.. I said I'm not saying cancer's going to kill me, I said, but something's going to kill me. [Chuckle]

..... He sort of put a block there, that he is positive in his mind that I am not going to get cancer anywhere else

I'm not as positive. I am positive but I am also realistic. It could, and so I guess in that way I am preparing myself, for if it does happen [F6:p. 16].

Gemma has the capacity to detach herself from her relationship occasionally and view it from a distance. Her words indicate that she is sometimes has morbid thoughts concerning their inter-dependent bond:

we just like to do everything together. And it sort of feels, sometimes I sort of feel it's bad, that we are so close, that if something ever happened to one of us, the other would be just devastated [F6:p. 16].

The interviews with this couple were indicative of their mutual concern and support of each other, which appeared to be helping them to meet their needs during a difficult

period of transition. The role of supportive relationships in the aftermath of mastectomy seems pivotal to the adaptation of the woman, and the relationship itself.

Lucinda was the only woman in the study who had divorced since her mastectomy. Lucinda had her mastectomy at age thirty, and has survived the last six years in spite of her fatal prognosis. Lucinda's already troubled marriage dissolved within two years of her mastectomy, and she was adamant that her ex-husband was incapable of offering her the support and affection she craved before and after her mastectomy. Lucinda didn't entertain the notion of re-marrying until meeting Imran, and, she didn't frame her comments on her new partner's response in terms of the word support, but she implies it many times as she refers to their year long relationship:

It's ah.. I guess he gives me what I've always wanted. Someone to care about me. Um.... He has no problems with the fact I have just one breast. It doesn't worry him in the slightest. Um. He's just really gentle, he's got a wonderful personality, very sweet

[QUIET PENSIVE TONE] Oh... Lots of things. I guess it's when someone looks at you and sees further than what you haven't got. Um.. and to know that you still have two sides. It's just not your left side there's your right side to. And even though I don't have a lot of feeling there. There is two sides to you. Having somebody just to, you know, cause you do. You know, [need] sometimes just somebody to hold you in the middle of the .night if you're not feeling all that wonderful, and terribly secure in what's going on Ah .. to me it's just really important to have [Imran] I didn't think it was. I just thought there was going to be me to look after me [Chuckle]

Um ... yeah it's just having somebody just to be there, and they, and that you know that they understand. And it's equally important to them as what it is to you.

...He knows everything, there's nothing about me that he doesn't know.Um.. He knows everything that's ever happened in my entire life [F4:p.

14].

Lucinda has found that her mastectomy has had little impact on her new relationship. She regards herself as much more than the sum of her parts, and knows that her new partner cares for her, regardless of having only one breast.

Tamara, at forty-two years is the same age as Gemma and Lauren, had her mastectomy six years ago, and, like Gemma and Sharon, she felt that her marital relationship was strengthened by their shared experience of her mastectomy:

Um, well probably if anything it's sort of brought us a lot closer together [F6:p. 8].well probably if anything it's sort of brought us a lot closer and um, I mean it hasn't made any difference to our sex life or anything, I mean nothing's sort of changed in that respect. I mean Gus still thinks that (even though I've put on half a stone), he still thinks I'm sexy to him [Chuckle] [F5:p. 3].

Like Sharon, Tamara had also endured a second operation to remove a malignant lump, which was excised just months prior to her fifth 'anniversary' following her mastectomy. In both cases, the 'fear of the unknown', (which is such a unrelenting notion in the stories of all the women), adds the spectre of death as a revitalised reality in these couples' lives.

Although Tamara doesn't mention marital support overtly, in much of her narrative she refers to aspects of their relationship and her crucial need of her husband's support. Her account casts light on the changing character of the needs she has of her lover over time. Although she is adamant that her relationship has been strengthened as a result of the mastectomy, she indicates that their lives have had very significant stressors in the living through of this experience. From the time of diagnosis and the period of her impending surgery to her later diagnosis:

[I went into the operating] theatre about eight o'clock. And Gus went, and Gus was with me the whole time and everything. I can remember, um, the night before I was going into have the surgery that um, we were sort of cuddled up in bed and everything and I was more or less saying, "Well! That's the last time you'll be able to feel that boob, because it might not be there after, you know after today", and that was when he used to keep saying, "Oh look! I didn't marry you for your boobs, I married you for you!" and he said that was the last thing, he said he'd rather have that off and still have me, than lose me and everything, so I guess that sort of helped a lot [F5:p.8].

Gus has supported Tamara by assuring her that she means much more to him than than “a breast”, and that the loss of one will not alter his feelings for her. However, she went on to explain that following her mastectomy, she became socially isolated from friends and her usual weekly routine was burdensome:

Tamara: Initially when I had the mastectomy we were really sort of, I was getting that way that I didn't want to leave the house. . even if he went out on a job, I was anxious for him to come home, I just sort of wanted to be here with him all the time and that and I was sort of looking for him coming home all the time

Interviewer: Do you think you were depressed at that time?

Tamara: No, I didn't feel depressed, I just sort of felt - I don't know. I just think I felt secure being at home or something, but I wasn't depressed at all.

Interviewer: You were probably healing perhaps?

Tamara: Pardon ?

Interviewer: Just busy healing ?

Tamara: I feel like I just wanted to be home all the time, for the first couple of months. And I think um, I s'pose because we did sort of get close after the operation and everything, and all through everything, I sort of got reliant on him being around and sort of being there for me and everything was all lovey dovey and you know for about the first couple of months, he'd have the kids running around and doing things for me. And I thought this isn't going to last forever [Laugh] [F5:p.9].

Tamara, says that she wasn't depressed, but the sort of emotional support she needs of her husband to 'be there' for her all the time indicates that she was feeling vulnerable, and found comfort in his presence.

Stein's (1994) research indicated that 30% of her sample had clinical manifestations of depression, even though they denied this was a problem. While this may also be the case with Tamara, another more holistic explanation of her behaviour is that Tamara was spending a lot of time at home in order to heal her body and spirit. Her arm was difficult to lift, so she would have required assistance in some of her daily activities,

and her emotional dependence on her husband's presence, and her reluctance to go out was the spiritual manifestation of her deepened awareness of life's uncertainty and her husband's support.

I 'spose that just makes you feel um,.. just lucky to sort of have the time that you have got together more or less. Everything will get back to normal sooner or later which it did [Laugh] I suppose really it sort of did bring us closer together. And that's why I sort of feel for women that their husbands sort of can't handle it or they don't even want to look at them or anything, cause I think it would be just so terrible, because I think that's a big part of your recovery really so, it's been really good in that respect [F5:p. 8].

Tamara reveals her husband's support as a largely intimate dimension, in which he assures her of his love and desire for her as his sexual partner. This assurance she perceives had the effect of bonding them closer together:

Um, well probably if anything it's sort of brought us a lot closer and um, I mean it hasn't made any difference to our sex life or anything, I mean nothings sort of changed in that respect. I mean Gus still thinks that (even though I've put on half a stone), he still thinks I'm sexy to him [Chuckle] But um, It hasn't made any difference at all in the way that Gus , sort of, I mean I've never ever had that feeling that he is repulsed by the way I look or anything like that. I mean everything is just normal like it used to be, so nothing has really changed in that respect anyway, it's all just the same [F5:p. 15].

Tamara is aware that her sexual life has not been negatively affected by the changes in her life, and that the support that Gus gives her regarding her femininity has been of enormous benefit to her self-esteem. Later in her narrative, she intimated that her earlier (post-mastectomy) emotional dependency on him had negative repercussions, possibly because she appeared to have outlived her high degree of need for his support, while he continued to nurture her. Tamara described her stressful [post-mastectomy] lumpectomy, and of how Gus had seemed to be acting in a jealous way

towards her mother in relation to who was taking her to the hospital. Gus' attitude angered Tamara, who's main concern was finding out the histological results of her second surgery. Tamara continued to elaborate:

Tamara: You see I was probably more touchy than anything, you know I was sort of probably

Interviewer: Do you think that he may have been at that time too over protective and that frightened him a little ?

Tamara: Yeah, I was going to say, even since I've had the mastectomy I've found that he is really over protective he's really scared that anything's going to happen to you, he's just really over protective and everything.

Interviewer: Do you feel "boxed in" occasionally, or do you feel you're OK with that?

Tamara: Oh no, actually he sort of thinks as times gone on, he's sort of got you know, like he sort of realised, (this is when I came home from hospital last time) - I think he realised that he did have to sort of let go a bit, and have a bit of freedom [F5:p. 18].

Tamara's portrayal of her spousal support, gives the reader an entry into the complex pressures that chronic illness may elicit within the dynamic of a relationship. While these pressures are not unique to couples who undertake mastectomy, the role of support may not always be viewed as positive interaction by both parties.

Like Tamara, Jill warmly acknowledged that her husband had been greatly supportive of her by bolstering her self-confidence with regard to openness to her changed body shape. This concept of support was described in this manner:

It has in some ways, only because, not that we both don't want to carry on the same [as we used to prior to the mastectomy]. Um, luckily, I did go through -in the early days [following the mastectomy] - I used to think "Oh how can he be attracted to me!" [as] I was getting used to the having one breast and I'd wear a little camisole to bed and things. I mean now, I don't even think twice about him seeing me naked. He's been so fantastic about that. So reassuring [F1:p.10].

Outside of their sexual interaction, Jill explained that she had virtually built a cross for her own back by her insistence on carrying on as normal following her

mastectomy. She didn't enlist the help of anyone (her own family and in-laws living out of state and overseas), despite having her active little boy to care for. Jill described the impact of the cancer diagnosis, and the uncertainty about her future hardest to assimilate. Between my first interview with her husband, and Jill's interview, she had 'another scare', in which he discovered another thickening in her remaining breast, which she had discovered two days earlier. She wanted to wait a few days before she consulted her doctor, because she rightly assumed that it was hormonally induced.

Jill alluded to her hitherto unmet need of support in the form of allowing her to express her fears and own vulnerability. This theme was evoked in response to my question regarding any sadness/anger or other feelings she may have had in response to her early loss of fertility -in the wake of her chemotherapy. This passage is worth quoting at length, as it gives the reader an understanding into how this disease has impacted on the life of the couple:

Yes, sometimes I feel very angry, very angry. [Sounding sad rather than angry] I suppose I've, as I've say in the past twelve months I've tried really hard not to get in touch with my feelings, I suppose. When I first found out I had cancer, my reaction, wasn't - I've never been in denial because I [pause] accepted right from the start that I had cancer, but people actually thought I was in denial. People would say 'Are you sure you're alright? you seem to be coping too well?'

But I've, it just felt that it had to be that way for Graham, and I have told him so since. Umm, and I've actually, my strength has sort of, the strength I had in the beginning has decreased quite a bit in the last couple of months. I think I'm just really tired out and I found resentment creeping into our relationship because I felt I had to be really strong and keep everything, try to keep everything normal.

I recently said to him, not so long ago. "When am I allowed to be weak?" Because he said to me "I just want you to be, I need you to be strong for me". He was having to spend extra time at work, and I said, "When am I allowed, when's my turn?"

It really hit me then, and I'm really tired of it.

Interviewer: "So you're recognizing that you have emotional needs?"

Jill: "Yes".

Interviewer: "The 'little girl' in you has perhaps learnt she is as important as the strong woman in control?"

Jill: No, I haven't wanted to be in control lately. I'm sick of it! [Laughter] And oh it hit me when I had a recent problem with my remaining breast. I told, when Graham found out about this - Oh, I don't know if I [Pause]

I had a, well, they said it was a glandular thickening in the right [remaining] breast because of the hormone situation, but it felt like quite a nasty sort of hardening. And I discovered it on the Monday and never said anything to Graham. I was going to wait until the end of the week. I felt it was hormonal but I wasn't sure'. I thought I'd wait until the end of the week and then I'd go to the doctor but [Graham] discovered it.

Because he often has this sort of thing of - "Have you checked your breast?", and he wants to check and [he] nearly went through the roof when he felt it. And I said "Don't panic, I knew it was there!" - and we had this sort of dramatic moment and he was panicking terribly again, and um, he said to me that he didn't know if he could cope if I, if anything happened again.

And I can see his point of view, but it made me really angry. Straight away I sort of want to say, "But what about me?"[Laughter]

And sometimes I don't know how I did it with Julian [her little boy]. I really tried hard to do everything myself. Even my neighbors would ask if they could help or do anything, but I was determined to keep everything as normal as possible [F1:p. 6-7].

Jill's narrative reveals she needs her husband to shoulder some of the burden of her chronic illness. She implies she wants him to be less vulnerable so that she can allow herself to mourn for her own losses. Jill certainly does not undervalue her husband's responses, it's more that her words reveal the suggestion that he hasn't allowed her to reciprocate in kind.

Mastectomy surgery may present as threatening to the partner as it is for the woman. Certainly, Jill's perception of her relationship following her surgery indicates that both of them need support. Some couples may not realise that they would probably

find it beneficial to ventilate feelings on an individual basis outside the marriage. Graham sought immediate support from his neighbours and his parents (via the telephone), but Jill did not seek help from her psychiatrist until shortly before our interviews. Certainly, this couple's willingness to share their experiences with me may have afforded them some sense of release, for in retelling their stories they are ventilating feelings.

As a participant and observer, I felt that Jill was very strained by the events surrounding her diagnosis and treatment, and her current need for support related to what she expressed as "... the fear of the unknown "[F1:p13]. Her own needs for marital support were often subsumed by her concern for her boy. She referred to her fear of him growing up without her, and this fear was reinforced by her intimate acquaintance with cancer and death in her own childhood. Referring to her baby stepbrother, she said:

He was only eleven months old when my mother died, I was six and a half thenI wouldn't want Julian to go through what I did. I mean my father didn't cope very well. He turned to drink and um he still provided for us, but he didn't manage, didn't manage very well and I always think "Oh at least Graham wouldn't do that and he could keep a level head", but I just wouldn't want Julian to have to go through that [F1:p. 8].

Jill's biological mother is alive, however, she has not seen her since she was three years of age. Since then, her beloved adoptive mother died of a brain tumour. She spent some years with her grandmother, but was estranged from her father because of her new stepmother. Many years later, this stepmother died of breast cancer, and her father died only nine days later. Jill's confrontation with cancer and death at a very young age has been relived by her in her recent diagnosis and treatment, and her real fear is not only for herself but for her son Julian's future also.

I used to think "Oh please God! I wouldn't want anything to happen!", and I used to worry a lot about how he'd manage with Julian. I know he'd always be a good father and look after him, but he would have been emotionally, falling to pieces! [F1:p. 8].

Jill's awareness of her husband's vulnerability seems fraught with feelings of anger and fear as she explores the possibility of her death, and her concerns about Graham's emotional ability to cope as a parent without her. Reading between the lines, Jill's narrative has indicated that until recent times, she felt fairly optimistic, and that her partner's dependence on her, coupled with his more pessimistic attitude has impacted on her consciousness.

I asked Jill if she felt that she'd been placed in a position in which she felt she'd needed to be strong, and she said.

I think so. I felt that I've needed to be strong. I felt like I'd been put in that position. He hasn't asked that of me but it was, is there. I just felt it was there [F1:p. 8].

I responded with a 'follow up' question, "You mentioned earlier that these roles may be shifting a little now, that you are starting to redefine those roles. Is that right?"

Yes, that's happening recently. I've been getting depressed again. I don't know if it's relevant, but I, funnily enough before the I had my breast off, I had the diagnosis of clinical depression, and I did actually say to the oncologist and the surgeon, having struggled with depression for so many years, cancer was easy to cope with. I don't know, I've been slipping [into depression] lately as I say. It's been really frustrating, because I have absolutely nothing to be depressed about I can only put it down to being emotionally tired out and I feel like its my turn. I need some support. I need to let my guard down and deal with a few things [F1:p. 9].

Jill remarked that this process of redefining or examining their roles in the wake of the mastectomy had begun, and that this had:

only just started because I've only recently opened up to him. I felt like I was turning into this nasty creature, and the doctor said to me "Part of it's probably medical as well as with your hormones all over the place."

But I've been so resentful of having to be strong and it was just building up and I finally realized I had to talk to him. I

couldn't go around being angry with him. He had no idea there was a problem. I was busy hiding it behind a mask.

So I, we discussed it recently and it was so hard for me to [tell him]. I didn't want to let him know that I couldn't handle it anymore. But anyway, it was the best thing I could have done.

I felt like I had a great weight lifted off my shoulders [Laughter] and I discussed how I've been feeling and that I need him to be strong. So we're starting to make progress there [Fl:p. 9].

The position of stoicism she adopted following her diagnosis (and has maintained until very recently), has served a purpose in keeping some sort of protective 'coping armour' around Jill. If she carried on 'as normal' then everything would be so. However, over the fourteen months since her mastectomy surgery, this position has become too much of a burden for Jill as she has begun to acknowledge the significant spiritual as well as physical insult that her mastectomy has had upon her life. This burden is manifest in the exacerbation of her depressive illness, during which she sought psychiatric assistance. In the face of her recent experience, she still maintains that she 'has nothing to be depressed about'.

Jill has thus indicated that she needs a strong, positive stance from her partner, and that even though he has been supportive as a sexual partner, she also desires support in the form of being allowed to express her vulnerability. It appears that Jill and Graham's usual life roles, in which she takes up the position of strength, no longer adequately sustains her. Since her surgery, Jill had come to realise that she required emotional support from Graham and was centred on her insecurity and sense of loss about her breast, but perhaps more overwhelmingly, her uncertainty about her/their future(s). Furthermore, Graham was able to seek support from different sources; his neighbours, his parents and from Jill, whereas she only had Graham (until recently, when she saw a psychiatrist). This leaves a large burden of emotional responsibility on Jill's shoulders.

What sets Jill's story apart from those of other women in this study is her experience of cancer-related breast surgery within months of weaning her first child. Jill's feeling's of mortality since her cancer diagnosis and mastectomy, put extra burdens on her role as nurturer to her three year old son.

Within Jill's chronological dialogue, her needs for support are respectively denied and poignantly acknowledged. Initially, she attempts to control the domestic exigencies of life (and chaotic life/death questions), but her past life, her husband and child's emotional dependence, have seemingly opened some part of her that had been closed for a long time. Jill expressed herself in this way:

So I, we discussed it recently and it was so hard for me to [tell him] I didn't want to let him know that I couldn't handle it anymore. But anyway, it was the best thing I could have done [F1:p. 9].

Jill's account demonstrates that the 'operationalisation' of support within the sexual relationship may be problematic even in the most loving relationships. The women have had their feelings of mortality challenged, their self-esteem is affected from somatic and/or psychological insults to their body mapping, and their sense of femininity suffers, even though they don't feel that they have been greatly affected by their surgery. Women who undergo mastectomy have essentially disfiguring surgery, which, as it is related to a sexually significant body part may make the negotiation for support even more difficult.

Reflections

In summation, this chapter has dealt with women's perceptions of marital support, and this support implies that the women (or indeed the couple) adjust positively to their changed situation. Certainly, the experiences of women studied within this chapter indicate that they continue to make adjustments to their lives following mastectomy and require the emotional reassurance of their partners long after surgery. The experiences that these women have discussed indicate that even when women perceive marital support, the process of living through their altered life status as a person who has undergone mastectomy and has (as opposed to 'had' cancer) is not an easy transition, for either party.

Of the seven women participants, two gave clear indications that they failed to procure the support of their husbands in the pre and post-operative phases of

treatment and recovery. Of these two women, Lucinda revealed that she perceived no emotional or physical support from her former spouse. Lauren's need for support was apparently only partly met. The concerns of these women are linked by their awareness of marital problems prior to the mastectomy and their comments were often overtly suggestive of marital/intimate conflict.

Men's Perceptions of Role Changes

Graham spoke of changes to 'normal' family routines following the mastectomy. These changes reflected his wife's need for more rest, particularly in the periods between the chemotherapy sessions. Graham reported that Jill insisted on carrying on as normal, in terms of the housekeeping and cooking. He said that her only concession to her changed status was having a nap with her little boy during his afternoon sleep period, and enrolling their child in family day care for one day a week.

Like Jill, Graham experienced the stress of his son's insecurity following her surgery, and he reported the little boy frequently touching her remaining breast to reassure himself of its existence. Graham spoke in detail of the nocturnal alterations to their sleeping arrangements, which resulted from these changes. Since Jill's hospitalisation, her three year old son was unable to settle to sleep without his Mummy cuddling him, and would wake up screaming for her when she got up to return to their bed. In the twelve months since the operation, the child has mostly slept with his mummy or his daddy in the 'big bed' while the remaining partner often has obliged to sleep alone in the spare bed. In recent weeks, they had variable success in 'weaning' him back to his own bed, but he often gets up in the middle of the night and 'nests' with them again.

We went back in there [to our own bedroom] and then he started to get out of his bed and [was] climbing in with us and I couldn't sleep, the three of us. That's not a queen size bed, and he was kicking me in the head and what have you, so I said "I'm going to sleep in there !" So that's been probably about a month. And we actually got him a new single bed on the weekend [MI.:p. 21].

Graham spoke good-naturedly about this, and indicated in a philosophical way that it had an inevitable affect on their intimate relationship. While sleeping difficulties in children may be problems faced by many parents, Jill and Graham's perception's of their son's behaviour since the mastectomy indicate that his/their sleeping patterns have been profoundly influenced by her period of relative isolation in hospital and the breast amputation. Graham and Jill's pre-mastectomy nocturnal living patterns have changed radically as a direct result of Jill's surgery, giving them more limited opportunities to engage in intimate physical ways. While Graham did not openly refer to a role change, he implied that his sexual role as lover was seriously challenged. Neither of them spoke of any sleep deprivation resulting from these changes, it is possible that this may have also been a concomitant part of this situation. If tiredness was also a factor, it may have contributed to their communication difficulties. Their little boy's up-front grieving of the loss of his mummy's breast created a 'ripple-effect' across all their lives that made their changed status difficult to ignore. This ripple effect was also experienced by Gus, who supported his wife through mastectomy surgery six years ago. He spoke clearly about the impact her hospitalisation and homecoming had on his own role in the family:

You got to kind of try to hold, in this case hold your wife up, support her, support the kids. I suppose hide your feelings to a certain extent. Ah be stronger and tougher than what you are [M5:p. 12].

Gus recognised that Tamara needed physical assistance around the house, and the family 'pitched in' to help. However, it is the emotional weightiness of his change in role, in which he speaks of needing to adopt caring behaviours within a facade of strength - which he is perturbed by.

[I had to be] very strong, because as I said before, the kids were young, you, you've got to put a brave front on there, and tell then everything's alright, when you know damn well it mightn't be. Ah, that was a bit hard. A lot of people did a lot of cooking, a lot of helping me, um,.. You're still trying to get a living in, where the kids got changed a lot and they had to come home and do their own thing and clean up and straighten up. Everybody had a job, everything ran well. Ah,.. The role really didn't change, only I took, I suppose Mum and Dad's

role, and had to toughen up a lot, and that's about it really [M5:p. 12].

Gus infers that he found it a difficult role caring for and reassuring his children, when he felt so emotionally exposed and vulnerable himself, he hints at the onerous burden of feeling the need to reassure them that 'everything was alright' when in fact he wasn't all that sure himself. As their three children then ranged in age from six through to fourteen, he no doubt felt it was best to focus on the positive in an effort to assist the return of domestic 'normalcy'. Gus highlights the catch-22 situation that some men are faced with. Even though he felt exposed and in need of emotional support, he was aware that his 'normal' role of the strong, coping figurehead was more necessary (in order - he assumed) to sustain the strength of the family. It is possible that men who adopt and maintain these roles bear a larger burden of emotional responsibility than they ought in the wake of the insult of mastectomy. Even so, he revealed that while they were very open with the kids, he felt guilty about his insecure feelings, and had to hide his feelings of powerlessness:

The kids were good they understood what was going on, we were very straight with them, so that took a bit of the pressure off. But you still get your moments when you are very down on yourself and you've got to hide that, pick it up. Ah, I suppose everybody's got to take two roles on every now and again, see what happens. I don't know [Chuckle] [M5:p. 12].

Throughout his conversation, Gus referred to others helping out in an undefined domestic sense, and how she got to the point where she wanted to do all the housework herself. He implies some form of friction arose between them on account of his admonitions to her to obtain assistance, and her refusal to do so. This passage has good fit with the analysis of Tamara's transcript, in which she had voiced concern about her spouse being too protective with her at times, to the extent where it became bothersome to her. Gus remarked that while his partner was at her lowest ebb following her mastectomy, she insisted on carrying on almost as normal:

ah, rock bottom, and she was pretty well down and she's a persistent bloody,... where she's very persistent with keeping the house clean and doing this and doing that and she wouldn't let any body else in. Ah I tried to suggest to have

somebody else in to do this, to do that. A few people helped out (type of thing). She wouldn't let them, she wanted to do the whole lot, and I eventually gave up on it, cause the fact you just can't keep on hammering away all the time, you know. Leave the bloody clothes alone, I'll get them off later, I'll do this, I'll do that, and you come home and you stuff yourself, so you know. By the end of the night she's had it, so go to bed a bit early or something like that. But she's pretty bloody persistent. I think that was half her, [trouble] she's just kept on choofing on -(you know?) She's gets a lot of pleasure out of doing it, where a lot of women think it's a chore to do the house work, it's not to her, that's what she likes doing you know ? [M5:p. 12-13].

Gus' perceptions of concern have good fit with the analysis of Tamara's perceptions of his support. She liked the initial family assistance, but later felt as though 'he wasn't giving her enough space', and the role reversal became a threat to her own sense of personal autonomy. This finding corroborates one of the findings within the present study of women, which suggests that the role of support from the loved one may be ambiguous, or ambivalently received by the 'needy person.' This should not be so surprising, as the unwell person strives towards and/or attains a position of wellness on the health/ illness continuum, her aspirations may exceed her capabilities, just as the care givers wish to care may exceed the necessity to give care. Indeed, there are doubtless many more positive or negative configurations to marital (and family) support, as couples react to the multiple stresses of mastectomy.

David, whose partner had a mastectomy which was later followed by a craniotomy for cerebral metastases, had sensibly assumed that the course of events following his wife's breast amputation would move in a linear fashion from illness to health. He said:

Yeah, yeah. No I'm pretty practical and I can adjust very quickly. You know. If its got to be done I'll do it and I'll get used to it [M3:p. 10].

There were no major household or role adjustments mentioned as a result of Sharon's mastectomy, and David said "there's [was] no change. We just carried on as normal"

[M3:p10], although her subsequent surgery had profound effects on their former lifestyle;

... Well . But since the brain tumour, yeah big changes. I've got to do everything. Sharon can do so much, but, ah I find myself, I've got to do most of the housework [M3:p. 10].

Sharon suspected there was a problem somewhere within herself, when she realised she wasn't as accurate with her figures in her office position. She promptly sought medical attention, had cerebral CAT scans and was hospitalised for urgent cranial surgery. Since this surgery, she has had to forgo her career, and her husband has also retired in order to care for her properly. David explained their position thus:

Sharon always handled every penny we ever got in the house. Once she had the brain surgery she couldn't work anything out. So I've had to take that over and, you know, and I've never touched money. Pay always went to her. I didn't care what she done with it, so long as I got fed. (Laughter) But since the brain surgery she says no, she can't handle it anymore, she can't seem to work it out, so I've had to take that. But there's really no hassle. As I say, I do all the housework. I do all the cooking [M3:p. 8].

David now takes the major care taking role for Sharon, whose motor movements were affected by weakening affect of the cranial radiotherapy, and noxious affects of the anticonvulsant drugs she was prescribed following her craniotomy.

Since this time, her drug regimen has been stabilised and her feelings of wellness have increased markedly. David explained the deleterious local effects of her radiotherapy, and his attempts to adjust the environment:

her whole head was red and just her face went bright red, and extremely itchy all over her head from the burns and that. Then her hair started falling out. That worried her a lot. She went completely bald. I was changing sheets and that two or three times a day because it was just dropping out everywhere, you know. Yeah. (Very sad sounding) [M3:p. 8].

No, not distressing, no. Just constant work all the time . Um I wouldn't get upset anyway, not in front of her. ... I prefer to keep working [M3:p. 8].

David clearly uses his commonsense, practical, 'get on with life and do what has to be done' approach as a form of protective buffer which seems to provide an orderly structure to the pitiless progression of his mate's illness. David's and Sharon's experience of cancer has been the most fraught with mortal complications, and serve as a sober reminder of the deadly potential of this disease

This couple's lives have also been the most heavily influenced in terms of their usual roles and expectations. They have nonetheless maintained a steady faith and a clear devotion to one another in spite of such massive personal changes. David's attitude to the threat of cancer is simply "You're not dead until they shovel the last bit of dirt over you" [M3:p1].

CHAPTER TEN

Women's Feelings Concerning Their Fertility and Menarche

The diagnosis of cancer has challenged all the women's views of mortality. For women who are still within the menarche, their choice of life extending treatment following surgery presents issues which may impact on the emotional lives of the women and their sexual partnerships. Lucy and Jill, the two youngest female research participants expressed strong emotions about their fertility in the wake of mastectomy and adjuvant therapy. Both of them had chemotherapy. Tamara and Gemma were concerned about the effects that chemotherapy and Tamoxifen respectively had on their lives as women. Of the four women, three inferred that they could have had clearer information about the metabolic effects of these drugs given at an earlier juncture.

Adjuvant therapy, so called because it is offered as an adjunct to localised surgical treatment, is a systemic approach to the treatment of cancer. Thus, hormone (Tamoxifen) therapy and chemotherapy are widely known as systemic or adjuvant therapies, and may be used whether the woman has had radiotherapy (X-ray) or not. The purpose of these treatments are to treat or arrest the growth of any undetectable cancer which may spread before the time of surgery. Thus, the likelihood of

metastatic spread or local recurrence of tumours is reduced and life expectancy increased. Research demonstrates that early diagnosed breast cancer in women who have chemotherapy and hormone therapy have a thirty percent lower recurrence rate per year and a twenty percent lower risk of death than women not receiving these treatments (National Health & Medical Research Council, 1995).

Early menopause (temporary or permanent) is an important side effect of chemotherapy, as are nausea, vomiting, tiredness and alopecia. Sherins and Mulvihill (1989) note that the likelihood of premature menopause and the probability that it will be permanent increases after ages 35-40 years.

Data concerning this risk in relation to Tamoxifen therapy are not conclusive, but side effects are, slightly increased risk of endometrial cancer, hot flushes, depression, vaginal dryness and discharge. A nursing pharmacological textbook suggested that it be used with caution in women within child bearing years, and that couples should adopt non-hormonal contraceptive methods (Alfaro-LeFevre, Blicharz, Flynn & Boyer, 1992, p. 653). This implies that, doctors who prescribe Tamoxifen to women pre-menopausally, have an over-riding concern to extend their lives, and may perceive the premature loss of procreative potential as of little significance to the women. Indeed, this is a possibly correct assumption in the immediate pre-operative and post-operative phases of treatment. In the diagnostic phase the woman has to deal with the problem of breast amputation, whereas in the post-operative phase she deals with both the loss of breast and the fear of death. For both the doctor and the patient, these concerns may well subsume other concerns, which may surface later, or during adjuvant treatment. Most women welcome the chance to extend their life potential, however, adjuvant therapy may induce early menopause, which may be interpreted as a further insult on already bruised self-esteem of the woman's womanhood undergone mastectomy. It may also be an added heartache for couples who had planned to have a child or more children.

Jill, who had chemotherapy in the months following her mastectomy, presented an emotionally contained, coping lifestyle for several months following her mastectomy. She said:

I've only cried once, and that was months after I had the operation. It suddenly hit me because we thought about having more children - and it suddenly hit me one day with my doctor saying, or my surgeon's saying (or, not the surgeon - sorry) my oncologist saying, "Well, I want you to wait another five years before you consider it [another pregnancy]. Looking at my age [36], I discussed with him [about] having more children, and said that we'd both almost decided that we would 'let go' because we were both so worried about me becoming pregnant. And he said it wasn't a bad idea to leave things as they were and not have any more.

So, in that sense, I, it just hit me one day. It was like I had to grieve for not having any more children. The enormity of it. That Justin was going to be an only child. I would never have just wanted to have one really. I always wanted at least two.

It would have been nice, I really would have liked it [F1:p. 3].

It is significant that Jill allowed herself to cry at this time, for it pinpoints the absolute importance that her mothering role has for her, and how having more than one child has always been part of her vision of the future. Jill is not immune to the implications this treatment has had upon her future life and that of her family. All her hopes and dreams of having another child have been dashed by the necessity for chemotherapy. Jill infers she would be too old to have another baby in five years, when the risk of pregnancy hormones stimulating cancer cells would not be as high. Jill said that the oncologist:

.. only spoke about fertility in the sense that of not bearing children, that it was, I shouldn't consider even thinking about it for five years after the chemotherapy, [or] it would be too dangerous. And straight away that stirred Graham and I up because I thought, in five years I'll be forty-two, Justin will be however old and I mean, starting all over again (?) and it wasn't what we'd always wanted from the start.

And then the danger side of it [the risk another pregnancy would have on my health], we ended up deciding O.K. ... I had a tubal ligation and I really felt like I had to do it, but I didn't want to [F1:p. 5].

This passage gives insight into the complex emotional issues of fertile women in the wake of mastectomy. If they have surgery which has invaded the axillary lymphatic system, women are strongly encouraged to have chemotherapy, radiotherapy or a combination of both. This therapy is known to be affective in reducing the risk of further cancer. The claim that the treatment will minimise the risk of cancer recurrence is welcome but the fact that this treatment can also radically alter the young woman's future plans may be the most difficult information of all to assimilate.

Jill was speaking to me at length about her husband's and her own response to the news of the risk her fertility posed, her tubal ligation and her subsequent (believed to have chemotherapy induced) menopause. I used the metaphor of her occupying an emotional roller-coaster in asking her if she had any further feelings about these issues, to which she responded:

Yes it was. It had been, it has actually The menopause side of it and the children side of it. You don't think of any of that when you first find out you've got cancer. But yes. That's been a big part of it. As big as the cancer really. It changes your whole life [F1:p. 6].

Jill reveals that the impact of chemotherapy on her future life and family planning has had as much force as has the cancer diagnosis. She is aware of the enormity of the treatment-related decisions she and her husband have been obliged to make. In her common sense way, Jill seems to have been able to partly resolve her personal loss following the mastectomy by focusing on her child and his future needs:

I thought I'd rather be here, as a mother for Justin instead of risking having another child and not being there for either of them [F1:p. 5].

Lucy, a mother of two girls, had her mastectomy six years before our interview. Her fertility was of great importance, because, she had recently formed a strong attachment to Imran, and they were planning to marry and to raise a family of their own.

Lucy had told her story in a mostly energetic, positive voice, even though her narrative often referred to very negative life events. Her voice and demeanour altered markedly towards the end of our interview, when I asked her if her chemotherapy had any effect on her fertility she said "No, not at all!" - declaring that, to the contrary:

... I actually fell pregnant not long after I came off chemotherapy. And the oncologist said "Oh God I don't even want to think about it. " Because I already had Liza, she had a disability. He said "it's really up to you, you can risk it if you want to, you can risk your own life. The chances of you surviving this cancer is pretty remote. You don't want to leave, you know the baby could be deformed or handicapped. There are no guarantees it's going to be normal. You wouldn't want to leave behind) the baby" so I um had it terminated, that was it (you know? [F4:p.32].

I asked Lucy if she received any genetic counselling or support during this time, and she said in a sad, contemplative tone:

Nothing, absolutely nothing! That was really sad because ... [very emotional. A long silence] I've had to be really brave [very upset] [F4:p.32].

Lucinda's distress was clear, and I gave her feedback to indicate this. She responded:

I hadn't really thought about it much Um.. After that. It's really funny you know, because I, I didn't want. I was just thinking about this today, going to work. I didn't want to have any [more] children to my husband, my husband at that time. Um.. I was only considering him, but I never thought about myself, and it's probably my biggest and only regret that I can think of, ever, that I have ever done. Because after that I had my tubes and everything, all the plumbing rearranged so. Not that it can't be undone and put all back together again [sigh] [F4:p. 33].

Lucy was counselled about the possible outcome of her womanhood. It could seriously endanger her, her baby or both, and she was not expected to live beyond a few months. Given this cruel scenario, in which she infers the oncologist 'put the

facts 'to her, she had little choice than to terminate the pregnancy, and she still feels the pain of this decision. It is unlikely a doctor would perform an abortion without the legal consent of her husband. However, Lucy indicated that her husband was unaware of her pregnancy, or it's termination, and she infers she did it more out of concern for him being left holding (another, possibly handicapped) baby, than looking at her own emotional needs.

When Jill and Lucinda related their feelings about how their fertility was affected in the wake of their therapy, it was obvious that both women were shaken by the impact it had (and indeed still has) on their lives. As Lucy says, since having a new partner, her unfulfilled wish to have another child is more of a reality:

So I mean, Imran doesn't have any children, and that's something that we have thought about. And I'd always thought that somewhere along the line, I'd have a son [F4: p. 28,].

However, she realises that this involves further delicate surgery, and if she is able to conceive following her fallopian tube reconstruction, it may be a risk for her and/or her child. While Lucy only inferred criticism of health services due lack of any counselling beyond the medical insistence on her pregnancy being terminated, her experience, and Jill's seems to indicate that they were both relatively unaware (at the time of their mastectomy), that pregnancy is a health risk. This may be due to the fact that they were unable to understand all the information given to them by the doctor, or it may mean that they weren't told until much later, at the time of the chemotherapy. We shall find that women perceived information giving was poor in regard to the variable effect that chemotherapy/radiotherapy may have on the menarche.

Jill clearly indicated that she had no idea that early menopause was an associated risk of her chemotherapy. I was inquiring about the problem of containing her post-mastectomy fertility when she mentioned menopausal symptoms and that she had undertaken a tubal ligation.

Interviewer: I wonder if we could talk briefly about how this episode - this surgery, has effected you in terms of your

fertility? You've already mentioned how difficult it's been for you and Graham to adjust the sexual part of your life in terms of the need to contain your fertility.

Jill: Yes well it has been. I suppose if I am really honest with myself, I feel very sad to be going through menopause at thirty-seven now, but chemotherapy's done that. I feel very sad about it but on the other hand it's let me off the hook about having children I suppose, because had I been going through menopause I had a tubal ligation and I really felt like I had to do it but didn't want to [F1:p. 4 - 5].

This part of Jill's story was somewhat confusing, so I asked her to confirm that she'd had her 'tubes tied':

Jill: I had a tubal ligation

Interviewer: I just needed to clarify that.

Jill: Sorry, I did have that at the beginning of the year after I had finished the chemotherapy, but unbeknown to me, the thing that was going on all the time, I was going into menopause anyway

Interviewer: Oh really?

Jill: That has, yes, been confirmed by my gynaecologist

Interviewer: And that was because of the dose?

Jill: The chemotherapy, the oncologist said, was causing that

Interviewer: And they didn't mention that chemotherapy may have that effect?

Jill: No, no, they never actually went into that. He only spoke of fertility in the sense of not bearing children [maintaining contraception][F1:p. 5].

Jill implies there is a need for information to be given to couples in written, as well as verbal ways, and that the stress of the doctors interview may not be the best or only way in which women can obtain information to help them make informed decisions about their healthcare. It seems that Jill may have had a surgical procedure which may

have been avoided, given that she had already begun to experience an iatrogenic menopause.

Jill didn't seem perturbed by the fact that she remained uninformed concerning the strong possibility of early menopause, although she may have felt some fear of being critical on account of my own association with the medical world. However, it is clear that she is disappointed to have lost the years of her menarche that would have accrued to her had she not contracted cancer. She bravely steels herself to look on the bright side of her early menopause:

.... As far as the menopause, I tell myself "ok. I'm going through it now instead of twenty years or something. So I always try and see the benefits of it [but] that always reminds me that the reason I'm going through it [the cancer] comes back [F1:p. 6,].

Jill is aware of radical changes in her life over a number of fronts, and they all seem to be in the form of an assault on her sense of womanhood. This insult to her experience of being a woman is a constant reminder of the reality of her 'differentness' to other women, and reinforces the fact that she has been given a diagnosis of cancer.

Tamara was also unaware of the fact that her chemotherapy could have ramifications on her hormonal state, and she remained unaware of this until much later:

..... about eighteen months after I had the mastectomy, because I was sort of missing periods now and then through the treatment, you know sort of on and off

I'd just turned thirty six, I was thirty five when I had the mammogram, and I had just turned thirty six. [when I had my mastectomy] So, and I've had, they weren't (sort of) regular through the chemo, then for about eighteen months after that, I was getting them one month and skipping a couple of months, and then it gradually (sort of), I went for a twelve month break without having them, and then got them one more time, and I haven't had them for about three years now so.

And I didn't really even know that I was going through menopause, it was just I, um getting these really burning hot flushes in a real sort of depressed state and I didn't know why and, you know I was sort of like [had] PMT full on, cause I used to be like that three days before my periods, I'd be slamming doors and yelling at everyone for nothing and they didn't know what had gone wrong [F5:p. 9-10].

Although it is not unknown for young women to experience early menopause, it is certainly not usual. At thirty-six years of age, Tamara expected her menarche to extend to forty-five to fifty-five years. She tells us that this experience of distressing, unexplained symptoms:

..It was terrible, and I ended up just going to my G.P. doctor and she said to me that chemotherapy can do things to your ovaries. And she said that I would be going through early menopause, 'cause that would explain the hot flushes, and she just put me on evening primrose oil tablets and vitamin B6 ... and it gradually sort of, and I felt a lot better you know, within a few months, so then it was just like a trade saying. When I was getting in a shitty mood, go and take some evening primrose oil tablet [Chuckle] [F5 :p10].

Viewing this period in retrospect, she recounted it with a self-effacing humour, but in spite of her ironic tone she drew a word picture of a fairly unsettled time in which she and her family were confused about her behaviour:

At that time I was just getting really depressed and I was even thinking about things, (you know ?) from years ago that really bugged me about, Gus and (you know), and I would be taking it out on him, ... [that was] before I found out from the doctors what was wrong, and I hadn't been on any medication or anything then. But it was terrible [F5:p11]

But I can really understand how people sort of going through menopause must feel, because I mean I've been feeling great for the last couple of years, but (you know) for just about six months there, it was really terrible especially not knowing why I was feeling like that,[P11].

Tamara reveals feelings that may have bordered on suicidal, and it is disturbing to note that her surgeon, oncologist or G.P. failed to acquaint her with the likelihood of her precipitate menopause. Tamara infers that she would have coped far better with her fluctuating moods had she been informed of their reason. I am inclined to believe that Tamara was not in a position to absorb information, but her husband Gus, attended most of her consultations and was very hungry for information.

Tamara harboured no rancour towards the health care team, because she had her three children as planned, however, she was careful to qualify this by noting:

Well, if I had have been planning to have any more children then I probably would have been angry

But I mean I didn't I wasn't sort of planning to have any more than the three that I had anyway, and I suppose after having a mastectomy I probably wouldn't even have thought about having another baby anyway, but um, oh no in away I sort of thought "Well I don't really need my period!". [Chuckle] ther in [me] that respect [chuckle] [F5:p12].

Tamara can now afford to be philosophical as she has had the family she had planned for, and her menopausal symptoms have gone. However, at the time she unknowingly experienced her 'change of life symptoms,' her capacity to manage her intimate associations within her family was threatened by her (apparently) inexplicable mood swings. Schain (1988, p. 158) noted that:

"Although the woman's sense of femininity, desirability, loveability and acceptability may be undermined if the breast is changed or missing, the negative impact can be horrendously intensified by the added distress of hormone depletion, especially if it was precipitously induced chemically".

She (Tamara) was aware of revitalising long buried grudges against her partner, and her self-esteem and sense of security was threatened. While Tamara makes no direct comment concerning her the affect her induced menopause had on their intimate relationship, the implications of her discourse infer that their intimate lives were deeply affected.

Fourteen months following surgery, Gemma was experiencing the effects of iatrogenic menopause as a result of Tamoxifen therapy. It is usual for women to continue this medication for five years following mastectomy. The action of this drug “.. blocks the effect of oestrogen on the cell, so it blocks the drive to grow. In most cases the cancer stops growing, even though it doesn't not kill the cancer cells” (NHMRC, 1995, p. 50). Oestrogen is a powerful potentiator of some forms of cancer, and is no doubt the reason why doctors advised Lucy and Jill not to entertain any idea of further pregnancies, at least for the next five years.

At the time of our interview, Gemma's menstruation frequency had diminished to two monthly intervals. Her reference to menopause emerged in direct response to an open ended question I had put to her regarding any changes she had noticed in her feelings of physical intimacy with her husband as a result of the mastectomy:

I must admit in some ways it has made a slight difference, as far as [Pause] I put it down to the Tamoxofin. Um because I mean I am having vaginal dryness and I'm having [Pause] I'm a little bit sensitive and things like this.

I am also finding that I'm sort of, I wouldn't say I'm not interested, that's not the point. I'm just taking a longer time to become aroused.. so then we were talking about it, we said well really it hasn't really made a lot of difference, as far as the number of frequency, but for instance, you know having an orgasm it doesn't seem to be as strong - any more [F6:p11-12].

Gemma felt strongly that her slow sexual arousal was directly linked to early menopause symptoms, and emphasised this by remarking again that her mastectomy had little effect on their feelings about one another. Once more, there could be a tendency to take Gemma's common-sense attitude and accept that she/they have been unaffected by the mastectomy, but this ignores the fact that her menopause symptoms are drug-induced and premature, and directly linked to her cancer treatment. The nature of the topic of this research is so inimical to usual discourse between relative strangers, (or indeed, even between some 'intimates') that Gemma shies away from any self-examination about what her lowered arousal has made her feel about her inner-self. However, she had indicated earlier that the sexual dimension of her life

was very important to her, so any change in the quality of her sexual feelings would be reflected in subtle processes of adjustment, for both marriage partners.

Jill and Lucinda share the experience of having their procreative ability curtailed, when they wanted to experience maternity again. Whether Lucinda is able to have her fallopian tubes successfully anastomosed, and then conceive and bear a child, is only one part of her wish to renew to motherhood. Whether she is able to maintain her wellness when her body is flooded with hormones, which potentiate cancer is perhaps the biggest question.

Reflections

Not surprisingly, it was the younger women in this study who were significantly affected by concerns about their ability to bear more children or maintain their usual hormonal life in the wake of post-mastectomy therapies. Two of these women were ignorant of what profound metabolic effects the administration of these therapies could trigger, and they have experienced some distress on account of this lack. While this small study cannot lead us to assume that the same applies to all women who have post-mastectomy chemo/radio, or Tamoxifen therapy, the insight of these women highlights the duty of care that health professionals have in imparting and reiterating knowledge in diverse ways.

It is obvious that medical specialists have time demands, and by the very nature of their practice may find it unrealistic to justify the amount of time necessary for counselling the woman and her husband about iatrogenic (and other) effects of mastectomy. Part of the problem may be time limitations, coupled with the fact that, historically, doctors have been very reluctant to relinquish any of their professional duties (powers). At a local level, it has taken the Cancer Foundation many years to convince surgeons of the benefits of referring their clients to the organisation for ongoing counselling and group therapy, which some women wish to avail themselves of.

A 'health consumer' interpretation of this lack of patient information giving, would emphasize the patients' ethical and legal right to be informed of the benefits and risks

of any medically sanctioned therapy. While it is obvious that these couples were informed about the positive health benefits of radiotherapy and chemotherapy, it is not as obvious they were given the autonomy to make their own treatment decision on the basis of all the information they required in order to reach that decision. The inference here, is that some doctors may unwittingly withhold vital information before treatment is commenced, because of concern for his/her already traumatised client refusing or delaying further treatment to extend her life expectancy.

This hypothesis may be controversial, as there is every reason to honour the testimony of these women, and to attend to the implied message within their words.

Unfortunately, paternalistic attitudes have prevailed in society for so long, in many ways still remain entrenched in the medical profession. The doctor may believe the best interests of 'his/her' patient are met by (kindly) overlooking educating the client. There exists a lack of respect for the patient as a free, intelligent person, capable of choosing appropriate treatment.

It is clear that the women featured in this chapter were not directly censorious about their medical care as it pertained to their fertility, but four of the women and two of their husbands were critical of pre-mastectomy medical care. Anger directed at the medical profession has emerged as a significant finding in both the female and male participants, and will be discussed in Chapter Eleven.

In conclusion, the issue of a woman's fertility and menarche are deeply personal concepts, which impact upon the woman and her sexual partnership in unique ways. Fertility is invested with notions of emotional intimacy as it is circumscribed with choice and option in a way that has not been possible in previous generations. That is to say, couples commonly deliberate and plan for children, and this family planning may reinforce the warp and woof of the intimate relationship. In counterpoint, any disparity between the procreation desires of the partnership may disrupt the weave in the intimate fabric of the couples' lives.

The intimate lives of the two couples in this study who wanted/want more children, have been greatly affected by the event of women's cancer-related treatment. The

women's stories concerning their experience speak for themselves, There is also a future dimension in the concept of Lucinda's (and possibly Jill's) hopes. Jill's iatrogenic menopause is unlikely to disappear when she completes her Tamoxifen therapy, and if it does, and she wants to reverse her decision concerning more children she and her partner will still be faced with reconstructive surgery to reverse her tubal ligation, as well as the risk that the bombardment of hormones will enhance cancer cell proliferation. Lucy and Imran face the same risks as they embark on their journey towards forming a family. Chemotherapy related menopause is not unique to women with breast cancer, but Tamoxifen therapy is. The accounts of the women in this study suggest that pre-treatment and intra-therapy counselling would be a valuable tool in assisting couples in coming to grips with the wider implications of this disease and its treatment.

CHAPTER ELEVEN

Men's and Women's Angry Feelings Concerning Their Treatment by Professionals

... she didn't sort of make an appointment for me, you know rush me in [for an appointment with a specialist] or anything. And that's why I thought, well maybe it isn't anything to worry about. But then when I read the report, I thought it was just staring her there in the face!

[Tamara : wife of Gus, p. 19].

First diagnosis from ... hospital. Whoever she saw down there was, didn't give the right information. You know we could have lost her through, well what can you say, professional incompetence, would be the word. They don't seem to care, or they don't know, one of the two. That's about it on that one really.

[Gus : husband of Tamara, p. 2].

Of the seven couples participating in the study, four women and two men were angry about the medical attention they received. Within this subgroup, there were two couples and one woman who were enlisted into the study as a result of a newspaper article outlining the purpose of the research. People were invited to respond by leaving a message on my answering machine. Of only five women who responded to this article, all said their partners were willing to be involved and three of these

women seemed extremely 'anxious to get things off their chests'. They seemed to want to pour out their hearts over the telephone, and began to tell me about the medical difficulties they had experienced in angry, distressed tones. I had a little difficulty in terminating these conversations, as I wanted to convey an empathic interaction, but I also wanted to collect this data 'fresh' so as to remain as free from bias as possible. Prior to contacting them, I had not considered anger as a major factor. However, by the time I arrived to speak to them with my tape recorder, I knew there was a strong likelihood that their anger may feature in the data. Two of their husbands had similar feelings, and a third woman, who had divorced since the mastectomy voiced strong feelings about the lack of adequate, timely medical attention.

Of the couples who were enlisted into the study via a 'snowballing' technique, one woman was critical of her care in the pre-operative and post-operative stage of treatment. Other couples inferred criticism in regard to poor information given by doctors in relation to the side effects of treatments, and these points have already been developed in the themes relating to fertility. However, the preponderance of the participants anger was levelled at doctors involved in the first part of what should have been a therapeutic interaction; that is, the diagnostic stage or illness. Two of the women and one of the partners expressed anger at the protracted periods elapsing between the first consultation time and subsequent surgery. They also reported what appeared to them as unforgivable casualness in overlooking evidence which suggested the need for urgent medical intervention. The implications for the medical profession arising from these criticisms will be discussed as recommendations in the concluding chapter.

Tamara told about the long period of time which elapsed between the time she discovered her breast problem and her diagnosis six months later. Even then she felt that, if it hadn't been for her own insistence on having a mammogram she would not have been diagnosed until it was too late. Tamara recalled the actual date of discovering her painful, inflamed right breast, which also had an exudate coming from the nipple. She remembered having to pad her bra to stop the discharge from soiling her clothes. At this time she sought the help of her female doctor, to whom she

explained she had stopped lactating just a year prior to this, as well as reporting having had a few bouts of mastitis while she was lactating. Her doctor prescribed a course of antibiotics, assuming mastitis, and Tamara responded to treatment. When she had a 'follow up appointment', Tamara reported that this doctor did not palpate her thoroughly enough:

.. when I went back in the ten days it had all, you know all the soreness had gone and everything, and she did examine me, but she was very - sort of- didn't really prod, she said I won't prod too much because you're probably a little bit tender there, anyway, and, [she said] Oh no! [you don't need to worry] everything's fine ![F5;p. 15].

Tamara said she was the person who suggested a mammographic study of her breast, and she implied that the doctor wasn't very concerned, and failed to initiate the investigations at the time of consultation.

Mammographic studies are known to be a more accurate diagnostic tool for women over forty, due to the large number of false positive results which occur in the former group. This occurs because women in the younger age group have more breast thickening resulting from cyclical hormonal fluctuations, and these thickenings result in radiological shadows, which tend to mimic the presence of a mass or tumour.

Tamara was thirty-six at the time of her diagnosis.

And it was only the fact I said to her that I was a bit paranoid about lumps because my grandmother died of breast cancer, and she said, "Oh no you've got nothing to worry about you've got no lumps or anything there." So she just said I was due for a pap smear in the following May, so she said when you're due for your pap smear, just go and have a mammogram then and she'll have the results of the mammogram when I go and have the pap smear. So that was six months down the track and I went and had my mammogram then [F5;p. 16].

In indignant tones, Tamara outlined the whole process that occurred prior to seeing her surgeon. She had nothing but praise for his support and surgical expertise, but later inferred she could have been far better informed about her treatment side effects. Her anger and disappointment lay with the treatment not given by her G.P:

.. the thing I sort of was getting really mad about, like after I'd seen, I'd actually got my mammogram back, and it had the report on it. It said highly suspicious of carcinoma, and Dr (GP) didn't even ask me to come in and speak to her, I mean she was still saying it was probably still from the mastitis, to me on the phone [F5:p. 19].

Tamara stresses the point that her doctor did not seem aware of the potential sinister “significance of the mammographic report”:

... she didn't sort of make an appointment for me, you know rush me in [for an appointment with a specialist] or anything. And that's why I thought, well maybe it isn't anything to worry about. But then, when I read the report, I thought it was just staring her there in the face ! [F5:p. 19].

Tamara's sense of personal outrage at the professional omissions she suffered in seeking care were confirmed by further anecdotal evidence she received from a friend who sought help from the same G.P only six months from the time of our interview

.. a girlfriend of mine went only six months ago, she had a sore boob and it was sort of red and tender and that. And I said, well you want to go and get it checked out and you know get a second opinion and that, And she went to Dr [the same female G.P] and she said, that she didn't even make her take her bra off! [F5:p. 19].

Tamara suggests that this doctor has not learned from her experience of Tamara's lumpless and ultimately cancerous breast, as she apparently continues to give women incomplete physical examinations. This participant finds this an absurd situation, for, as a female doctor, it was expected that she would do a more thorough physical examination than a male doctor, due to ease of examination.

.. really, [Tamara's friend felt that] it was almost as though she was too scared to, [examine her thoroughly] (I don't know) and being a woman doctor, you wouldn't think that she'd be bothered, you know sort of touching another woman

or anything, ... Then she went to another lady doctor up there, and she said she had to strip off from the waist and lay on the table and you know was examined all the way round and everything.[F5:p.19]

And when I did have the mastectomy it had spread to about six glands as well. So I mean it was well on it's way. I think my surgeon took about thirteen glands out, and it had spread to six. so you know sort of he just took those others beyond to check that it hadn't sort of spread any further [F5:p. 19].

Tamara's partner Gus' responded to the diagnosis with:

"I suppose you could say anger, anger would be the word [M5:p.1]"

So ah, the medical side of things, yeah, angry, pissed off, really. I think half the, especially [the G.P] being a woman, they should of delved in to it a little bit more, and maybe she could've saved her breast [M5:p .2].

Gus described the events leading to the ultimate diagnosis in uncompromising terms, and he believed that her early treatment was punctuated by inappropriate advice which may have contributed to her needing a total mastectomy. He said that from:

First diagnosis from ... hospital. Whoever she saw down there was, didn't give the right information. You know we could have lost her through, well what can you say, professional incompetence, would be the word. They don't seem to care, or they don't know, one of the two. That's about it on that one really [M5:p. 2].

Gus also believed that medical staff had an unfair advantage over those seeking treatment. When misdiagnoses of the kind Tamara experienced occur, there are no apologies or excuses given:

Up until him [meeting with the surgeon] I think all the other people just couldn't give a rats ! Ah in her [Tamara's] case I think there were a lot of people who just ducked for cover. Ah

oh, I know that's the cases now, you know they kinda, somebody makes a mistake they don't want to talk about it they just hope it just goes away. ... You can't, once that happened I think everybody's just looking after their degrees

The medical profession, if something goes wrong with one of them, they've given the wrong little diagnosis they all hide, they won't dob the other bloke in, they won't tell you where to go, what to do, or what to do about the problem. And that person keeps on practicing and giving out the same type of diagnosis to anyone that comes along [M5:p. 2].

Gus revealed that he had recently viewed a television documentary, called 'the Deborah Maybury Story' in which a young woman dying of terminal cancer was diagnosed under similar conditions to Tamara. She had a breast discharge and was mis-diagnosed with mastitis. This program was broadcast posthumously, and appeared to have stirred up memories of their own experience with the disease, as well as focusing on the poor education of some members of the medical profession.

Lauren's experience of cancer began thirteen years earlier when she was first diagnosed with a benign breast lump, since which time she has had eleven lumpectomies, and a mastectomy one year prior our interview. Lauren was one of the women who seemed to need to talk so much at our initial telephone contact, and, having met her and her husband at their home for the first time, she was anxious to begin the interview as soon as possible. James had ushered me into the kitchen, and Lauren rose to greet me from a table on which were piled large medical textbooks. She appeared nervous and 'edgy', and showed me into a room communicating with, but somewhat removed from the kitchen, where her husband remained reading the paper. I felt a little awkward because of the way in which Lauren arranged our seating. She insisted I occupy a low lying sofa, while she sat on a low footstool against a window at right angles to me. I set the tape up between the two of us, tested the audio tape and we began.

Lauren spoke almost non-stop for one hundred and five minutes. Her words tumbled over one another as she evoked her lengthy experience of breast lumps, her

mastectomy and her recent difficulties in getting a surgeon willing to perform a prophylactic mastectomy. Lauren's body language was closed, and she remained concentrated on her narrative, trying to maintain a chronological verisimilitude. Her tone was mostly harsh and bitter, with frequent flashes of anger:

I'm still angry today, but not just for myself but for other women that maybe are doing the same thing you know, but I can't do anything for them apart from perhaps allowing to do this interview and perhaps through that maybe someone gets some understanding of this aspect of [the disease] [F7:p. 8].

I felt she was pleased to be participating in my study, but I sensed she was slightly uncomfortable or antagonistic towards me, for as a registered nurse, I possibly represented - at least in part, the medical system that she perceived had alienated her. My intuition was partly true, as, much later in the interview she said

We don't necessarily have to learn that from the same channels, right [?] But just because you're a doctor or a nurse, or whatever, or a clergyman even doesn't mean that you have more understanding of that particular subject than what I do simply because you learnt it from a different source [F7:p. 21].

I had little reason to interrupt her monologue, except to clarify certain points, and I was careful to allow her narrative autonomy throughout our interaction. This was one of my most difficult interviews, as her process was almost unremittingly tense and angry, while her interview content was very dense or detailed and was delivered at a cracking pace. There was none of the usual ebb and flow of usual conversations, so that the time for reflective listening seemed diminished. However, as I struggled to process the complicated events and treatments that made up Lauren's narrative, I was aware of some sadness and wistfulness underlying her anger, and that it may have been much easier for her to express her anger rather than any sadness. While I cannot hope to do justice to this participant's extensive experience, it is necessary to briefly explain the nature of the events which so strained her relationships with some medical personnel.

Lauren's difficulties with doctors began when she had three unilateral breast lumps, and her doctor refused to biopsy them simultaneously. She sought another opinion, and this surgeon advised her that even though they were benign, it would be safer to have them removed. She has also palpated breast lumps which doctors have not been able to, and has had her 'disbelieved diagnoses' vindicated on subsequent mammography scans. On another occasion, she felt and could clearly visualise that her large biopsy scar was puckering, and she suspected another lesion was growing, 'hidden' behind the scar. Her doctor told not to worry, that this was a normal 'settling of the scar'. A later mammography study showed otherwise. Lauren has been alienated by the medical profession, and felt that because of her multiple breast lump phenomena, she was put into the 'too hard basket.' She resents having decisions made without her consultation, and feels angry when personnel cannot handle her need to assert herself and yet devalue her experiential knowledge base.

Frequent mammography tests, needle biopsies and lumpectomies are expensive, and reading between the lines, it appears that some medical staff have not welcomed Lauren's knowledgability and assertive attitude concerning what she believes her treatment should be. She has had more psychological distress in this year since her mastectomy, as she has met with resistance from doctors whose treatment strategies differ from those she wants. Lauren's plea seems to be for a comprehensive management plan, in which if she has more than one lump, they could be biopsied at the same time and at regular intervals. For instance, a doctor wanted to biopsy only one of her three breast lumps on a recent visit. While she has had her reservations about opting for a second prophylactic mastectomy, she feels the medical strategy in place cannot reassure her that all her lumps are not benign - and therefore:

I have been driven to have my breast off, right! The medical profession has driven me to it, because they will not acknowledge that I know enough about breast cancer to know what treatment I want. They won't give it to me ! [F7:p. 17].

Her distress has not been helped in recent years it would seem, by her increased knowledge of the treatment of the disease. She feels that doctors give her no credit for

her knowledge, and demean her legitimate request for mastectomy by wanting her to have a psychiatric referral:

I'm angry, and that anger takes me almost to the point of tears, because I don't think it's right, you know. I think it's demoralising and demeaning to women alone, demoralising and it's basically archaic type treatment you know. Because we [women] are intelligent, we're (you know), we can sit down and read as much as they can and maybe even if in that reading, our emotional aspects have taken us beyond what is right in their eyes because of our emotional makeup we should still have the right to say what we want [F7:p. 8].

Lauren makes an emotional plea to simply be heard as a feeling, thinking woman with a right to control her own body. She is aware of the controversial, feminist nature of her need for autonomy, and that it comes into conflict with the traditional medical view of women:

the doctors that I was seeing were all male, I didn't feel that, I knew that. The were all male (right)?, and I felt they were so preoccupied with sex, that it didn't allow them to ethically to do what I wanted them to do. I felt because they thought of my husband. If you understand what I mean, preoccupied with sex in the sense of, what the heck so you think you're doing woman, can't you think of your husband[F7:p. 9].

She qualifies her view to state that doctors do consider both partners, but she believes that cultural conditioning does bias male doctors towards a negative view of women's need for prophylactic mastectomy:

Well I think, they're thinking of it as being a coupled thing. I wouldn't say they were gearing it right to him, but I really do think that what they were doing without realising it ,(I mean this would be a subconscious reaction) um, is denoting perhaps their own. Their own [reaction] "Well how would I respond to this if I was the male, now this woman is coming along here, and she wants this done, what about her husband?". You see what I am trying to say? Well my G.P. here, my surgeon here, he put those things into words for me, and he said the problem is, it's a male dominated field when it

comes to breast surgery, and he said they don't always see that you can do without it. The breast [F7:p. 17].

There seems little doubt that for everyone involved in such a decision it would be a painful one, and objectivity would be difficult. Lauren finds it unfair she should have to work so hard to find a surgeon. As Lauren said in acerbic tones, surgeons don't mind performing other 'un-natural' procedures such as breast augmentation or reductions:

So that's why I get angry, if I get angry it's not. And if I get upset on account of it, the tears or what comes through there is because of the hurt that it brings, and when I talk about that it's a reminder of the hurt, the fight that you shouldn't have to go through, you know [?] [F7:p. 17].

Lauren was vulnerable looking, and her voice noticeably dropped at this point in the interview. For the first time there was a pained silence as she shed some quiet tears. She painfully iterated her sadness at being put in the position of having to fight and be angry. By her own experience and through the evidence gleaned from her own research, she could not understand the antagonistic stance taken by the consultants, to what she perceived were logical clinical stratagems:

I really don't understand when you can pick up a medical book from the library and you can read about breast cancer and it will say in there. You feel a lump, you go to the doctor, this is what the doctor should do, he should um,... biopsy that lump by needle aspiration or by removing it, you know. Ah, if he thinks it's a cyst he should needle biopsy that cyst to make sure that it is a cyst. Ok, ultrasound's are reasonably good these days and in the main they can um, assure us to a point that they are only cysts, but you should still have that needle biopsy, and you can't get it done... [or at least] if it's not my experience [having multiple lumps tested at the same time] it's not the experience of a lot of women for this one reason - cost [stated with emphasis] It's not cost effective to do every breast, every lump. I've been told that, I know that, it's not figment of my imagination. That is a fact ! [F7:p. 33].

What Lauren didn't say directly, was that she may be disadvantaged by being 'a public patient' as well as an unusually complex 'medical case' in a public system

with budgetary constraints. It is possible that her self perceived needs would not have been met with the same amount of medical dissension if she was insured under a private health fund.

In a metaphorical sense, Lauren seemed to me to 'come out fighting' throughout the interview I sensed she felt relieved that I had not challenged her, as physicians have done. I felt that as our interview finished, she had changed in her manner toward me, and for myself, I felt more included in her space and more comfortable about sharing time with her. I was pleased that I had followed my hunch at the outset of the interview, and let her take control, as it seemed that so much of her story involved people trying to overwhelm her with things she didn't want. Our next meeting for the coupled interview was much more relaxed, she was warmer and more contemplative and emotionally grounded in her responses.

Lauren's husband James, expressed anger towards medical personnel, but with less certainty than his wife. His overall narrative portrayed greater ambivalence towards the profession and tended to mirror his confusion revolving around Lauren's past mastectomy and plans for her second prophylactic mastectomy. Of the breast amputation he said "Well I think the first reaction that I can recall, was anger [M7:p. 1]. He described how Lauren had a lumpectomy, but that as the surgeon had been unable to dissect a wide enough margin of tissue on account of this 'safe margin' encroaching on the nipple, he had planned a course of radiotherapy to complete her local treatment of the tumour. Lauren had convinced him (James) that this was not a safe solution, and that radiotherapy would shrink her breast up "like a piece of cardboard," and she convinced him she would rather have a total mastectomy and forgo the radiotherapy. He went from feeling that the lumpectomy option was "not too bad" to feeling angry that it was necessary to take the whole breast. Reading between the lines, James sounded as though he was no more angry with the doctors than he was with himself or with Lauren at this juncture. However, in the year since her mastectomy, the issue of the doctors refusal to biopsy more than one lump concurrently, and the fact that they had only been very recently informed that these biopsies could be performed under ultrasound control was distressing for James.

He felt that his partner had been poorly treated, and expressed his anger in uncompromising tones. This is hardly surprising, as Lauren frequently said that if she could have congruent analyses of the status of all the lumps on her remaining breast done during one annual or six-monthly consultation, she would feel safe and secure enough to forgo any wish for a second mastectomy.

I mean, these are professional men (you know?) treating you like a piece of meat - (women). They can't give you a straight answer, if you ask for a straight answer, they say, "Oh yes, we're straight," but they never give you a straight answer, you know I mean so..

they call themselves professional people, because you know they might be alright but, but I reckon they're dickheads - but the trouble is, one, they are individuals, they don't work as a team or a unit on anything, cause one doctor will give you a different opinion than the next doctor, and he's different than the next doctor. So it's really based on the individual decision, instead of (you know) being in unity [in decision making]

.... They are all experts. Yeah, you know one doctor will say that you're cured and the next one will say, "See you back next week!"[C7:p. 18].

James, reflected the anxiety of his partner. They were not allowed access the degree of diagnostic screening they wished and believed necessary for their psychological well-being. Her limited access to diagnostic technology seemed to have compounded any difficulties Lauren may have had in communicating with the breast management team. This couple seem to have perceived as a result of their insufficient care, a sense of incomplete information, distilled out of dealing with changing medical personnel and incomplete diagnostic tests/interpretations. James angrily described this anxious period they were still enduring as the "... stress of not knowing the truth. Because we don't know, they won't give it to us. They won't tell us!"[M7:p. 28]. James probably feels that this untenable situation is pressuring him into making the decision to opt for Lauren's second mastectomy. His unenviable experience makes it easy to comprehend the reason for his anger. Zahlis and Shands (1991, p. 85) also found some of the men in their study had similar experiences. One man said of his problems encountered with physicians:

The insecurity amongst the professionals, the diverse opinions we got over some science that I thought was relatively common. That was the biggest shock for me, and the biggest thing I was unprepared for.

Lucinda recalled her painful psychological experiences from the time of discovering her breast lump, until the time of her cancer diagnosis several weeks later. Her story involved bemused scepticism concerning the medical profession, to open anger. Her voice had a girlish, playful intonation, but it sometimes took on a bitter, angry tone when she spoke of her experience preceding and immediately following the mastectomy. At the time of her mastectomy six years earlier, she described herself as undergoing a metamorphosis from an unassertive person with very little self-esteem, living in a marriage denuded of emotional meaning, to a divorced, independent and assertive woman with a new partner. She implied she had several misgivings about the treatment decisions that were being made at the time, but that her former husband derided her 'lay' intuition as being of no consequence:

mm... I wished I was more forceful. Um.. I guess I am now. I don't try and let people walk all over me now. Um... Cause my husband at the time. Cause he had all these wonderful certificates and I didn't have any certificate. [I had] no great education um..

He would say to me "He's the doctor, he has a piece of paper to say so, he knows what he is doing. He is correct. And where's your piece of paper to say anything different?" So I guess um.. I just went along with what people told me to be correct. I didn't want to upset anybody. I didn't want to put any demands on anybody. I didn't want to be any trouble to anyone [F4:p. 8].

Lucy discovered a pea sized lump in her breast, which rapidly grew to the size of an egg in three weeks, when she sought medical attention. For the next six weeks she had weekly consultations with her G.P who aspirated fluid from the cystic breast. The doctor assumed her lump arose from being hit by a cricket ball, as at that time she played a lot of indoor cricket. In spite of these treatments the breast lump grew to an alarming size, to the point where it was as large as an outstretched hand, and impacted into her axilla.

You can get angry, you can get really cross about it. What can you do about it? Do you forever hang on to that? ... It was nine weeks from beginning to end. Yeah.. And the whole time they're telling me, It's ... don't think it's cancer. "DON'T EVEN CONTEMPLATE THAT" [with emphasis] it's definitely not that. So I don't know who the student researcher was at [A large metropolitan teaching hospital], but I guess I probably am very thankful to that person that they had the curiosity to have a look. Because I don't think I would be here [F4:p. 8].

Lucinda impressed upon me just how large the tumour was, and clearly her attitude was one of incredulity. The implication of her attitude was that, in hindsight she could hardly believe that she had not pushed her doctor for an earlier surgical referral:

He'd been to see me [the surgeon] ... he was leaving my room and he said "To give you an indication as to how big it was "-. (I mean I knew how big it was, I could tell by my own hand) - but he wasn't a small person, and had quite large hands. And he said "I couldn't even hold it in my hand it was that big!" and I'm thinking... I mean Oh !

just wish that they'd done a bit more than what they did. I wish that they had taken it just a bit more seriously and not been so ready to um.. discount I suppose cancer as a possibility. That makes me really cross. It does make, makes me really very angry. Because I'd gone through things that I may have not have needed to go through

I kind of feel male doctors tend to think that you know, just because you're a woman that you don't know anything [F4:p. 4].

Lucy was placed in the invidious position of being told that cancer was out of the question, to having what she inferred was an almost accidental histological re-examination of her breast lump by a technician apparently intrigued by the size of the tumour. This person 'discovered' the tumour was a fast growing, malignant cell mutation. She was told she only had three to six months to live, and that her only hope for short-term survival was a mastectomy and radiotherapy. These events had a huge impact on this young, thirty year old woman and her young family, whose rocky marriage disintegrated within two years of surgery. Lucy became pregnant shortly

following her radiotherapy, and was not given any choice as to what solutions were available to her. The advice she was given suggested that pregnancy jeopardised her, and that her baby would stand a chance of being handicapped.

Lucy was angry about her protracted diagnosis at the hands of the G.P., but is quite philosophical in the sense that she is still alive six years later. However, she has got the 'last laugh' at considerable expense to herself, for the death sentence has not been removed, it is simply no longer a focus. She has also endured a mutilating form of surgery, which if biopsied /diagnosed earlier, may have meant that she could have avoided radical surgery, and she has had an 'iatrogenic abortion' and tubal ligation in the wake of her chemotherapy. One can appreciate that this woman has much to be angry about, and her experience is a sober example of the crucial importance of early diagnosis and treatment in arresting the course of this disease. Lucinda has beaten the odds regarding the surgeon and oncologist's predictions regarding her life expectancy, but has very possibly lost her breast as a result of a doctor's 'wait and see' approach.

Gwen had a radical mastectomy seventeen years ago, and she recalls being very dissatisfied with her surgeon's attitude towards her. She recalled her feelings as they sat in his office during her follow-up appointment after her hospitalisation for lumpectomy. She said she:

was extremely annoyed with him because it turned out his wife was English and he kept talking about - " Oh I know how the English and their stiff upper lip", as though it was, um, Well! I wasn't drooling and weeping all over the surgery! I mean I had things to ask ... so he sort of made it so that [it was] a little more (not coarse) but explicit in what he was going to do ... He was talking about having to slice through the nipple and this kind of thing. And I got the feeling he was trying to break me down and the more he tried that - I was damned if I was going to !

And post -op he was still like that ... saying that I, that there was a very good chance ... I had a 50:50 chance of it occurring in the other breast. And he sort of harped on that a bit as though I must be fearful and you know that sort of made me cocky. and as I went out the door I said "Ok! Well I'll see you in a couple of years time ! [F2:p4].

While her surgeon's motives were likely to have been professionally geared towards giving her an opportunity to express her feelings openly, her perception of the interaction infers that she disliked the powerful, controlling way he used language. Rather than her wanting to reveal her vulnerability, it had the opposite effect of making her defiant. She obviously had no wish to be controlled by a relative stranger.

As mentioned earlier, Gwen had a modified radical mastectomy in which tissue is dissected down to the muscle, but, because she was large breasted and the surgeon couldn't approximate the skin edges from a widely excised dissection, she required a skin-grafted augmentation, involving another body wound for harvesting of donor skin donor. The larger the wound, the greater likelihood there is for infection, and Gwen felt she had a temperature. She told the surgeon that she had a temperature:

and he looked at me and we talked about it and he said 'Yes, I'm afraid this is an emotional result of your operation' When I woke up cloudily next morning I suddenly, my brain had cleared slightly and I thought _ no way! This is an infection and if you've got an infection you've got to look at your nearest cut. And um, so then I was really cross, that I had been dismissed so lightly as a silly woman, especially as I hadn't been so emotional [F2:p. 4].

Gwen reveals herself as being more emotional than she acknowledges, and her interaction with the surgeon is quite clearly important to her. Her experience highlights the fact that surgeons, who are frequently male, require a great deal of sensitivity in interacting with mastectomy clients. Gwen felt he was almost teasing her about her British trait, whereas perhaps he would have done well to realise that one of the most effective short-term defences against stress is 'the brave front' of denial. If Gwen's coping style had served her well for four decades, it is unlikely she would jettison it spontaneously with a person who seemed less than sensitive to her feelings.

Reflections

The transcript analysis of both males and females revealed that the doctors and surgeons have the potential to play crucial roles in the rehabilitation of the diseased person and her mate. While these six individuals had many negative experiences which engendered angry feelings towards the medical profession, eight others were non committal or largely positive in relation to consultations interventions initiated by this group. To what extent can it be said that such negative feelings affect the intimacy of the individuals and couples concerned? I believe that these feelings have demonstrably affected people's intimate lives in obvious or sometimes very subtle ways.

Subtle effects have been observed in Tamara, Gus and Lucy. All have regretted accompanying their anger, regret that a diagnosis was not affirmed earlier, which may have avoided the need for radical surgery. A sense of wasted opportunity, sadness and loss at the of a breast that possibly could have been conserved - must (if only occasionally) pervade the thoughts of the 'see-er' and the seen, the 'toucher' and the touched, particularly in moments of sexual intimacy. Both these couples have indicated their acute awareness and sensitivity to their partner's feelings concerning the chest mutilation, so that the inference that this mutilation could have been avoided links a circle of association between loss/grief, regret, anger and the now changed intimate relationship.

The most obvious expressions of the effect that these angry feelings had on the intimate relationships of couples participating in this study are exemplified in the extraordinary narratives of Lauren and James. James and Lauren appeared in constant tension with the doctors and with each other. How much their intimate tension was associated with mastectomy related matters, or related to pre-existing marital difficulties (which they both acknowledged) could not be determined. However, their testimonies throughout this thesis leave no doubt that their undisguised anger towards the medical profession has had a dramatic, largely negative impact on their sexual/intimate relationship.

Of course, this phenomenological study looks at phenomena concerned with the persons who have experienced it. While it may seem too obvious to mention, doctors too are human, and may have the same desire to deny feelings or not wish to identify too strongly with patients who they suspect may die of cancer. Doctors, nurses and other health professionals who do not conform to acceptable professional standards may have their own fears of breast cancer, particularly if they are of the female sex. Perhaps the female G.P who examined Tamara was a mastectomate too. This may have accounted for her serious diagnostic omission, at least on the personal level. Quint (1963) takes a sensitive account of why nurses may avoid addressing 'the deeper issues' of mastectomy with women, because of their privileged information and gender, she believes they may not be able to minimise personal identification with it. If any health professionals find themselves in this position, they should seek help for themselves before they help others.

Of the four women focused on within this chapter, Gwen's antipathy towards her surgeon infers an uniquely personal view, which was not shared with or by her husband. To this extent there appears to be no link between her angry feelings toward her surgeon and her intimate life with her partner.

The perceptions of these men and women indicate that they had legitimate reasons to feel angry and dissatisfied with aspects of their medical treatment. Research into doctor -patient interaction undertaken by Chaitchik, Kreitler, Shaked, Shwartz and Rosin (1992), focused on specific case discussion and information giving to patients on an oncology ward. They concluded that patients and doctors differed in the meaning they assigned to information, and that patients are conflicted in regard to asking for the personally relevant information they want. This seems to indicate that clinical communication is a far more complex interaction than health care providers suspect, and that patients and doctors approach information giving in quite different ways. This variance in this aspect of patient care suggests directions for future research

While this study is too small to be able to extrapolate findings to other populations, the experience and perceptions of these couples or individuals have clear implications

for the medical profession. Girgis and Foot (1995), on behalf of the The National Health and Medical Research Council (NH&MRC) National Breast Cancer Centre have published a booklet called *Satisfaction with Breast Cancer Care: A Summary of the Literature, 1984-1994*, and found that breast cancer patients report dissatisfaction with their care in these areas:

- Provision of Information, particularly related to general information about treatments and different operations, the likelihood of side effects and practical ways of dealing with them, symptom control at home and economic support.
- Support for patients and families, and,
- Physical appearance and functioning.

Recommendations were put forward to ameliorate these problems, and there has been more public health awareness stimulation from the media since the advent of Breast Cancer Awareness Week began in 1994. Since then, the NHMRC published *Clinical Practice Guidelines: The Management of Early Breast Cancer* (1995) with bibliography for distribution to surgeons and general practitioners, and *A consumer's Guide: Early Breast Cancer* (1995), for consumers to access in medical centres. In the introduction to this volume, the writer says "Neither women nor the health professionals who cared for them have always appreciated the full range of options available to them" (p. ix). Both publications address many of the issues concerning information giving to women and families, and the need for a shared and sensitive approach to decision making before breast cancer treatment begins. As well as these larger publications, the Australian Cancer Society and the Commonwealth Government Department of Human Services and Health have published a colourful A4 size magazine style booklet, with a front page photograph of women of different ages and ethnic backgrounds called, *A look at current breast cancer research, treatment, support services and early detection in Australia* for general distribution. These publications are helping to disseminate appropriate information to women and their families, as well as provide doctors with resources which reflect the needs of consumers they serve. As three of the four women have had surgery six or more years

ago, it is hoped that in the intervening years, with these health care initiatives in place, doctors and surgeons have become more knowledgeable about the diagnosis and treatment of women with breast cancer.

In summary, early definitive diagnosis and treatment of any breast lumps is crucial in enhancing the long-term survival chances for women. Confident physical assessment skills and sensitive interpersonal skills are of significance at the potential crisis point facing the woman during a diagnostic 'work-up' for breast cancer. Doctors, like all health care workers, need to update their knowledge and skills, so that they may optimise their professionalism and client care. Mostly, they need to be sensitive to what knowledge their patients need, and to treat them with respect.

CHAPTER TWELVE

Implications and Recommendations

Although this study comprised a purposive sample and is too small to be able to generalise findings to a wider population, it nonetheless provides health care workers and social scientists a valuable insight into the lives of couples affected by breast cancer and mastectomy. These insights have specific implications for people involved in the care of families who have experienced this disease.

The findings from this study highlight the fact that the current management of breast cancer focuses primarily on the physiological aspects of the disease. Thus, treatment is aimed towards ameliorating the diseased body part with a variety of surgical, chemical and radiological interventions. Most of the women participants seemed unaware that their narratives indicated they were deeply affected by the mastectomy on an emotional as well as a physical level. They were relatively relaxed in talking about the physical effects of their surgery, not recognising that these feelings had spiritual/emotional repercussions on their day to day lives as partners. Most of the women had access to a Breast Cancer Support person, but, many of them remarked that these women were not appropriate to their own situation, being much older, not having a similar family situation, having had their mastectomy years ago, or talking too much about themselves. Only one of the women concerned reported having attended Cancer Foundation group sessions for mastectomates, which she reported as being helpful.

Male participants were more vehemently assured of the mastectomy having no impact on their intimate lives with partners. Most were distinctly uncomfortable in discussing

themselves, or their feelings, preferring the safety of denial within the role of the 'protective caretaker'.

These findings suggest that health service providers need to be aware that couples invest great store in the 'strong facade' which everyday parlance and social mores seem to insist upon. They may be unwilling to open up a dialogue with a professional because they do not assign any importance to the deep-seated feelings they experience. While denial is a useful short-term mechanism to defend against fear and uncertainty, in the long-term, it may be less therapeutic. This denial puts the burden of responsibility on the carer to be sensitive to 'give time' and 'give permission' to couples and/or individuals to speak about things not usually articulated. The experience of these couples suggests that they only need to be given the interest, and opportunity to express concern, and they will respond.

Implications for Social Science Research

The methodology chosen for this study also has implications for nurses and/or other social scientists intending to involve themselves in phenomenological research. If researchers take my argument seriously, they may be persuaded to take up Crotty's challenge to involve themselves in truly 'transcendental phenomenology', eschewing the subjectivism which the 'American' or 'new phenomenological' movement espouses. If so, they may elect to create new methods which may more realistically capture phenomenological essences. Conversely, they may elect to reject the transcendental stance entirely, proudly and courageously embracing the subjective humanism inherent in nursing. In doing so, they may (by developing new methodologies) evoke a new phenomenological movement; a uniquely Australian hybrid, or even revoke mainstream phenomenology tenets altogether. While the latter seems an extreme possibility, a resultant change may be the spur to a new philosophy and research methodology better equipped to examine human experience as nurses comprehend them.

Implications for Health Care Workers

There is a need for research into a new, holistic approach to the care of women and their partners following breast amputation and traditional therapies. This study involved couples who were only transitorily seeking health care assistance at the time of the interviews. The women revealed that they had somatic feelings, which had peculiar affects on them, and that these strange feelings across their flat 'numb-ish' (formerly highly sensate breast) were of some concern. These concerns were diversely expressed in terms of self-esteem, sexuality, intimacy, femininity and body-image. Some women inferred being touched on the mastectomy scar was a "sexual turn-off". These exquisitely personal, inter-related aspects of the woman's everyday intimate experience of herself, must naturally influence her partner, just as she is influenced by her partner's responses. This would pursue the hypothesis that the body (of the patient) needs active integration into the new body-schema by an intensive course of massage therapy, hydro therapy, heat/cold stimulation and 'reality imaging' with mirrors. This therapy may also benefit the husband and aid both partners in the resumption of a freely acknowledged, changed intimacy. This approach would need to be supported by controlled longitudinal studies, probably within a quantitative/qualitative research framework. It is possible that such research may prove the efficacy of such therapies. At best, this may involve the surgeon, who is an integral and crucial person in the treatment phase of the disease. He/she could be an instrumental person in enlisting candidates for the research, and holistic nursing therapists (or partners) would intervene when the surgeon assessed wound healing was optimal to begin.

This research has highlighted that the emotional needs of men are not being met. The surgeon is a key professional in so far as this person has the undivided attention of the couple prior to and following hospitalisation. It follows that if surgeons were to network their services, they may be able to initiate 'couple counselling' or male group work as part of their surgery service. Such surgeons could enlist the services of a psychologist, clinical nurse specialist or skilled group worker, in order to address the needs of partners. If all-male groups were undertaken as 'information sessions' (somewhat analogous to pre-natal classes), it may prove less threatening to males roles as 'protective caretakers.' If such a service were seen as 'a part of the package',

and principally as a way to meet the needs of his wife (which is 'a language' this study has highlighted he understands), he may be inclined to share his concerns with others.

Timely counselling by a professional may enable couples to comprehend the physical and emotional changes that occur in the wake of mastectomy, and how these 'apparently inconsequential' realities influence the intimate relationship in subtle ways. Health carers are in a position to develop close therapeutic relationships by encouraging couples to express their responses to these changes. Professionals encountering Stoic women (or couples) who years following mastectomy, still need to recognise that breast amputation (outside of mammary reconstruction) never passes, and is always a physical reality. Aspects of the breast surgery may influence the woman, or her husband for a long time. When women and husbands 'carry on as normal' after leaving the hospital, and deny the presence of the Cancer Foundation and the Breast Cancer Support Service visitor, they may never have the opportunity to talk about their day to day concerns about cancer and mastectomy. These women/couples may not be 'seen again' professionally for long periods, so, when oncologists, specialists, G.P. s and nurses encounter such clients, they should bear in mind that they may have ongoing, unanswered concerns or questions concerning mastectomy. Adequate time allowance, a relaxed, empathic, sharing (as opposed to 'detached professional') attitude and a genuine interest in the person's experience of mastectomy may be of benefit for women/ or couples who are too diffident in initiating emotional support. Where possible, the couple should be consulted together, as each partner is usually crucially involved in the mastectomy event.

This study also highlights that individuals and couples need to be encouraged and supported in taking control of treatment alternatives, to foster their access to informational resources, and to ask as many questions as they need. For people in highly stressful, medical circumstances, a second independent opinion may also assuage doubt.

This study has highlighted there is an urgent need to address the information and support of pre-menopausal women, whose hormonal and child bearing potential may be truncated or curtailed in the wake of breast cancer treatment. In the provision of

information, doctors and nurses are key professionals involved in disseminating information resources, and they are in an optimal position to provide clear, accurate and concise material couched in understandable language.

Technologically sophisticated and timely diagnostic intervention by physicians arose as a real concern of a number of participants, which indicates that all professional health care providers have a duty of care to update their diagnostic and therapeutic knowledge continually in order to deliver the best care possible.

All health personnel need to provide, sensitive, 'client based' care to patients. It is most important that professionals provide this form of advocacy, as it will convey empathy and respect to people at a time of physical and emotional vulnerability.

Future Research

There has been limited research relating to the experience of couples' intimacy following mastectomy, from the perspective of the couples themselves. It is hoped that this study will stimulate interest for continued research in this area. There is a general consensus that the emotional needs of men *and* couples are not being met. Health care workers need to continue to accumulate knowledge relating to how best they are able to meet the complex emotional needs of couples following this mutilating surgery.

Further studies using the same or similar approaches, with larger sample sizes, and different racial, cultural, and socio-economic groups are recommended. The couples in this study were part of a selective group, who were all urban (except one couple), Caucasian, educated, and from a socio-economically stable background. It could be significant for further research to compare and examine these findings, to see if there is any relevance for other couples experiencing mastectomy.

Further studies may entail:

- a qualitative (and/or longitudinal) study of denial or coping in male partners of women who have had cancer-related breast surgery;
- How non-verbal sharing influences the intimate relationship following mastectomy;
- A comparative study of how women's body cathexis is influenced/not influenced by holistic therapy (massage of mastectomy scar, hydrotherapy, therapeutic touch and talk);
- Following a phenomenological methodology to more closely approximate the mainstream, European philosophical tenets; that is, to bracket the experience of the subject and the researcher, and also involving the subject in the analysis: at least in terms of the 'intuited,' phenomenological themes.

Clearly, there are many complex issues, decisions, and physical and emotional consequences which affect the intimate partnership following mastectomy. In the face of the findings which suggest couples need support, only women appear to enlist it, and then they may only do so if sanctioned by their surgeon. Most prefer to 'get on with the job', (of living) and, like their menfolk, take a commonsense attitude that undermines the deeper expression of grief for the lost 'whole bodied' intimacy, and a shared life unsullied by the threat of death. Too often, doctors and nurses may be unaware of individual's or couples' deeper concerns, and may be unable to provide the time or skill to deal with them successfully.

Conclusion

It is crucial for health care professionals to 'listen to' and allow women and men to have a voice. This is the first therapeutic step to help health workers meet the challenges of the exquisitely subtle and complex messages that individuals and/or couples affected by the mastectomy experience transmit. This study has indicated that women and men were diffident about giving voice to what were assumed small concerns. This attitude was possibly engendered by social rectitude, and also by the

dominance of a medical approach, which is geared towards effective and fast problem solving of essentially physical ailments. People with expertise in the medical treatment of physical disease, are not usually so adept in dealing with existential concerns, or, if they do have the expertise, time constraints often work against an effective therapeutic outcome. With these constraints in mind, it is nonetheless important for all health care providers to anticipate and respond to these people's needs, for the emotional and physical effects of mastectomy have lasting effects on couples' lives.

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APPENDIX A**DEMOGRAPHIC DATA**

Name

Address

Phone no.

Marital status

Sex

Age

Religion

Educational level

Children by Age & sex

Occupation

Nationality

Doctor

Date of your/ your partner's Breast surgery

Radiotherapy

Chemotherapy

Tamoxifen Therapy

CODE

APPENDIX B**LETTER OUTLINING THE STUDY AND THE PARTICIPANT'S RIGHTS**

W. A 6027

15th April, 1994

Mr and Mrs

Dear.....

I am conducting a study as a graduate student in the Edith Cowan University Masters of Nursing Programme to document the intimate feelings of couples who have experienced cancer-related breast surgery. Although much has been written about women who have had cancer-related breast surgery, there have been no studies of this type, focusing on the intimacy between couples .

My interest in talking with you both is to hear your descriptions of how cancer-related breast surgery has affected your intimate life as a couple. Your stories will be a significant contribution to a holistic (rather than medical) interpretation of this phenomenon.

I am a forty-four year old, married woman with two children, and I have worked as a Registered Nurse in a variety of settings over the last twenty four years. Currently, I am employed as a Lecturer at the School of Nursing at Edith Cowan University, where I teach in the Undergraduate Program.

I ask for your participation in this study, but if you do not wish to take part, or want to withdraw at any time you are free to do so. If you agree to take part you will be asked to participate in two or maybe three tape recorded interviews. Each interview should take no longer than one hour, according to your needs.

Do take time to talk about this together and contact me if you wish to contribute. We can then arrange an informal meeting to get to know one another and discuss how the interviews will proceed, how the research will be handled to protect your privacy and obtain your written consent to proceed. (The proposal for this research has been reviewed and approved by the Edith Cowan University Ethics Committee).

Please contact me at the University on 383 8579, and if my office is unattended you can leave a message on the answering machine.

Again, I thank you for your interest and remain,

Yours Sincerely,

Lynne Amor,
R.N., B.A.

APPENDIX C

CONSENT FORM FOR RESEARCH PARTICIPANTS

(Sent to each participant)

I have granted permission to Mrs. Lynne Amor, who is engaged in post- graduate studies at Edith Cowan University to record an interview with myself

Of:

I agree to participate in this research on the understanding that;

- The purpose of this research is to gain a greater understanding of the little understood area of how couples intimacy is affected by cancer-related breast surgery. I understand that my contribution to this research may be helpful to future couples who experience the same sort of surgery, as well as health care workers who work with them.
- I will participate in (3) one hour interviews with the researcher, one of which will involve myself and the researcher, and (if my partner is participating) a further two interviews with my partner and the researcher.
- I understand that these interviews may renew painful feelings regarding my own and/or my partners responses to the breast surgery, but I am aware that I am free to disclose as much about my intimate life as I feel comfortable in revealing.
- I have the right to withdraw from the research at any time without penalty.
- I will receive a full and un-edited copy of the transcripts relating to my interviews to peruse (and keep if I wish). The researcher will also allow me access to her own

research diary, in which she will record her own impressions and feelings regarding the interview process

- I have the right to correct, add information to or edit the transcript if I desire.
- I will have access to the findings and discussion manuscript of the thesis prior to its final draft. The researcher will give me access to a final volume of the thesis following publication, so that I may read it at my leisure if I choose.
- My right to absolute confidentiality will be protected by the use of pseudonyms in all seminars or on all transcripts and other documents, and that the tape recordings and transcripts will be held in a secure place until destroyed. Both tapes and transcripts will be held in strict security by the researcher and tapes will be wiped four months following the last interview. Transcriptions will be destroyed after 5 years.
- I agree that the research data gathered for this study may be published provided I am not identifiable.
- I understand any questions I may have concerning the research may be directed to Lynne Amor, of the School of Nursing at Edith Cowan University, on: 383 8579

SIGNED

Witness (Researcher)

.....

DATE

APPENDIX D

RESEARCH QUESTION GUIDE

For women

- Can you tell me about your experience as a woman since your surgery for breast cancer?
- How has this treatment for cancer affected your bonds with your husband/partner?
- Are there any negative/positive aspects which you are aware of also?
- How your breast surgery has affected the intimacy within your relationship with your partner.
- Do you find it difficult to express your feelings?
- Background of nurturing?
- How would you describe intimacy?
- Is breast and/or nipple stimulation an important part of your sexual stimulation?
- Are you able to feel as comfortable with your partner's pleasuring of your remaining breast?
- Can you recall the first time following the surgery when you revealed your wound to your Husband ?

- Can you remember your feelings at that time? Who initiated this moment?
- Does your husband touch your mastectomy scar?
- How far into the future do you and your partner 'look'/ plan.
- Who's feelings were you most concerned about, your partners or your own?

Research Question Guide

For Men

- Can you tell me about your experience as a partner since your wife's/mate's surgery for breast cancer?
- How has your wife's/ partner's treatment for cancer affected your bonds with your he ^
- Are there any negative/(positive) aspects which you are aware of also?
- How has your partner's diagnosis and mastectomy affected the intimacy within your relationship?
- Do you find it difficult to express your feelings?
- Can you outline briefly your own background of nurturing?
- How would you describe intimacy?
- How far into the future do you and your partner 'look'/ plan.

- Can you describe the first time following the surgery when you saw your partner's wound ?
- Can you remember your feelings at that time? Who initiated this moment?
- Who's feelings were you most concerned about, your partners or your own?

APPENDIX E

Field Notes: Lauren's Interview

8th of September 1994

Lauren was one of the women who seemed to need to talk so much at our initial telephone contact, and, When I met Lauren and her husband at their home, she was anxious to begin the interview as soon as possible. James had ushered me into the kitchen, and Lauren rose to greet me from a table on which were piled large medical textbooks. She appeared nervous and 'edgy', and showed me into a room communicating with, but somewhat removed from the kitchen, where her husband remained reading the paper. I felt a little awkward because of the with the way in which Lauren arranged our seating, because she insisted I occupy a low lying sofa, while she sat on a low footstool against a window at right angles to me. I set the tape up between the two of us, I tested the audio tape and we began.

Lauren spoke almost non-stop for one hundred and five minutes. Her words tumbled over one another as she evoked her lengthy experience of breast lumps, her mastectomy, intimate feelings and her recent difficulties in getting a surgeon willing to perform an prophylactic mastectomy. Lauren's body language was closed, and she remained concentrated on her narrative, trying to maintain a chronological verisimilitude. Her tone was mostly harsh and bitter, with frequent flashes of anger,

I felt she was pleased to be participating in my study, yet I sensed she was slightly uncomfortable or antagonistic towards me, for as a registered nurse, I possibly represented in part at least, the medical system that she perceived had alienated her.

I had little reason to interrupt her narrative, except to clarify certain points, and I was careful to allow her narrative autonomy throughout our interaction. This was one of my most difficult interviews, as her process was almost unremittingly tense and angry, while her interview content was very dense or detailed and was delivered at a cracking pace. There was none of the usual ebb and flow of usual conversations, so that the time for reflective listening seemed diminished. However, as I struggled to

process the intellectual content of Lauren's narrative I was dimly aware that there may have been some sadness underlying her anger, and that it may have been much easier for her to express her anger rather than any sadness.

Within minutes from the end of the interview, Lauren was much warmer, and for the first time there was a pained silence as she shed some quiet tears. It was not necessary to 'debrief' her, as she resumed a (somewhat less) angry re-appraisal of the medical difficulties she had explained earlier. I was aware that she probably used this approach to defend herself from very powerful feelings of sadness and isolation. In a metaphorical sense, Lauren had seemed to me to 'come out fighting' throughout the interview, and I sensed she felt relieved that I had not challenged her, as her medical experience indicates happens frequently. I felt that as our interview finished, she had changed in her way of being toward me, and for myself, I felt more included in her space and more comfortable about sharing time with her. I was pleased that I had followed my hunch at the outset of the interview, and let her take control, as it seemed that so much of her story involved people trying to overwhelm her with things she didn't want.

I was intending to interview James on the same day, but as Lauren's interview and our following chat was longer than anticipated, we arranged her partner's interview for another day. I was aware of feelings of relief, as I keenly felt how emotionally and intellectually 'drained' this particular encounter had been for me. I was also aware of the onerous task awaiting me. Would I make sense of the intensely emotional and densely factual content?

APPENDIX F

Bracketing Memo: My own Perspective (presuppositions) on how Mastectomy may Impact on Men and Women

In the discussion concerning the background to the study, I outlined my long interest and nursing experience with nursing women who had breast amputations. However, my curiosity was levelled at their intimate experience once they resumed their lives in the home situation. Did their lives return to 'normal' in the wake of mastectomy? Was their experience of intimacy the same or changed? Not un-naturally, I am aware that I approach the research process with the 'excess baggage' of many nursing, personal and cultural understandings about breasts and breastlessness. I have undertaken to make this list as a 'revision sheet' to prod my awareness of my assumptions, so as to allow the participants narratives to remain as free of my own bias as possible.

- The fabric of women's lives will be in some way altered by the experience of breast cancer and surgery.
- The women in the study may reveal how painful the surgical procedure was.
- Based on my prior experience with couples at the bedside, I suspected that women would probably find it easier to speak about the mastectomy than their partners.
- Notwithstanding the latter, I assumed that separately or apart, men and women may have difficulty in speaking openly with me concerning their intimate experience.
- Before the interviews began, I assumed that I would reflect some of the awkwardness that participants felt in articulating about intimacy following mastectomy.
- Because of the fact that three of the women in the study ventilated feelings of anger at our initial phone contact, I assumed that this may play part in the subsequent audio taped interviews.
- I assumed that some men and women may not want to share their transcripts with one another, i.e, that some may wish to share aspects of their experience with me that they believe may be too painful for their partners to read.

- I assumed I would be unable to obtain 'pure phenomenological essences' of intimacy following mastectomy when the subject /phenomenon under study was not asked to bracket their pre-suppositions. Nor, (I perplexedly assumed) could I intuit on their behalf phenomenological themes.

APPENDIX G

Fifth Couple

Gus' Interview

I am in the home of Gus and
Tamara and the time is
4.50pm, on the 31st August
1994.

I wonder if you could tell
me about how Tamara's
breast surgery for cancer has
effected your life Gus.

Let me ask you about the
impact of the diagnosis of
cancer, and what sort of
impact that had. Can you
remember much about that?

It hasn't!

Um, well what can you really say, ah... it
hasn't really done anything to me, sexually, physically,
any way at all.

Um, devastating. You get um, you get ah absolutely no
support, ah, you got to kind of try to hold, in this case
hold your wife up, support her, support the kids. I
suppose hide your feelings to a certain extent. Ah,... be
stronger and tougher than what you are. Ah,... a lot of
anger I s'pose in this case, would be the first bit.

Yeah, I I suppose you could say anger, anger would be
the word. Why us, what have we done? But that type of
this I suppose goes through your mind. Why her
especially, because she's never harmed anybody, you
know.

You mentioned anger was the first emotion that you were aware of, would you like to elaborate on that some more?

Well when it first happened she got a, a discharge, and then it went away I think, and she went to Fremantle hospital to see what it was, and she was told there was nothing to worry about, completely normal, ignore it, go away. We went away, she still had a sore nipple and breast when we were away. Ah came back sore another doctor and they said the same thing, nothing to worry about, discharge, it will be alright, go away. So ah, the medical side of things, yeah, angry, pissed off, really. I think half the, especially being a woman, they should of delved in to it a little bit more, and maybe she could've saved her breast.

Earlier?

Delving into it earlier.

If they had delved into it a bit earlier?

Earlier. First diagnosis from Fremantle hospital. Who ever she saw down there was, didn't give the right information. You know we could have lost her through, well what can you say, professional incompetence, would be the word. They don't seem to care, or they don't know, one of the two. That's about it on that one really.

So do you remember how long it took for the discharge from the breast, to the time when she actually went in to have her biopsy, needle biopsy?

I'd be just guessing, I think about twelve months. I was like a six month period, we went away and came back and it didn't happen again I think, and then it just went on from there. Yeah I guess it would be that long.

That's a big amount of time, Well to me it is. Well you ... you're told (especially ing
 isn't it? woman doctor) that this is just normal it's only a
 discharge, but in your own mind, (well it was me that
 pushed her to a certain extent) - yeah, to me just looking
 at it, it wasn't normal. And they're saying there's no
 lumps, everything is fine, honky tonk, and when you
 looked at the breast, it wasn't normal, you could see it
 wasn't normal. It was red, it was inflamed, it had a
 milky discharge and I, I'm not expert, you know.

It was alarming to you as a Oh yeah! Definitely.
 lay person?

Mm. You know, you don't have to be very intelligent to see
 that something's wrong. And you know to try and hide
 your feelings and try to push it off a little bit further,
 give her support. And it's not easy because you've got
 other things like, our kids were a lot younger then too,
 so you've got your kids, you've got the worry of life and
 death type of thing, wether everything is going to be
 alright. Ah, there is not support for the men, what so
 ever, so you've got no one to turn to you know. I made a
 couple of phone calls, got on to a few people and had a
 chat to a couple of women, to more or less find out what
 I'm in for, what, how to support her, what to look for,
 what to ... not to say, to say, things like that. So yeah.

So did she know you had No.
 been doing that ?

So you were very concerned, and you decided to go out and find the information yourself?

Ah,.. yeah. You've got to find it yourself, you, you've got to, got to push for it, you can't, you've got to make the phone calls, you've got to push, you've got to ask, find out for yourself what's going on. Cause no nobody will tell you, no body will ring you up to let you know what's happening. No doctors, specialists, anybody. You more or less have got to be pretty pushy, pretty strong in that area. Which doesn't, I'm like that anyway so it doesn't really matter.

APPENDIX H

Emergent Themes: (Distilled Meanings from Significant Statements); A Sense of Loss in Relation to Women's Body Image

F/7:20b. Although she felt she didn't have a problem regarding her body image, she said she would look in the mirror following her mastectomy and say to herself- "this is me," but feel hurt about it. She has since slowly began to accept herself without her breast, but inferred that this was largely a mental 're-imaging' or refashioning of her private self, and that this self-concept was assisted by her husband's acceptance.

F/4:17bc. In retrospect she was aware of completely blocking out any feelings about her altered body shape as unimportant

F/4:17a. She didn't perceive that she wasn't the woman she was before, because she said she had rarely felt particularly womanly anyway.

F/1:1a. The woman said she has two poses in front of the mirror; her 'masculine view' (the mastectomy site) and her feminine view. She thought she looked quite normal from one side but she was really just fooling herself by adopting this approach

F/1:1b. The participant felt it was hard seeing other women with flimsy tops or no bra, as this tended to reinforce her sense of loss.

F/1:b. Breasts were an important part of the participants sense of femininity as she used to enjoy going bra-less as she regarded her breasts as small and firm.

.F/1:12b. She feels less sensual with only one breast, and said that there is no way of escaping this deficit in sensuality, however hard she may try to convince herself otherwise

F/1:11c. She no longer feels comfortable in many of the coital positions she and her partner used prior to her mastectomy, because these positions serve as a reminder to her that she now has a wound there instead of a breast.

F/1:3a. The severe linearity of her mastectomy scar is perplexing for one woman, who felt it would have been a little less severe had her nipple been able to be conserved.

F/2:7b. She remembered seeing the miss-spelt word 'mutila-ion' in her mind's eye, and this culling of the last T in the word symbolised her own physical state.

F/7:22a. Prior to her mastectomy, breast stimulation had played an important role in her sexual life, but since developing breast lumps in her remaining breast, and almost as soon as she had her mastectomy, she experienced her breast as a threat, and prefers not to be touched there, and has already 'disowned it' mentally.

F6. 31b. Since her mastectomy she has not had to alter the type of clothing she wears, apart from her bathing costume, but finds that even though she wears a prosthesis, she has to be careful about her upper torso bodyline because her surgeon excised so much tissue she has a little hollow between her collar bone and (former) nipple line which makes her asymmetrical.

67. 2:8c. She recalled that her mastectomy as a younger woman of forty-seven had affected her image of herself, for, even though she wasn't previously interested in the sensuous appeal of lingerie, she found herself hovering longingly around lingerie displays.