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What is the impact of TRAM flap breast reconstruction on self-esteem and perceived body image for women with breast cancer?

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**What is the impact of TRAM flap breast
reconstruction on self-esteem and perceived body
image for women with breast cancer?**

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ABSTRACT

Breast cancer is the most common of all cancers in women (26%) in Australia (Australian Institute Health Welfare AIHW, 1996; National Breast Cancer Centre NBCC, 1999). It is estimated that the lifetime incidence of one in eleven women in Australia will be diagnosed with breast cancer by the age of seventy-four (National Health and Medical Research Council NHMRC, 2000). Surgical resection continues to be the mainstay of treatment for early breast cancer, with approximately 50% of women diagnosed with breast cancer undergoing mastectomy (NBCC, 1999).

Both the diagnosis of breast cancer and subsequent mastectomy raises a number of psychosocial issues for women. In addition to the diagnosis of a potentially life threatening illness, these women contend with the psychological consequences that accompany the loss of a breast. During the height of development of breast reconstructive techniques in the 1980's, mastectomy became more commonly recognised as an important aspect of a woman's experience with breast cancer. Breast cancer not only causes pain, suffering and the possibility of death, but also threatens a woman's self-concept, self-esteem and feminine identity through its attack on her body (Derogatis, 1986).

To reduce the psychological impact associated with removal of the breast, breast reconstruction is increasingly being offered. In the past five years there has been an increase in the number of women seeking breast reconstruction, with an increasing

focus on quality of life issues and survivorship for women diagnosed with breast cancer (Wilkins et al., 1995). To date little is known about women's experiences of undergoing breast reconstruction.

Using a qualitative, exploratory descriptive approach this study investigated the impact of the transverse rectus abdominis musculocutaneous (TRAM) flap breast reconstruction, on self-esteem and perceived body image for women with breast cancer.

In depth semi-structured interviews, using both individual and focus group methods, were undertaken with ten women who had undergone a TRAM flap breast reconstruction between January 1st 2001 and January 1st 2003. Data was analysed using the process of thematic analysis to determine key concepts and themes that described these women's experiences.

Three main themes emerged from the findings of this study: "Loosing a breast matters", "The process of adjusting to a changing body image", and "Redefining normality". These themes and their sub-themes describe the experience of breast cancer survival and TRAM flap breast reconstruction for the women who participated in this study.

These findings will further the current knowledge base on this topic and therefore assist nurses in providing sound information and psychosocially appropriate support to

TRAM flap breast reconstruction patients and their significant others. Furthermore, this study's findings will be a further resource for women considering breast reconstruction treatment options following mastectomy.

DECLARATION

“I certify that this thesis does not incorporate, without acknowledgement, any material previously submitted for a degree or diploma in any institution of higher education; and that 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 .14.10.04

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CHAPTER 1

INTRODUCTION

Breast cancer continues to be a pertinent health issue for all women around the world. In Australia, one in eleven women will be diagnosed and half of them will undergo mastectomy. Breast reconstruction is becoming more available to women who must undergo removal of their breast. This thesis details a study undertaken to explore and describe the impact transverse rectus abdominis musculocutaneous (TRAM) flap breast reconstruction has on women's self-esteem and perceived body image.

This chapter will outline the background of the study topic in question and explore the significance of the topic in relation to this study. The research question and purpose of the study will then be presented.

1.1 Background

Over one quarter (26%) of the cancers diagnosed in women in Australia are located in the breast (Australian Institute Health Welfare AIHW, 1996; National Breast Cancer Centre NBCC, 1999). It is estimated that nearly 10% of women in Australia will be diagnosed with breast cancer, with a woman's lifetime risk of breast cancer occurrence standing at 1 in 11 (at age seventy-four) (National Health and Medical Research Council NHMRC, 2000). With Australia's current population figure of 19,989,348

(November, 2003) (www.abs.com.au), approximately 100,000 women will have been or will be diagnosed and treated for breast cancer in 2003. To date, despite developments in cancer research, surgical resection continues to be the mainstay of treatment for early breast cancer (NBCC, 1999).

Incidence of breast cancer

Two broad surgical approaches are used for treatment of early breast cancer, breast conserving surgery (BCS) and mastectomy (NHMRC, 2001). Breast conserving surgery involves the complete local excision of a tumour with histologically clear margins of normal breast tissue around the tumour also excised. Mastectomy is required when these clear margins are not attainable and the tumours are dispersed widely within the breast and overlying tissues (NHMRC, 2001). While early diagnosis has led to an increase in the number of women who undergo breast-conserving surgery (BCS), it is estimated that approximately 50% of women will still undergo mastectomy (NBCC, 1999), despite clinical studies showing no advantage of mastectomy over BCS in breast cancer survival in some groups (Early Breast Cancer Trialists' Collaborative Group, 1995). Based on the latest (1999) national figures, 10,592 new breast cancer cases were diagnosed in that year, 8,708 of which were treated by mastectomy (<http://www.aihw.gov.au/cognos/cgi-bin/ppdscgi.exe?DC=Q&E=/cancer>). It should be noted that these figures well exceed the 50% occurrence of mastectomy estimated by the NBCC in that same year (1999).

Psychological impact of mastectomy

There is now a large body of evidence, that has been well established over the past two decades, that highlights the psychological distress that is associated with a breast cancer diagnosis (Maguiere, 1976; Goin & Goin, 1981; Daniel & Maxwell, 1983; Schain et al., 1984; Derogatis, 1986; Walsh Spencer, 1996; Kissane et al, 1998; Neill et al., 1998; Hartl et al, 2003). In addition to dealing with a life threatening illness and its debilitating treatments, the impact of this diagnosis on a woman's body image and sexuality can be profound (NBCC, 2002). The focus of this study is on the impact of mastectomy and subsequent TRAM flap breast reconstruction on body image and sexuality. Beyond the number of psychological issues raised as a consequence of breast cancer diagnosis and mastectomy, this is not to say this experience ultimately leads to psychological distress.

In many cultures breasts are linked with a number of aspects of femininity, including motherhood and sexuality. It is not surprising then, that removal of a breast has long been known to lead not only to diminished feelings of femininity, but also lower self-esteem, decreased sexual interest and in some cases depression (Maguiere, 1976; Goin & Goin, 1981; Daniel & Maxwell, 1983; Schain et al., 1984; Walsh Spencer, 1996). Neill and colleagues (1998) found women express their psychological distress associated with mastectomy in terms of feeling their sense of self lacked "wholeness" after breast removal. In addition, is the issue of dealing with the diagnosis of a serious, potentially life threatening illness. Derogatis (1986) explained these concepts

by identifying that breast cancer is different from many other cancers, as it not only causes pain, suffering and the possibility of death, but also threatens a woman's self-concept, self-esteem and feminine identity through its attack on her body.

The psychological impact of mastectomy will be discussed further in Chapter Two (2.2, 2.6).

Breast reconstruction

To reduce the psychological impact associated with removal of the breast, surgical breast reconstruction is increasingly being offered. Despite an increasing trend towards breast reconstruction, the uptake of autologous reconstructive procedures is relatively low. In Australia, only 20% of women who have mastectomy opt for autologous breast reconstruction (NBCC, 1999). This figure is comparable to the United States of America (U.S.A.) (30%) and higher than the United Kingdom (UK) (5-10%) (Harcourt & Rumsey, 2001). In the past five years there has been an increase in the number of women seeking breast reconstruction, with an increasing focus on quality of life issues and survivorship for women diagnosed with breast cancer (Wilkins et al., 1995). Pertinent concepts of the reconstruction choice relate to restoring body integrity and easing the constant reminder of the breast cancer, thus empowering women to move forward with their lives (Hart, 1996; Nissen et al, 2000).

There are several different reconstructive surgery options available to women following mastectomy. The increasingly popular procedure of transverse rectus

abdominus musculocutaneous (TRAM) flap breast reconstruction is the focus of this study. Further explanation of this procedure is detailed in Chapter Two, as is a discussion of the identified benefits of reconstructive procedures over mastectomy alone.

1.2 Purpose

This study aimed to explore women's perspectives of how the experience of undergoing TRAM flap breast reconstruction has affected their psychological functioning in the areas of self-esteem and body image. This research will be a further information source for women considering TRAM flap breast reconstruction, by detailing women's experiences and perspectives of undergoing TRAM flap breast reconstruction. It is anticipated this study would benefit nursing by leading to an increased understanding of psychosocial consequences of this surgery for these women, thereby providing important information to nurses to better prepare them for providing psychosocial support to women before, during and after undergoing TRAM flap breast reconstruction following mastectomy.

1.3 Research Question

The two concepts found in the literature to be most influential on psychosocial outcome of women undergoing mastectomy and breast reconstruction, were body

image and self-esteem, which subsequently affect many other facets of a woman's life. Therefore, the question of focus in the research was identified to be:

What is the impact of TRAM flap breast reconstruction on self-esteem and perceived body image for women with breast cancer?

1.4 Significance

Breast cancer is the leading cause of cancer deaths in women in Australia. Since the introduction of mammographic screening in the mid 1990's there has been an increased incidence overall, but a decrease in the number of women dying from breast cancer due to earlier diagnosis. While this has led to an increase in the number of women eligible for BCS, approximately 50% of women will still undergo mastectomy (NBCC, 1999). This has resulted in an increased number of women who are breast cancer survivors. As mastectomy remains a major primary treatment, there are an increasing number of women eligible for breast reconstruction.

To date, research in this area has focused on comparing body image and sexuality outcomes for women who undergo breast reconstruction and those who choose to undergo mastectomy alone or some form of BCS. Little research focusing on the experience of reconstruction alone could be located, none of which specifically addressed TRAM flap breast reconstruction. The majority of these studies were undertaken using quantitative approaches, and have revealed contradictory findings.

With reference to the relatively low uptake of breast reconstruction in Australia, this has the potential to lead to difficulties for women in making decisions regarding whether to have breast reconstruction, and which type of breast reconstruction. In addition, nurses providing information, education and support to these women have limited conclusive information to guide them. It is evident further clarity of the benefits of breast reconstruction is needed. As TRAM flap breast reconstruction is becoming the most popular form of breast reconstruction following mastectomy, it is the focus of this study.

1.5 Summary

Through this study's exploration of the impact of TRAM flap breast reconstruction on women's self-esteem and body image, another information source will be available to both women considering TRAM flap breast reconstruction and health professionals working with these women, giving them a better understanding of the experiences encountered by women undergoing this form of breast reconstruction.

Mastectomy following breast cancer diagnosis is an increasingly common surgical procedure. The associated psychological sequelae have briefly been highlighted and will be discussed in Chapter Two. The increased focus on breast reconstruction following mastectomy to alleviate this impact on women, demonstrates the relevance of this study within the field of breast health. The increasing uptake of women undergoing breast reconstruction and the inconsistencies within the literature

regarding the benefit of breast reconstruction highlight the need for further clarification of women's experiences and the potential impact of this surgery.

Chapter Two will review the current literature regarding mastectomy and TRAM flap breast reconstruction, and the psychosocial impact of the experience, to further explore the inconsistencies within the literature previously mentioned. An explanation of the procedure of TRAM flap breast reconstruction will also be detailed.

1.6 Definition of terms

Breast Conserving Surgery (BCS): is the excision of a breast cancer tumour with preservation of the remaining breast tissue. Breast conserving surgery entails the removal of the tumour and a portion of the surrounding, unaffected breast tissue, giving clear histological margins. There is no specified limit to the size of the tumour able to be removed by BCS, however clinical practice guidelines recognise a tumour size of 3-4 centimetres as a practical limit (NHMRC, 2001).

Mastectomy: involves the complete surgical excision of the functional breast tissue, with preservation of the underlying pectoral muscles. This form of surgery for breast cancer treatment is indicated when tumours are widely dispersed within the breast, have ill defined histologically clear margins, directly involve the nipple or breast skin, or for women who do not choose BCS (NHMRC, 2001).

Adjuvant Therapy: refers to various forms of treatment used in conjunction with the primary treatment of the disease, (i.e. surgery). This may involve the use of drugs, as is the case with chemotherapy and hormone manipulation therapy, or localised treatment such as radiation therapy (NHMRC, 2001).

Breast Reconstruction: involves procedures aimed at rebuilding a breast removed by mastectomy. There are various methods practiced to achieve this aim, commonly by the use of a prosthesis or with tissue from other parts of the body (NHMRC, 2001).

Autologous: refers to a tissue or structure occurring naturally that is removed from, and subsequently returned to the same individual, (i.e. using tissue from another part of one's own body) (Mosby's Medical, Nursing & Allied Health Dictionary, 1998).

External Breast Prosthesis: is an artificial device placed against the surface of the body, designed to replace the physical appearance of the lost breast removed by mastectomy (Mosby's Medical, Nursing & Allied Health Dictionary, 1998).

Tissue Expander: is a device sometimes used to assist breast reconstruction. It is surgically inserted and gradually inflated to increase the amount of available skin cover. This device may later be replaced by a permanent breast prosthesis (NHMRC, 2001).

Pedicle: refers to a narrow stalk of tissue attached to a tumour, skin flap, bone or organ. With specific reference to the focus of this study, TRAM flap breast reconstruction, we refer to the pedicle as the rectus abdominis muscle attaching from its origin in the abdomen to the tissue flap site at the breast (Mosby's Medical, Nursing & Allied Health Dictionary, 1998).

TRAM flap: The transverse rectus abdominis musculocutaneous flap is the most common method of autologous breast reconstruction currently performed. It involves the surgical transfer of the skin, subcutaneous tissue, fat, and a portion of the rectus abdominis muscle, from the abdomen to the site of deficit left by mastectomy. The procedure may be pedicled, where the blood supply to the flap is maintained from its original donor site, or is transferred via free microvascular anastomosis of blood vessels. The procedure may be performed at the time of mastectomy as an immediate reconstruction, or at a later date as a delayed reconstruction (Harden & Girard, 1994; Clayton & Waller, 1996).

Seroma: is a possible complication of surgical procedures and presents as a swelling caused by the accumulation of serum (fluid) within the tissues (Mosby's Medical, Nursing & Allied Health Dictionary, 1998).

Mastopexy: is classified as a reconstructive cosmetic procedure involving the surgical lifting of the breast tissue (Mosby's Medical, Nursing & Allied Health Dictionary, 1998).

For the purpose of discussion of the findings of this study, the difference between minor and major complications associated with the surgery of TRAM flap breast reconstruction are defined below:

Major complication: refers to any complication related to the surgery that requires readmission into hospital and/or surgical intervention.

Minor complication: being any complication that does not prevent discharge from hospital or require rehospitalisation, (i.e. is treated in the hospital setting prior to discharge or is treated in an outpatient setting).

It should be noted that complications of TRAM flap breast reconstruction surgery can change their classification of minor or major, depending on the immediate severity of the complication at any one time.

The concepts of body image, self-esteem and sexuality are difficult to define due to their very complex, personal and individual nature. Remembering this, these concepts have been defined below for the purpose of recognising their context within this study:

Body Image: refers to the combination of conscious and subconscious attitudes the person has towards their body. These attitudes include past and present perceptions of self, as well as feelings regarding function, appearance and potential at any one time. Body image is central to the concept of self. It is a screen onto which a person reflects significant personal feelings, anxieties and values. Threats to body image can result

from pathological processes that cause changes in the structure and function of the body, (i.e. breast cancer surgery) (Stuart & Laraia, 2001).

Self-esteem: is a persons judgement of personal worth obtained by analysing and comparing how well behaviour conforms to the self ideal. Self-esteem is influenced via two sources, self and others (Stuart & Laraia, 2001).

Sexuality: broadly refers to all aspects of a person being sexual, not merely the act of sexual intercourse. Sexuality forms one aspect of a person's personality. Components of ones sexuality include sexual orientation, gender identity - that is a woman's perception of her femininity, and gender role - referring to behavioural expectations, values and emotional responses attributed to ones gender (Stuart & Laraia, 2001).

CHAPTER 2

LITERATURE REVIEW

This chapter will review the literature to explore and describe current knowledge regarding breast reconstruction and significant issues for the patient. An overview of the specific type of breast reconstruction that is the focus of this study, TRAM flap breast reconstruction, will also be provided. Upon reviewing the literature, the recurring issues identified to be most pertinent to the breast reconstruction experience are those of psychological benefit of breast reconstruction, body image, self-esteem, sexuality and education.

2.1 Nature of the problem

Breast cancer is the leading cause of cancer deaths in women in Australia (AIHW, 1996; NBCC, 1999). One in eleven women will be diagnosed with breast cancer before the age of seventy-four (NHMRC, 2000). Since the introduction of mammographic screening in the mid-1990's there has been an increased incidence of breast cancer diagnosis overall, but a decline in the number of related deaths due to earlier diagnosis. While this has lead to an increase in the number of women eligible for breast conserving surgery (BCS), it is estimated that 50% of women will still undergo mastectomy as primary treatment (NBCC, 1999).

The NHMRC Clinical Practice Guidelines for the Management of Early Breast Cancer (2001) report no difference in survival rates or spread of cancer between BCS and mastectomy options, therefore recommending all women should be offered BCS where appropriate. The same publication reports similar levels of psychosocial morbidity for either form of surgery, however levels of sexuality disturbance are less for those undergoing BCS (NHMRC, 2001). The most obvious benefit of BCS over mastectomy was found to be a much better preservation of body image (NHMRC, 2001).

In Australia only 20% of women who undergo mastectomy opt for breast reconstruction (NBCC, 1999). This number is on the rise due to an increased focus on the benefits and availability of breast reconstruction in developed countries (Wilkins et al, 2000). This figure is however, comparable to the United States of America (30%) (American Society of Plastic and Reconstructive Surgeons ASPRS (1991) as cited in Rowland et al, 1995), and greater than the United Kingdom (5-10%) (South and West Regional Health Authority SWRHA, 1995). There are many potential reasons for the relatively low uptake of breast reconstruction in Australia. Some of these may relate to the anticipated urgency of breast surgery, the consistency in which breast reconstruction is being offered, the availability of this surgery within the public health sector, the timing of the decision and the lack of educational awareness of both health professionals and prospective recipients of breast reconstruction.

2.2 Impact of Breast Surgery

Living with a diagnosis of breast cancer and its subsequent surgical treatment can have a profound effect on a woman's psychological and physical well being, and in turn, overall quality of life (Hartl et al, 2003). Surpassing the physical attributes it holds, the breast represents motherhood, a source of nourishment, comfort and nurturance, and aspects of feminine identity and sexuality that define womanhood (Grossman, 1976; Sawaya, 1994). Cohen and colleagues (1998) concluded the breast cancer experience does not simply involve aspects of body image related to surgical outcome. Through in-depth interviews with twenty women, these authors reported breast cancer results in an array of mental and emotional responses (Cohen et al, 1998).

Nearly half the women diagnosed with breast cancer requiring surgical treatment will undergo BCS (NBCC, 1999). For some women, however, this is not an option due to the size, pathology or location of the cancerous lesion (Yurek et al, 2000). Subsequently, mastectomy remains a major form of surgical treatment for breast cancer (NBCC, 1999). For over twenty years authors have identified that mastectomy results in a diminished self-esteem (Daniel & Maxwell, 1983; Schain et al, 1984). More recent studies have shown this is still the case (Al-Ghazal et al, 2000)

Although the impact of mastectomy is demonstrated most evidently in the areas of body image and sexuality, loss of function due to extensive axillary surgery that sometimes accompanies primary breast surgery, can also have a negative impact. Several different but entwined concepts are involved in the experience, not only the

physical aspects, but those of self-esteem, body image, sexuality, sexual function and femininity. Body image is affected from both a physical and psychological perspective. A qualitative study of the psychosocial support of twenty-seven women with breast cancer was undertaken by the National Breast Cancer Centre (2002). This study interviewed both heterosexual and lesbian women. It was found women's body image was affected by their difficulty to adjust to the physical changes and limitations that had resulted from surgery. Further findings showed this change in body image impacted on women's sexuality, demonstrated by a hesitance to take part in physical contact and avoidance behaviour in relation to exposing their bodies to partners, often resorting to concealment or cloaking of the chest area. The same study revealed a detrimental effect on sexual function. Women reported pain, limitation in range of movement, loss of sensitivity and skin sensation, and in some cases physical restriction secondary to lymphoedema. These complaints were found to lead to a decreased libido, decline in spontaneity, discomfort in sexual positioning, and an overall negatively impaired sexual experience. Similar findings have been previously introduced by Maguiere (1976) and Daniel and Maxwell (1983), who found that impaired feelings of femininity resulted in a decreased sexual interest and avoidance or abstinence of sexual intercourse in 30% (Daniel & Maxwell, 1983) to 80% of women (Maguiere, 1976).

For many women one area of ongoing dissatisfaction relates to the use of an external breast prosthesis. The use of an external breast prosthesis, although sometimes initially a positive experience as form may be regained, is commonly recognised to be

related to dissatisfaction in both physical and psychological functioning. A variety of commentary papers and research studies spanning the last twenty-seven years have concluded that external breast prosthesis are poorly accepted or integrated into the woman's self-concept (Luckman & Sorensen, 1987; Clifford, 1979; Schain et al, 1985; Bostwick, 1995; Al-Ghazal et al, 2000).

Psychological morbidity is not only related to the negative impacts of mastectomy on body image and sexuality, but also must incorporate the concept of living with a life threatening disease (Al-Ghazal et al, 2000). Easing psychological sequelae of breast cancer surgery has become the leading aim in the support of women with breast cancer (Fallowfield, 1996). Breast reconstruction is commonly postulated to lessen the psychological impact of mastectomy (Al-Ghazal et al, 2000). However, evidence of improved body image and self-esteem with breast reconstruction is somewhat contradictory. This will be discussed in later sections of the literature review (See section 2.7, 2.8).

2.3 Breast Reconstruction Decision Making

Neill and colleagues (1998) highlight the intellectual, emotional and social complexity that characterise the experience of considering breast reconstruction following mastectomy. While breast reconstruction has no cancer survival benefit, it can help improve the quality of life of breast cancer survivors (Rowland et al, 1993). More recently there has been a change in approach from questioning 'Why would a woman

choose to have a breast reconstruction?', to 'Why would a woman choose not to have a breast reconstruction?' (Handel et al, 1990; Schain, 1991). This changed perspective can be attributed to a number of reasons, including the development and improved modification of breast reconstructive procedures resulting in the delivery of greater aesthetic outcome, societal and generational changes in attitude towards breast reconstruction, increased consumerism and information seeking of women, and increasing availability of information.

Nissen and colleague's (2001) focus group study of seventeen women who underwent immediate breast reconstruction, found reasons for deciding to have a reconstruction were both psychological and physical in nature. Other studies have identified these physical concerns as being related to undesired body image disturbances incurred by mastectomy (Walsh Spencer, 1996; NBCC, 1999). A common finding in the literature was women's dissatisfaction with external breast prosthesis. External prostheses were disliked for both the body image disturbance they caused and practical limitations on clothing and activity (Hart, 1996; NBCC, 1999). Women reported feeling self-conscious and described the prosthesis as uncomfortable, unbalanced and embarrassing (Reaby et al, 1994; Rowland et al, 1995; Hart, 1996; NBCC, 1999).

Psychological reasons related to the breast reconstruction decision are psychosexual, not only related to aesthetic considerations, but also a desire to feel 'whole' and more feminine once again (Margolis et al, 1989; Hart, 1996; NBCC, 1999). Several studies also indicated the disfigurement of mastectomy served as a continual reminder of the

breast cancer, and that this factor became motivation for breast reconstruction (Hart, 1996; Nissen et al, 2002).

Reasons women choose not to have a breast reconstruction seem to be primarily related to the procedure itself. Both clinical opinion and exploratory, descriptive studies have identified women did not want further surgery and were concerned about post-operative pain, complications from the surgery and uncertainty of the final result (Handel, 1990; Hart, 1996; NBCC, 1999). Women also expressed concern that breast reconstruction may hide a recurrence of breast cancer (Handel, 1990; Hart, 1996; Harcourt & Rumsey, 2001), however it has been well documented that flap breast reconstruction in no way effects the detection of a breast cancer recurrence (NBCC, 1999; Ross et al, 2000). The NBCC (1999) held national focus group interviews with women who had breast cancer surgery, including breast reconstruction. They described women's apprehension related to breast reconstructive surgery being viewed by others as 'cosmetic' and 'unnecessary', thus implying unnecessary vanity. This view of breast reconstructive surgery acting as a deterrent to breast reconstruction was also evident in a review of the literature by Harcourt and Rumsey (2001). Schain (1991) acknowledged that there is not only the possibility of benefit from breast reconstruction, but also the possibility of immense emotional and physical anguish, when the replacement breast is not the same as the original breast.

A woman's decision to undergo breast reconstruction involves weighing up the pro's and con's of the anticipated breast reconstruction experience, as well as addressing a

number of identified barriers to breast reconstruction. Information on breast reconstruction is crucial to this process. A pilot study by Neill and Briefs (1997) explored plastic surgeons advice to women regarding breast reconstruction. They found disproportion between the enormous volume of information given, and the restrictively minimal time frame within which it is delivered. They concluded the timing and volume of information given may be a factor requiring further review. Therefore, it is evident the time allowed for decision-making may be a barrier to the decision making process. (This will be further explored in section 2.9). Another possible barrier to the reconstruction decision is related to the surgical advice given to the patient.

In a review of breast reconstruction practices in Australia undertaken by the NBCC (1999), it was identified that only half of the patients eligible for breast reconstruction are aware of this option at the time of diagnosis. McManus and colleagues (2003) using a postal survey, reviewed breast surgeon's current practices regarding immediate breast reconstruction in the West Midlands of the United Kingdom. Their survey found immediate breast reconstruction was not offered to all eligible patients, either due to not having the expertise to perform the surgery or surgeons selectively discussing this option dependent upon individual's tumour pathology and clinical co-morbidities (McManus et al, 2003). This practice was evident in Australia also with surgeons assigning suitability for breast reconstruction at their discretion, according to their expertise on related clinical issues (NBCC, 1999). McManus and colleague's (2003) study also highlighted surgeon's attitudes as a dependent factor upon breast

reconstruction advice. Of the two centres that did not offer breast reconstructive surgery, one surgeon expressed opposition to the principle of immediate breast reconstruction, and the other centre believed breast reconstruction should only be offered in non-invasive breast cancer cases (McManus et al, 2003).

Some studies have shown that women who decided against breast reconstruction felt the effects of mastectomy were minimal and had not impacted on their lives to the extent where they felt they needed breast reconstruction (Hart, 1996; NBCC, 1999). However, Daniel & Maxwell (1983) postulated that women chose breast reconstruction to alleviate the psychological impact of mastectomy. Whatever the final decision, the option of breast reconstruction may enable women to feel a sense of control in a life-threatening situation they are less able to control (Neill et al, 1998). The positive physical and psychological outcomes of breast reconstruction will be discussed in sections 2.5 – 2.9.

2.4 Types of Breast Reconstruction

Breast reconstruction is becoming a more popular option to help reduce the physical and psychological impact created by mastectomy (Stevens et al, 1984; Knobf & Stahl, 1991). Reconstruction of the breast is recognised as a safe procedure resulting in benefit to the psychological well being of the breast cancer survivor (NBCC, 1999; Wilkins et al, 2000). The first breast reconstruction procedures were attempted early in the twentieth century. However, these methods were often equally as disfiguring as

mastectomy and were deemed aesthetically unsuccessful (Bostwick, 1990; Neill et al, 1998). Advancements in surgical technique since the 1970's have yielded dramatically improved surgical morbidity rates and cosmetic outcomes for women requiring mastectomy and undertaking breast reconstruction (Neill et al, 1998).

The ultimate purpose of breast reconstruction is the creation of a symmetrical breast mound that looks and feels as natural as possible to that of the remaining breast (Silverstein et al, 1991; Watson et al, 1995; NBCC, 1999; Watier et al, 1999).

As early as the sixteenth century the possible psychological benefit of breast reconstruction and the need for this benefit following mastectomy had been identified by Tagliacozzi (1597), who described the anticipated psychosocial benefit of breast reconstruction (as cited in Walsh Spencer, 1996, p131);

“We restore, repair and make whole those parts which nature has given but which fortune has taken away, not so much that they delight the eye, but that they may buoy up the spirit and help the mind of the afflicted”.

Despite these goals, ultimately the primary concern of the surgical team is the treatment of breast cancer (Clayton & Waller, 1996), which ideally should not be compromised for aesthetic outcome (Ross et al, 2000). However, it has been found a small number of women make surgical choices for treatment of their breast cancer, with a primary focus on minimising the effects on their body image (NBCC, 2002).

There are several different approaches to breast reconstruction. These include non-autologous, that is using artificial implants usually with the assistance of tissue expanders, or autologous breast reconstruction procedures using a woman's own body tissue. There is an increase in the number of women undertaking breast reconstruction after mastectomy across developing countries (Wilkins et al, 2000; Koshi et al, 2003). Koshi and colleagues (2003) assessed the increasing trend of breast reconstruction in Canada and attributed this to an increased knowledge and understanding of the availability of breast reconstruction, and improved education of health care professionals regarding the benefit of breast reconstruction to the recipient. Autologous breast reconstruction is now the most widely accepted method of breast reconstruction (NBCC, 1999). Several quantitative studies found women undergoing non-autologous breast reconstruction demonstrated greater physical and psychological morbidity (Yeh et al, 1998; Wilkins et al, 2000).

Complications from breast reconstruction can be significant, leading to delayed healing, prolonged hospitalisation and poorer body image outcomes. Complication rates have been monitored in several studies, with conflicting conclusions. Wilkins and colleagues (2000) and Yeh and colleagues (2000) reported significantly lower rates of clinical complications with autologous breast reconstruction. However, Trabulsy and colleagues (1994) revealed similar complications rates. Four percent of autologous breast reconstruction patients had minor complications and 17% had major complications. Of those undergoing a non-autologous breast reconstruction, 3% had

minor complications and 20% suffered major complications. Possible reasons for different complication rates in these studies may include different levels of technical expertise, variable patient selection, follow up periods, and the time period over which the study was undertaken considering procedural development.

A small study of eight TRAM flap breast reconstruction patients and fourteen implant reconstruction patients found all but one of the TRAM flap group were satisfied with how the breast felt, compared with only three of the implant reconstruction participants (Cederna et al, 1995). Feng and colleagues (1994) discovered 92% of patients who had undergone autologous breast reconstruction following failure of silicone implant reconstruction, felt appearance related outcome was more pleasing than the previous method adopted.

The most popular method of autologous breast reconstruction is the transverse rectus abdominis musculocutaneous flap (NBCC, 1999). This method is preferred for its comparatively low complication rate, superior aesthetic outcome and greater patient satisfaction than other autologous methods (NBCC, 1999; Watier et al, 1999). The TRAM flap breast reconstruction was developed Dr. Carl Hartrampf using cadaver dissection (Priestly, 1992). The first TRAM flap breast reconstruction was successfully undertaken in September 1980 (Hartrampf et al, 1982). This procedure entails the transfer of skin, subcutaneous tissue, fat and rectus abdominus muscle from the abdomen to the site of deficit left by mastectomy (Clayton & Waller, 1996).

Initially TRAM flaps were pedicled flaps. This is where the tissue flap remains attached to the donor site and is tunnelled under the skin of the chest wall to the recipient site. Blood supply to the repositioned flap is maintained from the donor site (Harden & Girard, 1994; NBCC, 1999). Since its creation the procedure has been modified to the more common current practice of free TRAM flap breast reconstruction. With this method the flap tissue is excised and lifted freely to the recipient site. Blood supply is sustained via the deep inferior epigastric artery and vein and the adjoining perforators. These vessels are clamped, cut from the donor site and microvascularly anastomosed to the thoracodorsal or internal mammary artery and vein at the recipient site (Harden & Girard, 1994; Clayton & Waller, 1996). Ischaemic time refers to the period of time lapsed between clamping of the vessels at the donor site till anastomosis at the recipient site (Harden & Girard, 1994). The thoracodorsal vessels are located in the axilla and are the more commonly utilised recipient vessels. However, the internal mammary vessel approach is gaining in popularity as they require a shorter pedicle length thus facilitating less resection of the rectus abdominus muscle, allow for central flap positioning and avoid damage to the axillary anatomy (Moran et al, 2003). Moran and colleagues (2003) randomised study of 108 free tissue transfers utilising both sites for anastomosis of blood vessels indicated no significant difference in complication rates, cosmetic outcome or recovery time spent in hospital, thus concluding either location is a safe and acceptable practice. The length of the procedure is known to be between four to twelve hours or more (Harden & Girard, 1994). Post-operative monitoring of flap perfusion is crucial to its survival (Watier et al, 1999).

The free TRAM flap is argued to be preferred over the pedicled method, as it achieves greater aesthetic outcome and has lower complication rates (Elliot et al, 1993; Kroll et al, 1995; NBCC, 1999; Wilkins et al, 2000). Watson and colleagues (1995) identified major flap necrosis occurs in up to 10% of pedicled TRAM flaps, and fewer than 5% of free TRAM flaps. Elliott and colleagues (1993) studied the outcomes of 128 immediate TRAM flap breast reconstructions, using both pedicled and free methods. Sixty-three percent (N= 25) of the free TRAM flap group were classified as 'high risk' patients. Only 9.5% (N= 4) of this group encountered complications post-operatively. In contrast, 28% (N= 24) of the pedicled flap group was considered 'high risk' and 28% (N=24) suffered complications. It is postulated the lower complication rate of free TRAM flaps is due to a stronger blood supply (Elliot et al, 1993). However, the author did not identify the criteria to classify a participant 'high risk'. In addition data was collected over a five year period (1985-1990), during which time more advanced surgical techniques for the procedure were being adopted.

Ideal candidates for TRAM flap breast reconstruction are women who are in good general physical health, have sufficient abdominal tissue to remove, and have nil or minimal abdominal scarring which may impede blood supply to the rectus abdominus muscle (Harden & Girard, 1994; Clayton & Waller, 1996; Fritzsche, 2001). Transverse rectus abdominus musculocutaneous breast reconstruction is clinically contra-indicated in women who are heavy smokers or suffer from obesity, diabetes, cardiovascular disease or hypertension (Carlson, 1994; Harden & Girard, 1994; Neill

& Briefs, 1997). These factors may impede microvascular blood supply and wound healing, therefore increasing the risk of complication during the recovery period.

Smoking and obesity are considered to be major risk factors for complication. Kroll (1994) found current smokers had higher complication rates than those who had stopped smoking, with the group who had never smoked having the lowest complication rate. Watterson and colleagues (1995) study of 556 TRAM flap breast reconstructions identified a complication rate of 39% for smokers and 21% in non-smokers. The same study revealed a 31% complication rate in women who weighed 25% over their ideal body weight, and only a 21% complication rate in the remaining group. Kroll and Netscher (1988) in their quantitative study, showed markedly obese women had a complication rate of 41.7%, compared with the moderately obese at 31.4%, participants of average weight at 22.7% and clinically thin patients at 15.4%.

Complications of TRAM flap breast reconstruction may include infection at the flap or donor site, seroma or haematoma, or abdominal hernia secondary to excision of part of the rectus abdominus muscle (Clayton & Waller, 1996; Fritzsche, 2001). Respiratory complications may include bronchiectasis, atelectasis, pneumonia and pulmonary embolus. These complications may be due to anaesthetic time, post-operative immobility and alteration in respiratory pattern secondary to abdominal surgery and pain (Fritzsche 2001). Fat, skin or flap necrosis may occur, and may be either partial or complete (NBCC, 1999; Fritzsche, 2001). If flap necrosis is minimal the breast flap

may be preserved, however a flap no longer viable must be surgically removed (NBCC, 1999).

Once a woman has recovered from TRAM flap breast reconstruction she may opt to undergo surgical revision procedures. A delay of approximately three to six months before undergoing revision procedures is suggested to give the breast time to 'settle', therefore allowing better estimation of aesthetic outcomes (Sawaya, 1994; Bostwick, 1995; Watson et al, 1995). Reconstruction of the nipple-areola complex is commonly undertaken to complete reconstruction of the breast. A nipple can be created by using skin from the surrounding flap itself, or using a graft from the contra-lateral nipple if size permits. The areola pigment is achieved by tattooing, or skin grafting from an area of darker pigment, commonly the upper inner thigh or labia majora (Bostwick, 1995; Spear & Arias, 1995). Kroll and colleagues (1995) discovered women in their study who underwent nipple reconstruction were given greater aesthetic outcome scores by a blinded independent panel of nine judges, none of which were members of the reconstructive surgical team. Women may also have surgery on the contra-lateral breast, for example reduction, or lifting of the breast by mastopexy (Watson et al, 1995; Harcourt & Rumsey, 2001). The ultimate goal of revision procedures is to create balanced symmetry of the breasts.

2.5 Timing of Breast Reconstruction

Transverse rectus abdominus musculocutaneous flap breast reconstruction may be carried out as a delayed or immediate procedure (Bostwick, 1995). Immediate breast reconstruction is where the TRAM flap procedure is performed at the same time as the original mastectomy, as a single operation. Delayed breast reconstruction is performed at least three months after mastectomy to allow for sufficient healing time and recovery of tissue integrity (Silverstein et al, 1991). Previously, delayed reconstruction had been the standard practice for TRAM flap breast reconstruction (Bostwick, 1995). In recent years immediate breast reconstruction has become the more popular option, and is now the standard for TRAM flap breast reconstruction (Elliot et al, 1993; Bostwick, 1995). From a clinical perspective immediate breast reconstruction is seen to be of distinct advantage as there is a single anaesthetic, hospitalisation and recovery period, as well as a benefit of cost efficiency in comparison to delayed breast reconstruction (Elliot et al, 1993; Bostwick, 1995; Bremner-Smith et al, 1996). However, immediate breast reconstruction requires access to both a plastic/reconstructive surgeon and a breast surgeon at the time of surgery. In addition access to an extended theatre time is crucial as the procedure may last between four to twelve hours. Clinicians have identified these factors as a barrier to accessing this type of surgery within the public health care system (Nicole Rankin, personal communication, March, 2003).

Several authors have argued that immediate breast reconstruction provides superior cosmetic outcome and improved psychological coping (Kroll & Baldwin, 1992; Kroll

et al, 1995; Watson et al, 1995; Tran et al, 2000). However, other studies measuring patient satisfaction between immediate and delayed procedures identified conflicting results. Several studies found women's satisfaction to be greater with immediate breast reconstruction (Kroll et al, 1995; Watson et al, 1995; Neill et al, 1998; NBCC, 1999; Sandau, 2002). Harcourt and Rumsey (2001), on reviewing a number of studies on the psychological impact of breast reconstruction, concluded that delayed breast reconstruction was associated with higher patient satisfaction. Difference in satisfaction between groups was not significant in a study by Mock (1993). Preference for the timing of breast reconstruction was explored by Al-Ghazal and colleagues (2000), with 76% (N=63) of the delayed breast reconstruction group retrospectively stating they would have preferred to have had an immediate breast reconstruction. Other studies have shown a lesser degree of psychological morbidity with immediate rather than delayed reconstruction (Stevens et al, 1984; Schain et al, 1985; Yeh et al, 1998; Al-Ghazal et al, 2000; Al-Ghazal et al, 2000; Contant et al, 2000). Mock (1993) however, identified no significant difference in psychological morbidity between the two groups. Methodological flaws highlight problems when interpreting Mock's results. Mock (1993) studied 58 women undergoing immediate breast reconstruction, and 48 delayed breast reconstructions. Four tools were used to assess psychological morbidity, three of which are commonly used and deemed of high validity. However these three tools showed no significant difference between groups. The only significant difference was reported from the scores of the Body Image Visual Analogue Scale (BIVAS), however this tool was yet to be tested. No details on the development of reliability and validity of the BIVAS were provided.

The author recognised the weakness in methodology of using a tool that had not been validated. Potential reasons for the differences in these studies results include different sample sizes, different tools used to measure the same variable and timing of the application of the tools.

Immediate breast reconstruction is viewed to deliver psychological benefit by avoiding the distress of suffering the loss of a breast, with many authors arguing that these women do not endure as great a grief and sense of loss associated with mastectomy (Noone et al, 1985; Bostwick, 1995; Clayton & Waller, 1996; Neill & Briefs, 1997; Al-Ghazal et al, 2000).

Advocates for delayed breast reconstruction believe this method is more advantageous as the time lapse will help to assist adjustment to a changing body image, and the experience of loss may lead to greater appreciation of the reconstructed breast (Schain et al, 1985, Winder & Winder, 1985; Harcourt & Rumsey, 2001). Several authors argue the loss of a breast was an unnecessary experience to bear (Noone et al, 1982; Schain, 1985). The variations in conclusions regarding women's psychological experience of immediate and delayed breast reconstruction, as contrasted above, may relate to the date of publication. In the early to mid-1980s TRAM flap breast reconstruction was a relatively new concept and the 'conventional' method was delayed pedicled. Perhaps these changing insights into immediate breast reconstruction lead to some controversy between researchers and field experts alike. Rowland and colleagues (1995) argue the decision to reconstruct demonstrated

positive adjustment to the breast cancer diagnosis. While Hart (1996) postulated a delayed reconstruction decision was also indicative of healthy adaptation as it expressed effective use of problem solving skills. This difference may reflect that preference of the timing of breast reconstruction will also be different for individual women.

2.6 Psychological Benefit of Breast Reconstruction

The psychological impact of breast surgery is related to the loss of an original body part and the subsequent effects this has on the self-concept of a woman (Mock, 1993). Women are not only faced with this modification of self but are also dealing with living with the life threatening disease that is breast cancer (Harcourt & Rumsey, 2001).

Harcourt and Rumsey (2001) argued it would be untimely for health care professionals to make assumptions about which surgical treatment option for women with breast cancer delivers the best psychological benefit. The research literature reviewed here again highlights contradictory findings of the psychosocial benefit of TRAM flap breast reconstruction. Some findings are inconsistent with the seemingly logical idea that breast reconstruction, as opposed to mastectomy alone, would yield better outcomes of self-esteem, body image and related psychological issues including sexuality. While several studies recognised a significant psychological benefit of breast reconstruction (Rowland et al, 1993; Hart, 1996; Al-Ghazal et al, 2000; Al-Ghazal et al, 2000), there is also evidence of negative psychological outcomes of

breast reconstruction. Nissen and colleagues (2001) comparative study on the quality of life of BCS, mastectomy and breast reconstruction patients, revealed that women in the breast reconstruction group had a significantly higher level of mood disturbance and impaired well being in comparison to the mastectomy group. The authors proposed no explanation for this. When comparing differences in post-operative sexuality and body change stress between surgical groups, Yurek and colleagues (1998) reported equivalent levels of distress between mastectomy and breast reconstruction groups. It should be noted that of the 190 women participating in this study only 29 women had breast reconstruction, compared to 78 women undergoing BCS and 83 women living with mastectomy. The small number of women in the breast reconstruction group may not have allowed accurate representation of findings.

Al-Ghazal and colleagues (2000) compared psychological distress of three groups of women; those who had mastectomy only, mastectomy with breast reconstruction or BCS. Using the Hospital Anxiety and Depression Scale (HADS), the authors found rates of anxiety to be 69% (N= 139) for the mastectomy group, 55% (N= 66) for the breast reconstruction group and 38% (N= 97) in the BCS group. Depression rates were 10% (N=20), 2% (N= 3) and 7% (N= 19) respectively. These findings clearly indicate a decreased level of anxiety in reconstructed patients over mastectomy patients, and lower rates of depression for breast reconstruction patients than mastectomy and BCS patients. However, anxiety figures remain significantly higher than the normal population. Overall findings of an earlier study undertaken by Al-Ghazal and some other colleagues indicated an excellent correlation between cosmesis

and anxiety, depression, body image, sexuality and self-esteem (Al-Ghazal et al, 1999). This conclusion is supported as the BCS group had the least negative effect on sexuality, satisfaction and anxiety, and the breast reconstruction group had a more positive effect on these concepts than those who underwent mastectomy alone. Interestingly, the breast reconstruction group showed a lower rate of depression than the BCS group. It should be noted however, that varying degrees of BCS required can leave a significantly sizeable breast defect.

Decreased levels of psychological distress in women over one year post operatively was identified by Harcourt and colleagues (2003) in three groups; mastectomy, immediate and delayed breast reconstruction. They concluded breast reconstruction can offer psychological benefits, however some participants reported improved psychological functioning without breast reconstruction. This finding may indicate that psychological distress may ease with time, due to the utilisation of one's personal coping mechanisms. This idea was reiterated by the works of Harcourt and Rumsey (2001). Despite varying degrees of psychological function during the mastectomy and breast reconstruction experience it is postulated that a certain level of distress is anticipated and helps to initiate preparation and utilisation of coping mechanisms (Hart, 1996).

The work of Al-Ghazal and colleagues (2000) highlights the complexities of the breast surgery experience and the need for more research to be undertaken to explore these differences.

2.7 Body Image and Self-Esteem Following Breast Reconstruction

Body image is a component of one's self-concept, often described as a mental picture of self (Mock, 1993). Self-concept has been established to be the views a person has of himself or herself that are deemed most important, and subsequently assist formation of the personality (Combs et al, 1976). Body image has been defined as the perceptions and attitudes one has regarding their physical state, including aspects of appearance, health, skills and sexuality (Mock, 1993; Roid & Fitts, 1998). Self-esteem refers to the degree of self worth and competence one attributes to oneself, dependant upon the person's self ideal (Stuart & Laraia, 2001). Pedro's (2001) study looked at factors influencing the quality of life of long-term survivors of various forms of cancer. It was found self-esteem was the greatest predictor of health related quality of life. This highlights the importance of self-esteem on the quality of life.

Hart (1996) describes the benefits of breast reconstruction as including enhanced body image and self-confidence regarding appearance. Several studies have shown outcomes related to body image of BCS participants to be superior, with breast reconstruction participants having a better body image than mastectomy participants (Wellisch et al, 1989; Al-Ghazal et al, 2000). Nissen and colleagues (2002) discovered improved aspects of body image in patients with breast reconstruction. A study by Al-Ghazal and colleagues (2000) found women undergoing BCS had a higher self-esteem than TRAM flap breast reconstruction patients, and the TRAM flap patients had a greater self-esteem than the mastectomy group.

Reaby and colleague's (1994) Australian study compared women who had undergone breast reconstruction, women living with an external breast prosthesis, and a surgical control group who had not undergone mastectomy. There was no significant difference in body image scores between those who had breast reconstruction and those living with breast prostheses. The same study's findings on self-esteem found those having breast reconstruction had a higher self-esteem than the prosthesis and control groups. Interestingly, the control group had more negative perceptions of their body than both other groups (Reaby et al, 1994). This highlights the complexity of the interrelated concepts of self-esteem and body image. The authors suggested the finding of more negative perceptions of self in the control group, may be due to the control group not having faced mortality issues, as the other groups had when diagnosed with a life threatening illness. No further investigation by the authors was undertaken to explain these findings. Related methodological weaknesses of the study include that no demographic data of the control group was taken, and the control group was not interviewed as the other groups were. It is not clear if inconsistency in data collection contributed to the variance in results.

It is evident that few studies focused on self-esteem and body image following breast reconstruction. These studies have been of small sample sizes with unclear conclusions. The NBCC's (2002) report on psychosocial support for women with breast cancer highlighted the current literature's lack of adequate methodologies used to measure the variables of self-esteem and body image. This may be one reason for the limited research in this area.

2.8 Sexuality, Sexual Function and the Reconstructed Breast

Sexuality broadly refers to the combination of physical, functional and psychological attributes, expressed as one's gender identity (Mosby's Medical, Nursing & Allied Health Dictionary, 1998, p. 1484). As the breast is synonymous with feminine identity it is expected the loss of a breast and its subsequent reconstruction will have changing effects on a woman's sexual being.

Rowland and colleagues (2000) concluded from their findings that breast reconstruction recipients were more likely to report a negative impact on their sex lives than those undergoing BCS or mastectomy. Yurek and colleagues (2000) study established that recent postoperative sexual behaviour and responses are disrupted more so for reconstructed patients than mastectomy or BCS patients. The researchers found that reconstructed patients had decreased rates of activity and fewer signs of responsiveness than BCS participants, and at times lower than that of mastectomy patients. Participants who underwent mastectomy or BCS reported feelings of greater sexual satisfaction than those having breast reconstruction. These findings could be due to the fact that the acute recovery period for a TRAM flap breast reconstruction immediately post-operatively is substantially longer (7-14 days) and more physically punishing than those of BCS or mastectomy. Further explanation could include the sometimes-extensive surgical refinement required on the flap to achieve aesthetic outcome. This commences months after and may continue for years after the original reconstructive surgery, leading to several surgical procedures and hospital admissions.

Al-Ghazal and colleagues (2000) exploration of sexuality among various forms of breast surgery found that 25% of the reconstructed group felt 'quite a bit' or 'very much' less sexually attractive, compared with 18% of the BCS group and 68% of the mastectomy group. This shows sexual attractiveness of the breast reconstruction group to be superior to the mastectomy group. Mock (1993) postulated her findings of no difference in self-concept between breast cancer surgical groups to be suggestive of a continuing adaptation of self to a changing body image, self-esteem and sexuality.

2.9 Nursing Role in Breast Reconstruction Education

Education is a large part of the nursing role when caring for women considering breast reconstruction. It has long been recommended health care professionals be equipped to clearly, accurately and consistently deliver information, understanding and support to women considering and undergoing TRAM flap breast reconstruction (Winder & Winder, 1985). Education should commence before the decision to reconstruct has been made, and continue during and after the surgical treatment phase (Neill et al, 1997; Neill et al, 1998; Fritzsche, 2001).

Several studies on breast reconstruction have revealed women felt they required more education on certain aspects of the breast reconstruction experience (NBCC, 1999; Nissen et al, 2002; Harcourt et al, 2003). Specific topics women undergoing TRAM flap breast reconstruction requested further information on included pain, length of recovery, sensation, nipple excision, abdominal surgery and drains (NBCC, 1999;

Nissen et al, 2002). Women identified the sources of information given to be most useful were from human sources as opposed to multimedia resources (Ward et al, 1989). Several authors have suggested more information and education should focus on advantages and disadvantages of breast reconstruction options, anticipated outcomes, hospital procedures, recovery and complications (Hart, 1996; NBCC, 1999; Contant et al, 2000; Harcourt & Rumsey, 2001). Several authors caution that women with high expectations of the surgery may be disadvantaged and experience emotional distress later on if these expectations are not achieved (Pruzinsky, 1993; Contant et al, 2000; Harcourt & Rumsey, 2001; Nissen et al, 2002). This highlights the importance of accurate information.

Many women undergoing TRAM flap breast reconstruction will be cared for in non-cancer surgical wards. The relevance of this was highlighted by Hicks and Fide (2003), who investigated the educational abilities of non-breast cancer nurse's working with TRAM flap breast reconstruction patients. They found definite educational needs were required. Specifically, with cancer related items, followed by general nursing care items, with the most development required in the areas of psychosocial impact, specific clinical knowledge and patient management. The authors recommended further professional development for nurses working with TRAM flap breast reconstruction patients.

Timing of breast reconstruction is a pertinent issue for women considering TRAM flap breast reconstruction (Neill & Briefs, 1997), (see section 2.5). Women commonly

meet with plastic/reconstructive surgeons with a date for mastectomy already booked (Neill & Briefs, 1997). In some cases the time period between seeing a surgeon and undergoing surgery for breast cancer can be very short [3-5 days (Neill & Briefs, 1997), up to 1-2 weeks (Elliot et al, 1993)]. This urgency impressed upon these women calls for life changing decisions to be made within a disproportionately short time frame (Margoese, 1994; Neill & Briefs, 1997). This is commonly perceived as a problem for women as their ability to process the large volume of information is impaired by the constraints of time and also their affected mental and emotional state secondary to a recent diagnosis of breast cancer (Clayton & Waller, 1996; Rosenqvist, 1996, Neill et al, 1998). Harcourt and Rumsey (2001) questioned the viability of informed decision making within this context. A focus group study conducted by the NBCC (1999) showed women expressed concern about the rush to make a decision. Women commented that after the shock of diagnosis they were too overwhelmed to comprehend further information given on breast reconstruction options available to them and felt completely unable to make a decision during this time (NBCC, 1999).

The obvious task for health care providers, including nurses, is to determine the specific level and amount of information each individual woman requires. Continual clarification that these needs are being met as they change is required (Neill et al, 1998). Involvement of the woman in decision-making is seen as an integral component of the breast reconstruction decision-making process (Neill et al, 1998; Pedro, 2001). Access to information is crucial to this process. The role of the nurse is to assist the woman by providing and clarifying information (Pedro, 2001), with the

aim of facilitating psychosocial adjustment throughout the breast reconstruction experience (Al-Ghazal et al, 2000).

The need for accurate information and educational support for women is a consistent theme in the literature reviewed. This indicates a perceived deficit in this area identified by most authors, and signifies the importance of education to the TRAM flap breast reconstruction patient.

2.10 Conclusions and Justification

Nurses require further knowledge to enable them to fulfil their role as resource and support person for women undergoing TRAM flap breast reconstruction. Cohen and colleagues (1998) acknowledged the importance of furthering nursing knowledge in order to better enable nurses to meet the requirements of breast cancer patients.

It is evident more women are suffering from breast cancer yet fewer are dying as a result (Stephen Haplin, personal communication, May 2003). As there are more women eligible for breast reconstruction there is an increased need to provide further information to women considering this option. Transverse rectus abdominis musculocutaneous (TRAM) flap breast reconstruction has rapidly become the most popular form of autologous breast reconstruction, therefore research into women's experiences of this procedure and its effects on self-esteem and body image will assist to clarify the inconsistencies of previous research.

The review of published research highlights the impact breast cancer can have on the psychological and emotional aspects of a woman's quality of life. All aspects of the psychosocial experience of breast reconstruction explored in the review indicated contradictory findings. This could potentially lead to further confusion for women considering this treatment option, particularly at a time when the decision making process is already under stress. Education became a necessary inclusion in this study's framework, as evidenced by the obvious impact of education discovered in the literature. A qualitative focus group study by the NBCC (2002) found women felt information was inconsistent and lead to confusion regarding treatment options. Harcourt and Rumsey (2001) recognised the inconclusiveness of current research and called for more theoretically based studies to further investigate psychological effects of breast reconstruction.

Breast reconstruction is argued to improve psychological outcomes for women. Despite this, the studies reviewed highlight contradictory results. It is important to acknowledge this, despite possible methodological reasons for this discrepancy. Breast reconstruction is but one aspect of a woman's breast cancer experience. Many other factors related to the diagnosis of breast cancer may impact on these results. Despite these discrepancies, breast reconstruction uptake is on the increase. The need for women to be adequately prepared and to have realistic expectations of the outcomes of these procedures has been highlighted. There is still much we do not know about the experience of women undergoing TRAM flap breast reconstruction.

2.11 Summary

This literature review investigated current research findings related to the experience of breast reconstruction, in particular that of TRAM flap breast reconstruction. The psychological impact of breast cancer diagnosis and subsequent primary breast cancer surgery was highlighted. An overview of breast reconstruction methods, with a specific focus of TRAM flap breast reconstruction, was undertaken. The literature review highlighted the complexity of the physical, mental and emotional impacts that breast reconstruction incurs. These concepts were particularly related to psychological impact, body image, self-esteem and sexuality.

The analysis of this literature review has become validation for further research in this area. From this literature review it has been demonstrated the findings within current literature show differing and at times inconsistent results. Few studies have focused on the TRAM flap breast reconstruction experience, despite this becoming the most common breast reconstructive procedure. Of the studies and professional opinion presented in this literature review, few are Australian sources. The majority of research studies relating to this primarily subjective topic are of quantitative research design. Further clarity of the impact of TRAM flap breast reconstruction on women's psychosocial health is needed within a representative setting of Australian practice.

TABLE 1; SUMMARY OF THE LITERATURE

AUTHOR	SAMPLE	METHODOLOGY	TOOLS/METHOD	KEY FINDINGS	COMMENTS
Al-Ghazal et al, 2000.	577 participants; 254 BCS, 202 mastectomy, 121 breast reconstruction.	Quantitative study assessing psychological aspects of patient satisfaction.	Hospital Anxiety and Depression Scale (HADS), Rosenberg Self-Esteem Scale (RSES), self devised Likert scales on satisfaction and sexual attractiveness.	Greatest satisfaction and sexual attractiveness found to be highest in BCS group, then reconstruction group, lowest in mastectomy group. Some degree of anxiety experienced in 69% of mastectomy group, 55% of reconstruction group, 38% of BCS group. Depression experienced in 10% of mastectomy group, 2% of reconstruction group, 7% of BCS group. Body image and self-esteem scores were highest in BCS group, then reconstruction group, lowest in mastectomy group. Concluded that breast reconstruction can provide benefit over mastectomy.	Authors do not define variable of 'some degree of anxiety'. More references pre 1990 than post 1990.
Yurek et al, 2000.	190 participants; 78 BCS, 83 mastectomy, 29 breast reconstruction.	Descriptive, quantitative study using various tools within a structured interview, to compare sexuality and body change stress between groups.	Sexual Self Schema Scale for Women, Breast Impact of Treatment Scale (BITS), Body Satisfaction Scale (BSS).	Reconstruction group had the lowest rates of activity and sexual responsiveness. Equivalent levels of distress found between mastectomy and reconstruction groups, being higher than that of BCS group. Lowest body satisfaction scores in mastectomy group.	Validated tools. Part of a parent study. Write up included a thorough critique of the current literature.
Contant et al, 2000.	103 women undergoing breast reconstruction with silicone implants.	Quantitative questionnaire study on motivations, satisfaction and information of immediate breast reconstruction patients.	Self report questionnaire partly developed by the authors and consisting of parts of the Rotterdam Symptom Check List (RSCL).	Satisfaction strongly correlated with the need for information. 70% of participants were satisfied with their breast reconstruction. Concluded sexuality does play a role in the reconstruction decision.	Although this study is not TRAM specific, it does investigate the reconstruction decision and factors determining satisfaction with immediate breast reconstruction. Does not explain or validate the development of the questionnaire. Minimal recent references.
Contant et al, 2000.	103 women undergoing breast reconstruction with silicone implants.	Quantitative questionnaire study on motivations, satisfaction and information of immediate breast reconstruction patients.	Self report questionnaire partly developed by the authors and consisting of parts of the Rotterdam Symptom Check List (RSCL).	Satisfaction strongly correlated with the need for information. 70% of participants were satisfied with their breast reconstruction. Concluded sexuality does play a role in the reconstruction decision.	Although this study is not TRAM specific, it does investigate the reconstruction decision and factors determining satisfaction with immediate breast reconstruction. Does not explain or validate the development of the questionnaire. Minimal recent references.

AUTHOR	SAMPLE	METHODOLOGY	TOOLS/METHODS	KEY FINDINGS	COMMENTS
Elliott et al, 1993.	128 participants; 86 pedicled TRAM flaps, 40 free TRAM flaps, 2 supercharged TRAM flaps.	Prospective study monitoring the complications of immediate TRAM flap breast reconstruction.		Free TRAM flap is superior due to lower complication rates. Free Tram group had 63% 'high risk' patients with only a 9.5% complication rate, while the pedicled TRAM flap group had 28% 'high risk' patients with a complication rate of 28%.	Does not state specific process of data collection. Article was predominantly narrative of the procedure itself. Extended research period (1985-1990), during which time further surgical improvements were being made thus affecting complication rates associated with TRAM flap surgery.
Neill & Briefs, 1997.	3 Plastic surgeons spanning demographically from east to west coast of USA.	Qualitative study of structured interviews, two face-to-face, one self recorded response, regarding factors influencing advice given to women about breast reconstruction.	Structured interview.	5 themes; 1. technical issues and challenges. 2. patient centred challenges. 3. aids to patient decision making. 4. illusion of no loss. 5. age Time constraints greatly affect the consultation process.	Pilot study. Is this study's small sample representative of such a large area? Self recorded interview may allow for development of bias or predetermined answers within data.
Reaby et al, 1994	95 participants; 64 prosthesis, 78 control group- not having had mastectomy, 31 breast reconstruction.	Mixed method study comparing self-esteem, self-concept and body image between groups.	Interview, RSES, Polivy body image scale.	Greatest satisfaction levels with outcome were found in the reconstruction group. Reconstruction group had a higher self-esteem than the other two groups. Nil significant difference in body image or self-concept between groups was found. Control group had more negative perceptions of self.	Australian study. Control group was not interviewed and demographic data was not collected. This inconsistent data collection did not allow for explanation of the control groups results.
Al-Ghazal et al, 1999.	254 women who had undergone BCS.	Quantitative, objective study questioning if cosmetic outcome of breast surgery influences psychosocial morbidity.	Objective measurement of nipple retraction and deviation. Subjective scoring of aesthetic outcome by a panel of 2 breast surgeons, 1 plastic surgeon, 1 breast care nurse and a male and female not related to the area in question. HADS, RSES, body image questionnaire.	Concluded the cosmetic result achieved impacts on psychological outcome. Strong correlation found between cosmesis and the variables of anxiety, depression, body image, self-esteem and sexuality.	Results shown to be statistically significant. Further prospective study recommended to explore the direction of causality between well being and cosmesis.

AUTHOR	SAMPLE	METHODOLOGY	TOOLS/METHODS	KEY FINDINGS	COMMENTS
Mock, 1993.	257 participants; BCS, mastectomy, immediate and delayed breast reconstruction groups. (N= not specified).	Quantitative, mailed questionnaire assessing body image in women treated for breast cancer.	BIS, Tennessee Self-concept Scale (TSCS), Body Image Visual Analogue Scale (BIVAS).	BIVAS showed BCS group had higher body image scores than mastectomy or reconstruction groups. BIS and TSCS showed nil significant difference between groups.	Multi centre study. Does not specify participant group numbers thus showing representation within the study. Methodologically weak- BIVAS gives only significant findings, yet is the only tool not to be validated.
Nissen et al, 2002.	17 participants having immediate breast reconstruction; 8 implant reconstructions, 9 TRAM flaps.	Qualitative study assessing quality of life after breast reconstruction.	Focus group interview.	Women chose breast reconstruction for physical and psychological reasons related to anticipation of mastectomy. Identified a strong need for more education. Moderate to high level satisfaction with breast reconstruction, however final appearances were often lukewarm. Breast reconstruction helped women gain a sense of normality.	Recent study of well represented results. Larger sample size in future research would increase transferability and therefore validity of results.
Al-Ghazal et al, 2000.	121 participants; 36 implant, 23 tissue expander, 13 Latissimus dorsi, 4 TRAM flap breast reconstructions. 32 of these participants underwent immediate reconstruction, 62 had delayed reconstruction.	Quantitative study comparing the psychological impact of immediate and delayed breast reconstruction.	HADS, RSES, BIS.	8% of the immediate reconstruction group felt less sexually attractive compared with 32% of the delayed reconstruction group. Anxiety and depression rates were lower in the immediate reconstruction group. Body image and self-esteem scores were higher in the immediate reconstruction group.	Small number of TRAM flap participants in relation to other group numbers. Small sample of immediate reconstruction patients compared with delayed reconstruction patients, possibly leading to the overstatement of findings.
Yeh et al, 1998.	62 participants; 36 TRAM flap, 7 Latissimus dorsi, 4 implant, 15 tissue expander immediate breast reconstructions.	Medical record audit study assessing morbidity and outcome of immediate breast reconstructions.	Review of medical records during recovery period from reconstructive breast surgery.	Those undergoing prosthetic breast reconstruction had higher rates of major complications. Obese patients were found to be more likely to develop major complications.	Dated references. The accuracy of hospital documentation should be questioned.

AUTHOR	SAMPLE	METHODOLOGY	TOOLS/METHODS	KEY FINDINGS	COMMENTS
Neill et al, 1998.	11 participants; 6 TRAM flap, 4 saline implant, 1 silicone implant breast reconstruction.	Qualitative study analysing the process of choosing breast reconstruction following mastectomy.	Individual interviews, with one to two follow up interviews six months later.	'Getting my life back' became the goal of breast reconstruction. 3 main themes; 1. 'information seeking' - women required more information. 2. 'talking it over' - in an attempt to clarify and reinforce decisions. 3. 'seeking normality' - strong focus of the reconstruction process. Reconstruction was found to minimise the negative effects of breast cancer and it's treatment.	Follow up interviews allowed for thorough data collection.
Wilkins et al, 2000.	273 participants; 56 implant, 128 pedicled TRAM flap, 66 free TRAM flap breast reconstructions. 161 of these participants underwent immediate reconstruction, 89 had delayed reconstruction.	Quantitative, prospective, questionnaire study of the psychosocial outcomes of breast reconstruction.	Medical Outcome Study Short Form-36, Functional Assessment of Cancer Therapy- Breast. Completed questionnaires pre- operatively and one year post-operatively.	Delayed reconstruction group had lower pre-operative body image scores, however demonstrated higher levels of pre-operative functioning. Immediate reconstruction group did not show significant changes in body image. Delayed reconstruction group demonstrated a particularly significant gain in body image scores.	
Kroll et al, 1995.	237 participants; 68 women had free TRAM flap breast reconstruction and 169 pedicled TRAM flap breast reconstructions	Descriptive, subjective study comparing factors affecting aesthetic outcome of different methods of TRAM flap breast reconstruction.	Aesthetic scores were given to each participant by a panel of 9 independent judges, none of whom were a part of the reconstructive team.	Bilateral TRAM flap breast reconstructions were found to be superior to unilateral ones. Immediate TRAM flap breast reconstructions received superior aesthetic scores to delayed TRAM flaps. Free TRAM flap breast reconstructions were given higher aesthetic scores than the pedicled method, however this was not statistically significant. Women who had completed revision procedures received higher scores.	All TRAM flap breast reconstructions in the study were performed by the one surgeon. The 'independent' judges identity was not specified. Authors recognised that multiple regression analysis rendered findings of superiority of free TRAM flaps insignificant.

AUTHOR	SAMPLE	METHODOLOGY	TOOLS/METHODS	KEY FINDINGS	COMMENTS
Pedro, 2001.	62 participants; not cancer site specific.	Quantitative study of the quality of life of long-term survivors of cancer.	RSES, Rosenbaum Self Control Schedule (RSSS), Norbeck Social Support Questionnaire (NSSQ), Quality of Life Index- Cancer Version.	There was a positive correlation between self-esteem and health related quality of life. Social support influences health related quality of life. Concluded that self-esteem was the greatest predictive factor for health related quality of life.	This study highlights the importance of self-esteem on quality of life, although is not cancer specific. Several validated tools have been used resulting in thorough testing of the variables.
Harcourt et al, 2003.	103 participants; 56 mastectomy, 37 immediate breast reconstructions, 10 delayed breast reconstructions.	Prospective quantitative study investigating the psychological effect of mastectomy with or without breast reconstruction.	Semi-structured interviews, HADS, BIS, European Organisation for Research and Treatment of Cancer- Quality of Life Questionnaire (EORTC-QLQ-C30). Participants were tested pre-operatively, then at 6 and 12 months post operatively.	Psychological distress was found to decrease in all groups one year post operatively. More than one quarter of participants felt they had not been given sufficient information about their situation. Reports of feeling comfortable when fully dressed at 6 months and 12 months respectively= Mastectomy; 62.8% - 68.4%, Immediate reconstruction; 75.9% - 62.1%, delayed reconstruction; 28.6% - 83.3%. There was no significant difference in satisfaction found between groups, however scores improved for the delayed reconstruction group, remained static for the mastectomy group, and decreased in the immediate reconstruction group.	Multi-centre study. Prospective, follow up methods of data collection substantiates the results. Does not specify method/s of breast reconstruction studied.

CHAPTER 3

CONCEPTUAL FRAMEWORK

This chapter identifies the conceptual framework utilised for this study. Roy's Model of Adaptation was chosen to guide this study. The concepts inherent in this theory will be explained and their application to the study will be discussed.

Although this study is specifically exploring the impact of TRAM flap breast reconstruction, the experience of being diagnosed with breast cancer and undergoing a mastectomy will also be discussed within the context of this conceptual framework. It was identified by the women in this study that it was not possible for them to separate the breast cancer and breast reconstruction experience (see Chapter Five). Roy's Model of Adaptation is applicable to both experiences and therefore will both be explained within this context.

3.1 Conceptual framework

Roy's model of adaptation was utilised in this study as it focuses on the constant adaptive process inherent with the changing facets of life related to breast cancer diagnosis, surgery and breast reconstruction.

Roy's model of adaptation was developed by Sister Calista Roy in 1964, and was first published in 1970. It has since become the favoured curriculum of conceptual frameworks for undergraduate nursing students across the world (George, 2002). This theory based conceptual framework was chosen for inclusion in this study as it illustrates the processes a person dealing with illness may undergo, whether these are dealt with positively or become maladaptive, and the nursing role inherent during this time. Within the context of this study, this refers to women dealing with breast cancer diagnosis, subsequent mastectomy and TRAM flap breast reconstruction.

Roy defines adaptation as 'the process and outcome whereby thinking and feeling persons, as individuals or groups, use conscious awareness and choice to create human and environment integration' (George, 2002, p.296). The woman choosing breast reconstruction after mastectomy creates a new environment that she must live within. A changing body image, effect on self-esteem, interpersonal relationships and role identity are just a few issues these women will encounter.

Roy drew from the works of Von Bertalanffy's general systems theory (1968) and Helson's adaptation theory (1964), to define the scientific and philosophical assumptions of her conceptual framework. In summary, Roy's scientific assumptions followed the idea that human awareness is derived from thinking and feeling, which in turn mediates human action. Decisions made are accompanied by an inherent accountability for the integration of creative processes. Philosophically, adaptation should focus on awareness, not a false consciousness. The aim of adaptation is to

achieve self-control, balance, quietude and faith (George, 2002, p.296-298). The decision to reconstruct a lost breast does not eradicate the need to deal with the diagnosis of cancer and its subsequent treatment. Adding to this is the need of adaptation to the woman's revised physical, social and emotional being.

There are *four major concepts* of Roy's model of adaptation:

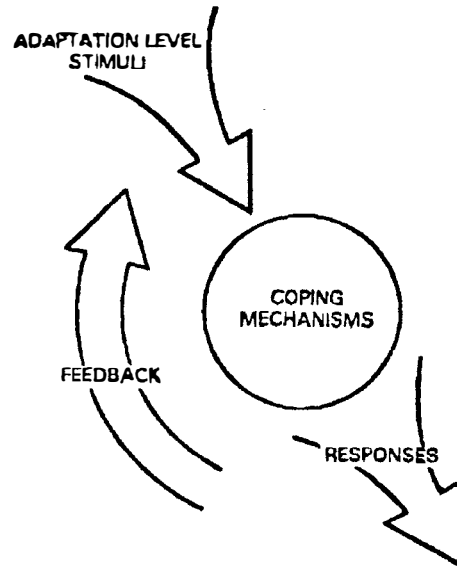
1. Humans as adaptive systems;
2. Environment;
3. Health; and
4. The goal of nursing.

Humans as adaptive systems applies to both individuals and groups. Roy adopts a holistic approach of the human system being greater than the sum of individual parts. Characteristics of the human adaptive system include inputs in the form of stimuli, control processes resembling coping mechanisms, and outputs in terms of behavioural responses (see Figure 1) (George, 2002, p.299-300). These inputs are both external and internal in nature. To illustrate this Roy defined three types of stimuli. The first is focal, that is the issue immediately confronting the individual. Secondly are contextual stimuli referring to all other stimuli present and relevant to the immediate issue at the time. Thirdly, residual stimuli are factors that the individual brings into the situation, for example, attitudes, beliefs, past experience and characteristic traits (Fraser, 1990). For the woman with breast cancer the focal stimuli are the diagnosis of cancer and the issues associated with death and dying, along with the anticipated loss of a breast.

Contextual stimuli include issues regarding self-esteem and body image impacts incurred by mastectomy, the choice to undergo breast reconstruction, adjuvant therapy, relationships, support and coping mechanisms, and family and situational context at that time. Residual factors include attitudes to death and dying, past hospital experiences and previous utilisation of coping mechanisms.

The aim of adaptation of the human system is to demonstrate integrity and wholeness by being able to meet the goals of survival, growth, transformation of the system and environment, and its mastery. Maladaptive responses do not achieve this goal and threaten the human systems survival and growth (George, 2002). Within the context of breast cancer, maladaptive responses refers to women feeling unable to cope within their current situation, therefore affecting their ability to function satisfactorily within their everyday lives. Deciding to undergo breast reconstruction may be an adaptive response to counteract the maladaptive consequences of mastectomy.

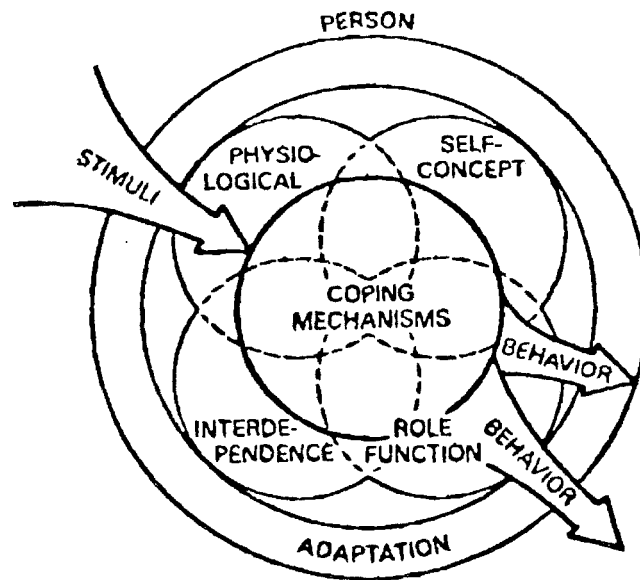
Figure 1; Components of the human as an adaptive system.



(George, 2002, p.300).

Adaptation is seen through *four adaptive modes* (see Figure 2). All modes are interrelated and therefore change will require adaptation in more than one mode (Fraser, 1990, p.64).

Figure 2; Four adaptive modes.



(George, 2002, p.305).

A) Physiological: This mode comprises of a persons physical response and interactions with the environment. It is formally composed of the basic needs of survival including oxygenation, nutrition, elimination, activity, rest and protection (George, 2002, p.305-306).

In terms of breast reconstruction, the woman must consider the immediate intensive recovery period of TRAM flap breast reconstructive surgery and the physical restrictions incurred over the extended recovery period of approximately six to eight weeks. These physiological consequences of breast reconstruction may effect a woman's functioning in everyday life.

B) Self-concept mode: This mode looks at a person's need for psychic and spiritual integrity or the need to know oneself with a sense of unity. It consists of a person's beliefs or feelings about herself at any given time. It is divided into two subgroups, physical and personal. Physical refers to body sensation, body image, sexual function and effective coping strategies for loss. The personal refers to self consistency, self ideal, moral/ethical/spiritual self, self-esteem and effective interpersonal relationships (George, 2002, p.306-307).

For a woman with breast cancer receiving a TRAM flap breast reconstruction this mode is of particular importance. As mentioned in the literature review, women often commented on the need to feel 'wholeness' about themselves. Concerns often focus on the sensation of the new breast and intimate relationships with significant others including the issue of sexual function. Body image and self-esteem are drastically affected as a result of the alterations to one's self-concept, this being the focus of this study.

C) Role function mode: This mode focuses on social integrity, that is, knowing who one is in relation to others. Social integrity is derived from a set of expectations of how a person in a particular situation will behave in relation to another person who holds another position. This mode involves the concepts of role clarity, role transition, role performance and coping with role changes (George, 2002, p.307).

D) Interdependence mode: This mode applies to the integrity and security of nurturing relationships. It involves the giving and receiving of love, respect and value with significant others and support systems. Adaptive behaviour results in an effective pattern of dependence and independence (George, 2002, p.307).

These last two modes are also distinctly pertinent for a woman undergoing a TRAM flap breast reconstruction. Due to an altered body image women often feel apprehension related to significant others viewing their body postoperatively and the related implications on intimacy. Their role as a woman has been changed by the cancer and subsequent surgery and must be redefined and accepted by others, this often resulting in changing relationship dynamics.

Environment is defined by Roy as ‘all conditions, circumstances and influences that surround and affect the development and behaviour of humans as adaptive systems, with particular consideration of person and earth resources’ (Roy & Andrews, 1999, p. 52).

Health is ‘a state and a process of being and becoming an integrated and whole human being’ (Roy & Andrews, 1999, p. 54). This definition of health for the purpose of this conceptual framework transcends the simple absence of disease.

The goal of nursing is the promotion of adaptive responses in relation to the four adaptive modes. The nurse does this by first assessing behavioural responses and their

stimuli. It must be noted that coping mechanisms are not always observable, however these can be assessed through behavioural responses that can be observed, measured or subjectively reported on. The nurse should then compile a nursing diagnosis of maladaptive coping mechanisms and responses. Goals should be set with the patient. Intervention includes modification or removal of stimuli. In some cases this is not possible, however effective coping mechanisms can be taught and monitored. Evaluation of the intervention should also take place (Alligood & Marriner-Tomey, 1997, p.179-181).

It is not the intention of this study to intervene as described above. It is however applicable to use this conceptual framework as the researcher is able to describe and explain the experiences of women encountering this unavoidable process of adaptation when undergoing breast reconstruction. It gives a basis for understanding the challenging process a woman in this situation encounters, and enables the researcher to report on the positive and/or not so positive responses to this transition.

The strengths of this model include its holistic focus on all facets of the person as a whole. It is logically organised and easily applicable. Its use in nursing research has been well established.

3.2 Summary

This chapter discussed the application of an established nursing theory used to guide the study. The theory discussed substantiates the methodology used and highlights the concepts applied to guide the collection of data derived from the interviews. Further, Roy's Model of Adaptation was used as a tool to guide and prepare the researcher for discussion of possible issues related to the experience of breast cancer and breast reconstruction.

CHAPTER 4

METHODOLOGY

This chapter will outline the process and methods utilised to conduct this study. The research design will be presented, and participants and their recruitment into the study will be outlined. The theoretical perspectives underpinning the methodology, and the tasks of data collection and analysis will be discussed. Rigour and ethical considerations will also be addressed.

4.1 Research Design

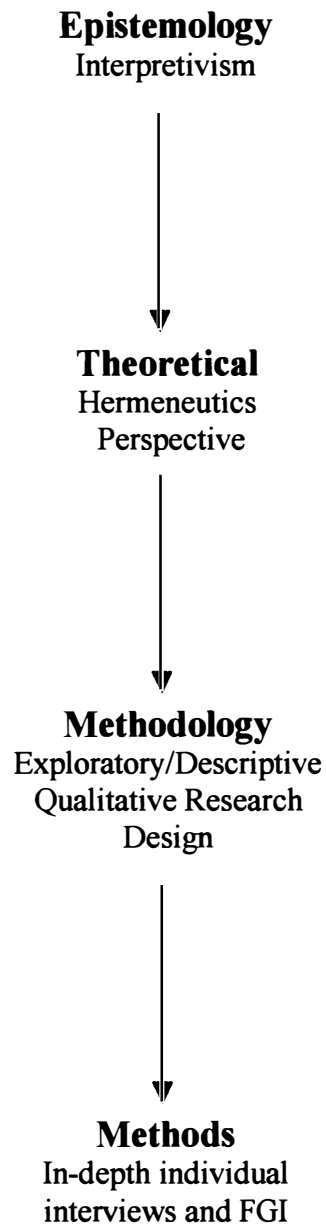
This study is a qualitative, exploratory and descriptive research design. This methodology was chosen for its appropriateness to the research question. Qualitative research involves a 'systematic, subjective approach used to describe life experiences and give them meaning' (Burns & Grove, 1993, p.35). Within the context of this study the qualitative data is the detailed verbal descriptions collected by the researcher, through interviews with participants. Exploratory/descriptive methodology acknowledges the complexity and uniqueness of human experience, and the importance of studying these experiences from a subjective perspective. Exploratory/descriptive research design supports the approach that recognises the need to study people holistically. This is important as the experience of breast cancer diagnosis, mastectomy and subsequent breast reconstruction affects all facets of the person as a whole. The

aims of this study are to explore and describe these experiences. This design was pertinent to the objectives of this study as it allowed the exploration of experiences, in detail and depth, from the perspective of the women who have lived the experience.

4.2 Theoretical perspectives

Crotty (1998) outlined four crucial elements of the research process. The first of which is epistemology, which refers to the knowledge that directs, guides and informs the theoretical perspective of the study. It is the theoretical perspective that determines the methodology and subsequent methods of the research study. These concepts are demonstrated in Figure 3.

Figure 3: Elements of the research process utilised within the study



(Crotty, 1998, p.4)

The theoretical framework for this study will incorporate the appropriate and relevant theoretical perspectives of Interpretivism and Hermeneutics. These historically embedded, semantic concepts guided the processes involved in this study and provided a contextual base for data analysis.

Interpretivism evolved with the purpose of attempting to understand and explain human and social reality. It is specifically linked to the cultural origins and historical interpretations of the social life world (Crotty, 1998). The first major pioneer of interpretivism was Max Weber, who outlined that the basic process of interpretivism involved contrasting the 'interpretive' approach of understanding needed in the human and social sciences, with the 'explicative' approach of explanation that is found in the natural sciences (Crotty, 1998).

Heinrich Rickert and Wilhelm Windelband recognised a 'logical distinction' by the mind, between the human/social sciences and the natural sciences. They theorised the natural sciences as looking for consistencies, regularities and the 'law' that obtains, naming this scenario '*nomopathic*'. Where as, the human sciences being concerned primarily with the individual, naming this '*idiopathic*'. Wilhelm Dilthey furthered this view, arguing that there is a substantial difference between the two sciences, and therefore there was a need for different methodologies to guide investigation (Crotty, 1998, p. 67).

Despite the differing views within the field at the time, Weber's perspective was most widely and credibly accepted. Weber defined sociology as 'a science which attempts the interpretive understanding of social action in order thereby to arrive at a causal explanation of its course and effects'. To this end Weber argued, he was only willing to accept causal explanation if, on the basis of past experience, it appears probable that it will always occur in the same way (Weber, 1968, p. 3). He attempts to explain and understand human experience through interpretivism, naming this ideal exploratory understanding (Weber, 1962).

Interpretivism applies to this study as its aim is to gain further understanding of women's experiences with TRAM flap breast reconstruction, and through their description of experiences, identify and explain the psychosocial impact this procedure has on self-esteem and body image for women with breast cancer. This study used idiopathic context to identify nomopathic application of TRAM flap breast reconstruction on self-esteem and body image. However, there was no attempt in this study to identify causal explanation or direction.

While interpretivism refers to the principle of data analysis, hermeneutics refers to the specific processes of thematic identification. Hermeneutics came into modern use in the 17th century by providing guidelines for scholars within the science of biblical interpretation. The processes of these guidelines involved theories, principles, rules and methods, known as hermeneutics (Crotty, 1998).

Hermeneutics is derived from the Greek word 'hermeneuein', meaning to 'interpret and understand with the aim of rendering it familiar, present and intelligible' (Palmer, 1969, p. 12-14). More recently hermeneutics has been applied to unwritten sources also, such as human practices, events and situations. Medieval philosophers signify the application of hermeneutics to unwritten sources by identifying that the way things are, (*ordo essendi*), shapes the way we perceive things, (*ordo cogitandi*), and this is expressed in the way we speak, (*ordo loquendi*). In modern times this order has been modified to believe *ordo loquendi* shapes *ordo cogitandi* and also *ordo essendi*. This emphasises that language is crucially important to the situations people find themselves in, events that occur, the practices they carry out and ultimately the understandings they are able to reach (Crotty, 1998).

Freidrich Schleiermacher is well noted as the founder of modern hermeneutics. His focus was on incorporating empathy into the interpretation of experience. By using empathy the researcher can extract more useful information. The interpreter should ultimately attempt to enter the mind of the person and recognise their standpoint, even if it may not be the same as the interpreter's, in the hope of identifying how the person arrived at it and what formed its basis (Crotty, 1998, p. 92-93, 108).

Wilhelm Dilthey, Schleiermacher's biographer, focused on life and history as inseparably intertwined. He identified historical and social contexts as the major sources of interpretive understanding. He recognised that the passages humans write, the language they speak, the art work they create, and the actions they perform are all

expressions of meaning, and that these expressions ultimately reflect the period of these people's times. Dilthey postulates that human understanding can never exhaust the real, and that our worldview that guides our actions is not embedded in intellect, but in life. Accordingly, Dilthey aims to elaborate on a methodology for gaining objective knowledge and avoiding philosophies that fail to take into account the focus of the historical nature of the world and our place within it. His sociological focus on hermeneutics saw empathy replaced by cultural analysis (Crotty, 1998, p. 93-95).

The hermeneutic circle is integral to the process of understanding, which hermeneutics focuses on. This is a method of interpretation, requiring the relating of whole meanings to parts and back to whole again, and being able to move freely between parts and whole (Crotty, 1998, p. 92). This is representative of the process of analysis and synthesis. This process results in initial understanding leading to further development of understanding, thus illuminating and enlarging initial understanding.

In conclusion, hermeneutics is a means of deciphering indirect meaning and revealing hidden meanings (Kearney, 1991). It identifies a possibility of gaining understanding deeper than the subject's own recognised understanding. Hermeneutics is definitely a tool to help achieve authenticity of interpretation and richness of meaning (Crotty, 1998).

Hermeneutics is applicable to this study as the aim of this study is to interpret and understand the psychosocial experiences of women undergoing TRAM flap breast

reconstruction. This understanding was developed by in-depth exploration of women's experiences, their reflections and thoughts on this experience. As the way individuals speak reflects their perception of events, individual and focus groups interviews were used to explore women's perspectives. The concept of the hermeneutic circle was applied to the analysis of the data, breaking down the concept of psychosocial impact into various areas including self-esteem, body image, sexuality, relationships, education, support and recovery situation. These were each analysed and given meaning to, and then synthesised to identify the realm of psychosocial impact TRAM flap breast reconstruction had on these women.

4.3 Research Question

“What is the impact of TRAM flap breast reconstruction on self-esteem and perceived body image for women with breast cancer?”

4.4 Participants

Participants for this study were women who had undergone a TRAM flap breast reconstruction procedure following mastectomy for breast cancer, between January 1st 2001 and January 1st 2003 at a private hospital. Timing of the breast reconstructive surgery included in the study's framework was that of both immediate and delayed reconstruction. All women participating in this study must have had at least a six-month, up to two year period since their breast reconstructive surgery to allow for

diversity of the staging of recovery from TRAM flap breast reconstruction surgery. Both surgical methods of TRAM flap breast reconstruction, free and pedicled (see Chapter Two), were included in the study, as the difference in surgical method was not anticipated as a direct influential factor of the outcomes proposed to be studied. Approximately eighty-two women were identified as having undergone this procedure during the applicable time frame. To be eligible to participate women were required to be English speaking and over 18 years of age in order to give written informed consent.

4.5 Recruitment

Formal approval to include their patients in the study was obtained from all four plastic/reconstructive surgeons performing TRAM flap breast reconstructions at the hospital during the proposed time period. Each surgeon was exceptionally supportive of this research project, highlighting the surgeons vested advocacy and recognition of the importance of psychosocial issues related to TRAM flap breast reconstruction. Once ethical approval was granted by both Edith Cowan University and the hospital, information packages were sent out to eligible participants. These packages were forwarded to eligible women through their plastic/reconstructive surgeon's office in order to maintain patient anonymity from the researcher. The surgeons provided a cover letter (Appendix 1) outlining the purpose of the study and assuring women they were under no obligation to participate. An information form (Appendix 2A) explaining the study and what participation would involve was also included in the package.

Women who were interested in participating were invited to contact the researcher by phone with any queries, and return the consent form (Appendix 3) to the researcher in the stamped self-addressed envelope provided.

Eighty-one letters of invitation were distributed, with a response rate of 65% achieved. Ten participants were required to complete the study. Purposive sampling was undertaken to recruit an even sample of both delayed (5) and immediately (5) reconstructed patients. A small portion of women who live in the rural community were also purposively chosen (2), in order to give a representation of the experiences of living within this setting. Purposive recruitment was not related to which surgeon performed the surgery, however patients of all four surgeons were included. Women were contacted by telephone and interview times were arranged.

Women who had expressed an interest and were not included in this study were contacted regarding the completed participant selection and thanked for their interest. These women were notified of the intent for further research in this area to be conducted by the researcher, and all verbally consented to be recontacted regarding this at a later time.

4.6 Study participant demographics

Fifty three of the eighty one potential participants responded to the initial letter of invitation, giving a 65% response rate. Ten participants were selected from the

respondent group. The participant sample consisted evenly of women who had immediate (5) and delayed (5) reconstruction. The time lapsed since undergoing TRAM flap breast reconstruction ranged from ten to thirty-one months, with an average time frame of eighteen and a half months. Nine women were married, while one woman had been widowed prior to her breast cancer experience. The mean age of participants was forty-eight and a half years, with ages ranging from thirty-nine to fifty-nine years. Six of the participants had undergone adjuvant therapy, five women receiving chemotherapy and one woman undergoing radiation therapy. Two of these women also commenced hormone therapy. Four women commenced their adjuvant therapy prior to breast reconstruction, while two women who chose immediate reconstruction underwent adjuvant treatment post TRAM flap breast reconstruction. Five of participants suffered complications when recovering from TRAM flap breast reconstructive surgery. Two women encountered minor complications, while three suffered major complications, those being defined as requiring surgical intervention or rehospitalisation. One woman's TRAM flap failed and a subsequent permanent implant was used to reconstruct her breast at a later time. Nine participants had undergone revision procedures by the completion of this study. Two women lived within a rural community, the other eight women living in the metropolitan area.

Table 2; Participant Demographics

	N=10
Married	9
Widowed	1
Metropolitan	8
Rural	2
Chemotherapy	5
Radiation Therapy	1
Immediate reconstruction	5
Delayed reconstruction	5
Viable tram flaps	1
Failed tram flaps	9
Revision procedures	9
Minor complications	2
Major complications	3

4.7 Data Collection

Two approaches to data collection were used. In depth, face-to-face individual interviews and focus group interview. Maccoby and Maccoby (1954) define an interview as a face-to-face verbal interchange in which the interviewer proceeds to elicit information or expressions of opinion or belief from the interviewee. Kahn and Cannell (1957) used a more specific definition describing interviewing as a specialised pattern of verbal interaction, undertaken for a specific purpose and focused on a specific topic, with subsequent elimination of extraneous material (Mischler, 1991).

Words make up the data of this research, via the data collection processes of interview and focus groups. The dissemination of findings will occur through the interpretive interactionism of transcripts (Roberts & Taylor, 2002).

4.7.1 Individual interviews

Interview is an appropriate form of data collection for this research study as reflection is the key to making sense of human existence, as lived experiences accumulate and are made sense of as they are remembered. Varying factors to the interview process include whether a question is phrased positively or negatively, the order or sequence of questioning, and particular social attributes, expectations and attitudes of the interviewer. Language is not a clear tool, perhaps like mathematics that can be used with precision (Mischler, 1991, p. 2). Answers may depend on the way a question is formulated and the wording of the question and the interviewers characteristics. Questions written as text in the interview schedule are often not executed as planned when asked in the interview setting (Mischler, 1991, p. 14).

Brenner (1982) argued that interview techniques used should not influence the answering of questions other than to facilitate the achievement of adequate responses. In order to achieve reliability and precision of data collection, interview techniques

should be clearly outlined before commencement of data collection procedures (Brenner, 1982). Interview techniques also need to be flexible as the development of an interview occurs through reformation and specification of questions, by which they take on particular context and shades of meaning (Mischler, 1991).

The individual interviews were organised to take place at a time and venue convenient for the participant. All individual interviews were undertaken at the residence of the participant, excluding one that took place at the home of the researcher, at the participant's request. A series of open-ended questions and prompts were used as specified in the interview schedule (Appendix 4). These questions were related to the experiences of breast cancer diagnosis, treatment decisions, reconstructive surgery experiences, and psychosocial outcomes related to breast cancer and breast reconstruction. This interview schedule was piloted with two women in a similar situation prior to the commencement of this study, with positive feedback and one or two minor amendments to phrasing. With participant permission these semi-structured interviews were tape-recorded. Interviews lasted between forty-five minutes to two hours.

4.7.2 Focus group interview

Participants were invited to further participate in the study by attending a focus group interview. Focus group interview has been described as a qualitative methodology that allows for the 'systematic study of the world of everyday experience' (Nyamathi &

Shuler 1990, p. 1282). The main feature of a focus group interview is that it reveals the attitude and perceptions of the participants in relation to the focus of the interview (Krueger, 1998), and that is the reason it was chosen for this study. The focus group interview allows for the collection of data in a non-threatening group environment and stimulates a spontaneous interaction between the participants that often provides a broader and more candid result.

As outlined by Nyamathi and Shuler (1990), focus group interviews are a crucially important tool for obtaining the insights, perceptions and attitudes of participants in a group interaction setting of dynamic atmosphere. Focus group interviews have the advantage of encouraging individual expression, group interaction and group identification of problems and their possible resolution (Krueger 1988). This is potentially important to this study.

Hansler and Cooper (1986) and Morgan (1988) outline the two main advantages of using the focus group technique: the potential to stimulate a spontaneous exchange of ideas, and the expression of views, attitudes and thoughts being less threatening in a group environment. These authors postulated a major disadvantage of this technique is that the findings cannot be assumed to be true of the whole community. Several researchers have raised concerns stemming from issues related to socialisation, such as forced compliance, the desire to fit in and the conflict between passive and active participants (Beck, Trombetta & Share, 1986; Hansler & Cooper, 1986; McQuarrie & McIntyre, 1987).

Because of the nature of the topic of this proposed research, focus group interviews have been included as they can be less threatening than the single interview for women. In providing a group environment it is hoped the women may be more relaxed and this would have a beneficial effect on the data collection. Focus group interviews are also a way of influencing in depth discussion. For example, once an issue is raised by one participant it could prompt a response and further discussion by the others.

A focus group interview was used to clarify and further define common issues identified from data analysis of the individual interviews, within a supportive network setting. This hermeneutical-like approach to data collection assisted in accurate interpretation of prevalingly subjective data, thus increasing reliability and validity.

The focus group interview was held at the hospital. Eight of the ten women in the study attended. The other two women notified the researcher of their inability to attend, one due to prior engagement and the other describing difficulty commuting from her rural residence. The focus group lasted for approximately two hours. The focus of discussion was regarding key concepts and issues identified from the individual interviews as per the focus group interview schedule (Appendix 5). Again with participant permission, the focus group session was tape-recorded. All tapes were transcribed verbatim in Microsoft Word format.

4.8 Data Analysis

The qualitative research data is in the form of words that make up texts, language and discourses that carry in them the meaning of human experience. Therefore, data analysis must be approached with respect for these people and their experiences. The anticipated outcome of this qualitative analysis will be that readers, who understand and value the knowledge-producing assumptions of qualitative research, deem the findings valuable.

Thematic analysis of the interviews and focus group was undertaken. This is a method of identifying themes, essences or patterns within a text. The grouping of themes and sub-themes allows descriptive interpretation of human experience, by deciphering explicit and implicit themes and their meanings (Roberts & Taylor, 2002). A manual approach to thematic analysis was used. A record of analytical progress has been kept by a tagging system known as thematic identification. This shows the pathway through which the researcher has made sense of the words and put them into some order for interpretation. This requires reading, looking and listening with wakeful alertness in order to appropriately identify relevant words, phrases, sections of dialogue, and gross and fine connections between parts of the transcript (Roberts & Taylor 2002). Transcripts were analysed separately and then were combined to identify common themes. It is here the hermeneutical approach of analysis and synthesis was used, discussed previously as the hermeneutic circle.

Firstly, accuracy of transcripts was checked. Each individual tape was listened to in order to familiarise and submerge the researcher within the data. Topics of discussion were identified and colour coded into the categories of diagnosis experience, body image, self-esteem, relationships/support, life impact and miscellaneous topics of importance to the women. All topics identified and discussed were able to be categorised into Roy's Model of Adaptation modes; physiological, self-concept, role function and interdependence. Commentary of discussion topics and related thoughts and feelings were added to transcripts. A summary of each individual transcript's topic identification and discussion was completed. The merging of these separate data analysis resulted in a listing of descriptive experiences associated with the experience of breast cancer, mastectomy and breast reconstruction. These anecdotal extracts were then used to explore and interpret important issues related to these women's experiences. Commonalities and differences were identified to develop emerging themes and sub-themes.

4.9 Rigour

Within a qualitative study it is important to uphold rigour in order to attempt to uphold validity and reliability of the processes of data collection and analysis. The term 'rigour' refers to the strictness in judgement and conduct of the researcher, thus demonstrating evidence of methodological accuracy and worthiness. It is important a researcher conducting qualitative research understands the concept and importance of rigour. The concept involves acknowledging the complexity of the research and it's

participants, and addressing relevance to participants concerns (Hall & Stevens, 1991). The researcher should be willing to let go of old ideas, (known as deconstructing), and be open to forming new ideas, (known as reconstructing). This process can often be evidenced by an audit trail (Burns & Grove, 1993). Rigour in qualitative data collection indicates what 'reliability' and 'validity' would in quantitative data collection (Roberts & Taylor, 2002).

Categories for determining rigour are identified by Sandelowski (1986) as credibility, fittingness, auditability and confirmability. Credibility refers to the extent to which recognition of the lived experience described in the research is similar to the participants. Fittingness is the extent to which findings fit into other contexts outside the study setting. This can be demonstrated by the degree to which readers find it has meaning and relevance to their own experiences. Auditability is demonstrated by the production of a decision trail to determine the extent to which the research project has achieved consistency in its methods and processes. By demonstrating credibility, fittingness and auditability, confirmability is achieved. It relies on the confirmation that the project establishes neutrality from the researcher's stated biases (Roberts & Taylor, 2002, p. 380).

In attempting to uphold rigour within this research project, a set of field notes were kept by the researcher. These included ideas of the expected and unexpected outcomes experienced throughout the data collection processes. Experiences with participants

during interviews and focus group were also noted. This assisted in demonstrating auditability and conscious exclusion of the researcher's biases, thus also aiding the practice of bracketing. The complexity of women's experiences was acknowledged and the discussion of these facilitated, with the semi-structure of the interview schedule and the flexibility within the interview process to discuss what topics women felt were important to them. Credibility was sought within the focus group interview via the processes of recognition and clarification.

4.10 Ethical Considerations

This study has been approved by Edith Cowan University and the hospital through which this study was conducted (Appendix 6 & 7). Several strategies were in place within this study to ensure the principles of research ethics were upheld. The information form included in the package explained the research, its aims and objectives, and risks and benefits to the participant (Appendix 2A). Informed written consent was obtained from all participants who agreed to contribute to the research (Appendix 3). Participants were also aware that participation in the interview and/or focus group would be confidential as personal details were coded and pseudonyms have been used throughout the transcripts and thesis publication. Participants were informed they may withdraw their participation at any time and this would have no impact on their relationship with their surgeon, or any health care provider. There were no physical risks identified as a result of participating in this research. However, due to the personal and somewhat emotive topics that were discussed, it was anticipated some

women may experience some level of emotional distress. To deal with this possible outcome all women who participated were given access to information on support and counselling services that are available from the Professional Counselling Service of the Cancer Foundation of WA if required (Karen Anderson, personal communication, March 2003). During the research process if a participant had become distressed, the interview would have been ceased immediately. The participant would be given the opportunity to withdraw, recommence after a short break or on another occasion. This intervention was not necessary during the process of data collection of this study. Benefit to the participant was anticipated to be received through discussion of their experiences within a supportive and familiar setting in the focus group. Several women participating in the focus group expressed this benefit.

The data will be stored secure at the university premises, along with the tapes for a period of five years after the date of publication of the research study, at which time they will be destroyed. The only people having access to the data were the researcher; Olivia Hill, supervisor; Associate Professor Kathryn White and two transcribers, undertaking this work at Edith Cowan University.

CHAPTER 5

FINDINGS

5.1 Introduction

This chapter will present the findings of this research within the context of achieving the aim of this study, which is to explore and describe women's perspectives of how the experience of TRAM flap breast reconstruction affected their psychological functioning, specifically within the areas of body image and self-esteem. This exploration was achieved through thematic analysis of the individual interviews and focus group interview. The following three main themes and their sub-themes emerged from the process of data analysis:

1. "Loosing A Breast Matters"
 - Recognising the impact of loss of a breast.
 - I am more than a breast.
 - Struggling to gain acceptance.
2. "Adjusting To A Changing Body Image"
 - Timing of breast reconstruction.
 - Situational factors influencing the process of adjustment.
 - Finding support throughout the process of adjustment.
 - Surgeon's acceptance and recognition of the women and their situation.
3. "Redefining Normality"

It is through these themes and sub-themes that these women's experiences will be described. Further discussion of these findings and their implications will be discussed in Chapter Six.

Throughout the process of data analysis it was clearly evident the experiences of these women living with breast cancer, and the subsequent surgeries, was immensely profound. For all women the impact of their experiences were expressed to be substantial and personally intense for them, but was also described as impacting on their families in many ways. The life changing impact of a diagnosis of cancer, regardless of its origin, has previously been well documented (Carpenter et al, 1999; NBCC, 2003). Similar findings were apparent for the women in this study. Although somewhat distinctive from each other, the breast cancer experience and the experience of TRAM flap breast reconstruction will be reported on jointly. Upon data analysis it became evident the women themselves were unable to separate the two experiences and viewed them as one ongoing experience. These women simultaneously dealt with the intensity of being diagnosed with a life threatening illness, coupled with the intimacy of the experience of losing a breast and undergoing breast reconstruction. The one experience being a decision made secondary to the consequence of the other. It was therefore felt the most accurate representation of these women's experiences would be achieved by reporting them together, in order to best describe the entire complexity of these experiences.

The findings of this study will be presented as a description of the experiences of the women under the headings of the themes and sub-themes derived from data analysis. Throughout the following chapters the women have been given pseudonyms to allow for anonymity. Sentence exemplars used will be indented, and single word exemplars will be italicised within the text to identify them as pertinent words describing the experience being reported. The importance of the use of exemplars is to explain the experiences using the women's own words to most accurately express their feelings and thoughts.

5.2 “LOOSING A BREAST MATTERS”

The theme “Loosing a breast matters” identified how the overall experience of the amputation of a breast was an immensely personal and significant experience for these women. The effects it had on psychosocial well being were described by the women as profound and somewhat unexpected. The women in this study highlighted concern that the feelings they endured regarding their experiences were not recognised by others for their intensity and the profound effect it had on their lives. From the interviews it became apparent that women found it difficult to express the extent of their feelings related to their experience of mastectomy and TRAM flap breast reconstruction, and that this sharing of experiences was not encouraged. The women commented that societal impressions served as a barrier to this expression and implied further pressure on them to cope with their situation. The concept that what was happening to these

women really did matter to them was hidden away from others and sometimes even suppressed from themselves.

This theme, through its sub-themes, explores how the impact and effect of the experiences encountered were not anticipated. Similarly, it highlights the women's extent of surprise in realising how important their breast was to them. This surprise is evident in the interviews as not only resulting from the mastectomy experience, but also at the time of diagnosis, and related to the anticipation of the effects of mastectomy for those who underwent immediate TRAM flap breast reconstruction. The women expressed feelings that society's attitudes towards their experience led to feelings of increased pressure to cope with their situation and a need to be identified as more than a breast.

Each participant describes their experiences by commencing their narrative at the time of diagnosis. This was the beginning of their journey and provides context and the broader framework for their experiences of TRAM flap breast reconstruction. All women discovered their breast cancer through routine mammogram or a self detected lump. One woman ignored her lump for several months highlighting no particular reason and expressed regret. Most women described the experience of the initial diagnosis of breast cancer as '*overwhelming turmoil*', '*a state of shock*'. Several women described their diagnosis as a '*surreal, out of body experience*', stating that it was like it was not really happening to them. Some women had a family history of breast cancer and stated they somewhat expected the diagnosis, however only in two

cases was this claimed to alleviate distress at the time of diagnosis. Several women commented that being told they had to have a mastectomy was more of a shock than the original diagnosis. Although, one woman who had a mastectomy after an initial lumpectomy reported she coped better with that news than the news of her original diagnosis, attributing this to her previous experience of personal stress.

When dealing with the diagnosis of breast cancer the women in this study described experiencing emotional distress. Gina describes her reaction at the time of diagnosis:

“Disbelief. I just went numb...I remember just trembling. I was just shaking...I remember rolling over onto my side and just curling up, and I knew I was in the foetal position but it was all I wanted... I think I did go into shock”.

(Gina)

Anne and Stephanie describe a state of disbelief at their diagnosis:

Anne:

“It’s like an out of body experience, it’s not happening to you”.

Stephanie:

“It was almost like twilight zone. It’s like you’re not really there, but you’re there, like is this really happening or isn’t it?”

Several women described episodes of depression resulting from the news of the breast cancer diagnosis and the anticipation of what would follow. Comparatively, Paula was the only woman who denied any distress and described her diagnosis as a '*nuisance*' and '*inconvenience*'.

“We just thought ‘Oh well, there you go. Life’s like that. Get on with it’. Don’t have too many options there. I can’t see any alternatives. It wasn’t too bad”. (Paula)

Paula initially described minimal effect on her life, however later contradicts this to describe significant impacts of surgery, both positive and negative. This indicated that perhaps the experience was more devastating than she verbalised when asked.

Some women told of feeling lucky the breast cancer had been detected when it had. Gina described feeling '*robbed*' and reported this gave her motivation to fight the cancer:

“I just felt that I was going to be robbed. And my attitude was ‘No, you’re not going to take this away from me. I’ve waited so long to have my four perfect kids and my perfect family...This can’t be happening, you can’t take this away from me now’”. (Gina)

Few women stated they could not cope with the diagnosis and experienced varying forms of depression as a result. Pre-existing life issues producing stress, accompanied with minimal support at the time of diagnosis, were identified by women to make their situation more difficult. Stephanie described her situation at the time of diagnosis:

“Everything was wrong, nothing was right” (Stephanie)

However, when coping with this diagnosis most women described adopting a very ‘matter of fact’ approach. The source of their distress was related to the diagnosis, the threat to their mortality, and the loss of their breast. Primary concern was not for themselves, but for how the consequences of their death may impact on their families, in particular their young children. For most of the women this concern resulted in a motivation to enable coping and fight breast cancer. All women who commented on the issue of death and dying stated they were not afraid of death, but afraid of the process of death. Barbara describes a little about facing her own mortality following breast cancer diagnosis:

“I said to my G.P. ‘If I don’t have it (mastectomy) done, what will happen?’, because I thought ‘Okay, you know what, well really I didn’t like my life and I didn’t really want my life’...I just thought it was a means of getting out...My doctor said ‘Well what happens is that it (breast cancer) grows like a big cauliflower and gets very smelly’...and I sort of thought ‘Oooohhh yuck, if I’m just going to die that’s alright, but if I’m going to get all smelly like a

cauliflower, I don't think I want to do that'...It was sort of a decision to live really". (Barbara)

All of the women, except Paula, indicated they experienced facing their own mortality. Paula stated she did not, as she never felt it was an issue.

The concept of facing their own mortality is further evident by women commenting on a fear of recurrence of the cancer. The nature of these feelings was variable among the women in this study. For some women it was only an issue at times of yearly checkups when they were reminded of their mortality. As was the case for Gina:

"And then every time I had to go for a CT scan...every twelve months...it was like so scary. And lucky, lucky, lucky, everything would come back looking okay. So it was like we breathe again and go on". (Gina)

Anne stated the fear of recurrence became a big issue for her once her chemotherapy finished. For Anne chemotherapy had become viewed as a protective factor against the cancer:

"It was just constantly on my mind. The pain in my back - it's back, the pain in my head - it's back, the pain in my stomach - it's back". (Anne)

This fear of recurrence was constantly on her mind to the point where she described it as becoming an obsession. She viewed herself as a hypochondriac and became depressed. She found anti-depressants prescribed by her general practitioner gave her some relief. However, despite this turmoil she never let on to the outside world of her distress.

Several women noted the fear was eased after undergoing breast reconstruction, as they were no longer constantly reminded of having had breast cancer. Those women whose lymph nodes tested negative for cancer involvement commented on a definite decrease in concern and a sense of relief.

All women reported a short time period between breast cancer diagnosis and primary breast surgery. This ranged from as little as one day to a maximum of three weeks for one woman's immediate TRAM flap breast reconstruction. All women, except one, stated this rush was welcomed due to a sense of urgency related to the removal of the cancer. Stephanie explains:

“When I read the report you just see this word ‘invasive’ and you think ‘oh yay, do you really want this stuff moving through you? Let them get it out and let it go’. Absolutely, I would much prefer to have it done boom-boom than have any time to worry about what is happening, or is it getting any worse or anything like that, or just the stress of knowing what’s coming”. (Stephanie)

Paula was the exception. She expressed feeling rushed, describing a likeness to being '*railroaded*', and decided to take charge of her situation and postpone surgery until she was ready:

"It is a short time and that's why I asked the G.P. to wait because she'd already organised I'd see the surgeon and do this and do that. It was all going to happen within days and I said 'Hang on a minute', you now, there's no rush here. I mean it's not going to change in the next couple of weeks, not really, I mean not significantly anyway, and I need time' ..I was annoyed when a doctor tried to roll me through the system too quickly...There's no need for that pressure...a few days for head space...I need time to use my network to find out who the best surgeon is who will meet my needs...That week for me was really important to take control back and think that I was actually doing this in my order, not in someone else's order". (Paula)

Not only did the women need to come to terms with the diagnosis of having to live with breast cancer, they were forced to face their own mortality and make important life changing decisions, all within a relatively short period of time. Paula felt she was able to regain control over her situation as a form of coping, by making informed decisions about her own healthcare. Although Paula felt she could control this aspect of her experience, all women described this next sub-theme as one aspect they had no control over.

5.2.1 Recognising the impact of loss of a breast

It was evident from the interviews that women who underwent delayed breast reconstruction did not think having to live with the loss of a breast would have such an impact on them. Several described feeling they would be able to cope and would not need a breast reconstruction, only to be surprised by the subsequent emotional impact of mastectomy. Upon realising that it mattered more than they had anticipated, these women then decided to go ahead with breast reconstruction.

All women who had delayed breast reconstruction and experienced living with mastectomy reported a decrease in self-esteem and confidence, and feelings of appearing '*abnormal*'. All women used external breast prostheses and all experienced dissatisfaction with them. Prostheses were described as '*inconvenient*', '*a pain in the butt*', '*embarrassing*', '*a nuisance*' and '*uncomfortable*'. They made women feel self-conscious and therefore restricted clothing worn and activities undertaken. External breast prostheses were describe as a constant reminder of the breast cancer. Julia describes her experience of using a prosthesis post mastectomy:

"I just think they were big factors for me, like I couldn't hack it, like washing the prosthesis every night with a little nail brush and sticking it to my skin. And then I got a horrible irritation on the skin...It was just horrible, and each night you'd peel your boob off...It just wasn't right". (Julia)

Stephanie's experience with the prosthesis went beyond aesthetic self-perception, to affect her inner self-image:

“That (prosthesis) actually looked fine, that was okay, but I knew it wasn't okay. It doesn't matter what anybody else could see, whether they knew me or they didn't know me or just walking the streets, you would have thought nothing. But I knew it was all wrong, I knew that it was just totally wrong”.

(Stephanie)

The consequences of this experience were commonly described as periods of depression and in some cases isolation from others. Several women stated they simply could not cope with living with mastectomy and a prosthesis. Barbara tells of the effects of mastectomy and the prosthesis on her level of functioning:

“I couldn't be bothered putting this thing (prosthesis) on all the time and I didn't want anyone to see me, because I've got a large breast and a nothing. It was just so plainly visible that I ended up sort of hiding at home...I was withdrawing completely”. (Barbara)

Stephanie:

“I always wanted to go home, I couldn’t wait to get home...Put a gown on so then I could just rip this all off...and everybody just leave me alone”.

Anne admitted she would pretend to others she was coping by acting ‘*normal*’. She summarised her difficulties adjusting by saying:

“At the end of the day...it probably would have been easier if you lost two”.

(Anne)

Women identified the expectation that the benefits of surviving breast cancer would overcome the significance of losing a breast. This expectation was not reality, as explained by Gina:

“Balancing that sort of ‘uggh!’ repulsion with also the fact that ‘Hey, I’m healthy now, I’m happy, I’m still alive’...this conflict going on. I should be thinking ‘I’m still here, I’m still alive, so I really have got nothing to worry about’”. (Gina)

Gina found minimal disruption with the use of her prosthesis, yet states it as a consideration in her decision to undergo breast reconstruction:

“I was going to yoga classes. And here I am stretching, bending over and ‘plop’. It landed on the floor in front of me. So I just picked it up and popped it

back in and thought ‘That’s it, I’m having a reconstruction’. That was the final deciding factor”. (Gina)

Julia explains her thoughts of not wanting a breast reconstruction and then later identifying the need to go ahead with it:

“I didn’t want a reconstruction at the beginning. I just thought, you know, if I’m going to have one breast, I’ll have one breast, you know, I’ll have a prosthesis. But each time I showered and looked at myself in the mirror I just looked abnormal, it wasn’t right”. (Julia)

Gina anticipated surviving breast cancer would be enough of a challenge and not having a breast reconstruction would not matter to her:

“I didn’t really care because I really just wanted to live. And if I had to lose a breast to live then that was okay. But on the other hand, I remember not wanting to be seen naked by anybody..I didn’t even want my husband to see the scar. I would always wear a big t-shirt to bed, even when making love”. (Gina)

As highlighted by Gina the experience of living with mastectomy mattered to the women. Its impact affected body image, feelings of sexuality and subsequently raised issues within relationships. This experience was described by many of the participants.

Several women who underwent delayed breast reconstruction stated the impact of losing a breast was greater than expected for several reasons. Surviving breast cancer was anticipated to be compensation enough for the loss of a breast, but was not. Women felt their breasts were not important to them, but they were. Some women thought an external breast prosthesis would be fine, but it was not. The prosthesis may have looked fine, but it did not feel right for them. Women were surprised to the extent that they chose to conceal themselves. What made this surprise difficult was that the women experienced feelings of guilt - after all they were still alive. These women identified linking the need to have a breast reconstruction with an inability to cope, as opposed to viewing breast reconstruction as a strategy to help adjustment. Women who underwent mastectomy and had delayed breast reconstruction were faced with having to adjust to the loss of a breast, resulting alteration in body image, use of a prosthesis and an altered lifestyle secondary to these issues. It was through this phase of dealing with an altered self-image that these women discovered motivation to reconstruct their breast. For these women the degree of ongoing stress experienced due to losing a breast was a surprise.

5.2.2 I am more than a breast

The analysis highlighted the complexities of the women's experiences in relation to their self-image. While losing a breast mattered, there was a need to be acknowledged as more than a breast. The women's struggle to seek ways to express their feelings of

who they were was being challenged by the mastectomy, yet at the same time not wanting the focus to be on 'breasts'. This was expressed by Barbara:

"I became really angry at this thing about, you know, the concentration on 'You've lost a breast, you're no longer a woman'. And I sort of thought... 'Well you know, blow that, I'm more than a breast you know, and I don't want to become a part of the breast industry'". (Barbara)

Women did wish to be identified as more than a breast, however not having a breast did matter to them a great deal. That is, the breast was a part of who they were, but not the sum of who they were. The loss of a breast altered women's perception of who they were. Some viewed themselves as '*skewed*' and '*mutilated*'. Stephanie explains the effect first seeing the mastectomy site had on her self-image:

"I was expecting obviously to see nothing. And it's not really so much how did I cope with looking at the scar? The scar was fine. It's how does one cope looking at yourself? You're totally skewed. So you have this whole feeling of almost like a mutilation. That's how I felt. I felt like, oh my god, this is total mutilation". (Stephanie)

Facing this change in appearance, viewed by most of the women as '*deformity*', was described as an '*awful*', '*terrible*' experience. Julia depicted her experience by likening herself to a monster, describing an image of horror:

“I looked abnormal. I looked like the one eyed, one horned, flying purple people eater. It was just weird, I just didn’t want to look at myself like that”.

(Julia)

Women described the altered body image as making them feel ‘*abnormal*’. This altered body image made women feel more self-conscious of their bodies, and was described by women as leading to diminished self-esteem and deteriorating confidence levels. This impacted on women psychologically, in some cases resulting in depression, withdrawal from society and even isolation from the outside world (see section 5.2.1). The diverse effects of the loss of a breast indicates the experience not only impacted on the way women looked and subsequently felt, but in fact impacted on their whole lives, as described by Stephanie:

“The thing is, it (mastectomy) changes your whole life, I mean it changes every area of your life, whatever area you choose to talk about or just mention, there would be some kind of impact”. (Stephanie)

The women who underwent adjuvant therapy reported hair loss, secondary to chemotherapy, exacerbated this body image disturbance. Women who had suffered hair loss described this experience as particularly ‘*traumatic*’ and ‘*distressing*’, with some women actually stating the effects of hair loss were worse than losing their breast. Anne explains her trauma related to hair loss following chemotherapy:

“The hair loss has to be one of the worst things ever, ever, ever. My husband said to me he’d never seen me so bad, even when I found out I had cancer...It took two weeks to come out and it was the worst two weeks of my life, the worst two weeks”. (Anne)

The description within the interviews of the trauma resultant from hair loss, further demonstrates that the breast cancer experience is not just about losing a breast and these women do not wish their experience to be viewed within that context.

Although some women did not wish to be identified by their breast cancer illness, they identified so strongly with this piece of their anatomy and the consequent affects the loss of it incurred. A small number of women found socialisation with a group of women with similar experiences, (i.e. a breast support group), offered a connection and comfort through understanding and support. Barbara explains her connection to her local breast cancer support group:

“It’s a little community and people sort of come out of the woodwork and say ‘Well I’ve had it, and I’ve had it, and I’ve had it’, and they invite you to different things...It’s sort of entering a special group, you know. Even though you sort of don’t want to identify (with breast cancer), but it does I think because they value their life too”. (Barbara)

5.2.3 Struggling to gain acceptance

Although most women reported being well supported throughout their breast cancer and TRAM flap breast reconstruction experience, several women highlighted issues related to the acceptance of their situation by others. Women felt society viewed breast reconstruction primarily as a cosmetic procedure, thus implying vanity. Women also indicated others expressed views their breast reconstruction procedure was a minor form of surgery, leading to low levels of empathy associated with the recovery phase. Women felt pressure on their decision to reconstruct their breast due to society's implied view that the need to reconstruct a missing breast is a sign of impaired coping. Women indicated this added pressure to the breast reconstruction experience, and made women feel unable to express their true feelings to others within society, as it was anticipated the lack of understanding from others would not allow the provision of support needed by these women.

Most women referred to their age as being a deciding factor in the breast reconstruction decision, indicating societal standards of worthiness for breast reconstruction and a need to justify their decision. Gina explains:

“Okay, the deciding factors were, because I was still young. If I was maybe in my late sixties or seventies, I wouldn't have worried about it. It wouldn't have been an issue as much...I'm young and I felt I had a lot of living left to do. And I wanted to live it as normally as possible...We're still looking to live another

thirty, forty years and the rest, and I'm not prepared to go through the next thirty of forty years having to worry". (Gina)

The concept of living a lengthy life feeling '*normal*' was a similar consideration for Patricia:

"I felt I was just too young to have just a mastectomy...I think if I was seventy-five I wouldn't think twice, but I was only forty at the time and I sort of thought 'I've got a lot of years ahead of me to actually look at deformity like that'...I just thought I was too young to do that...If your coming to the end of your life, you might not see it (breast reconstruction) as crucial". (Patricia)

However, Julia opposed this concept of an age limit defining when it would not matter anymore:

"I'm sixty in a few months time and I'd definitely still have it done". (Julia)

Most women felt the need to attempt to justify their decision to reconstruct by saying they felt they were still young enough and if they were older they would not have bothered. This indicated a societal impression of worthiness based on youthful age. Due to society's implied impressions of breast reconstruction, some women struggled with feelings that the decision to reconstruct was made due to a failure to cope on their part.

Julia describes further societal pressures on her coping with mastectomy and decision to have a breast reconstruction:

“I just felt this is silly, you know, surely a prosthesis is okay, you know, I can live with a prosthesis. But the longer it got, the worse it got”. (Julia)

Women expressed concern that others had minimal understanding of the TRAM flap breast reconstruction procedure. The women explained they felt this was evident through a lack of concern and empathy during their physical recovery. Patricia explains others expectations of her during the post-operative recovery phase:

“My dad stopped at the shops on the way home (from hospital) and made me get out and go and look at something...And halfway through I thought ‘Do you realise?’ ...I was so exhausted”. (Patricia)

Paula talks of people’s attitudes of the underestimated seriousness of the procedure:

“I don’t think anybody that hasn’t actually been there appreciates just how big a piece of surgery this actually is... Because it’s elective people don’t appreciate just how serious it is... People think ‘Well how hard can this be? Why would somebody put themselves through that?’”. (Paula)

Patricia then went on to liken the expectations of others putting pressure on women to cope with their situation, to that of an obstetric experience:

“But isn’t it like having a caesarean? Like you get out of hospital and you’ve just had this baby and your supposed to just be sparkling”. (Patricia)

From the interviews of the women residing in rural locations it was expressed this pressure to cope was intensified within this setting. Although the two women commented the rural community was more supportive comparatively to their experience of urban communities, they indicated they were very much identified and everyone knew what had happened to them. Both women indicated that the lack of privacy, due to ‘*gossip*’, was problematic. Linda explains the attitude within her rural community:

“Everybody in town knew, yeah. Those that were important to me were the ones that I told what I wanted to tell. Those who wanted to say I was on my deathbed or whatever, like they could. Those that were important to me knew the real story and what else got said didn’t worry me at all. I’ve lived in a small town long enough to know There’s a couple of others in town, just sort of a few months ahead of me I guess, that they were talking about as well. And there will be others afterwards”. (Linda)

“Definitely gossip, you’ve got people, you know, like telling other people you’ve got no hope, and all of that sort of stuff. So you’ve got to go out and prove, not so much prove, but you’ve got to make sure that those that are important to you know the true story”. (Linda)

“(In) A small town there are sort of more snobby, talkie, catty sort of women. Which I suppose, yes, I am more self conscious when I’m around those people”. (Linda)

Both of the rural dwelling women identified that knowing everyone was talking about them and watching them lead to increased pressure to cope with their experience within that community. One woman experienced depression, resulting in isolation from the community. The other woman revealed being more self conscious around certain people in the community who were known to be more prone to ‘gossiping’. Yet, the same woman expressed minimal adverse effects from her experience with breast cancer and breast reconstruction, and stated it did not matter to her what others in the community thought of her. Obviously it mattered to both women, and their experience with this was intensified by the rural community’s concentration on them.

The experience of being diagnosed with breast cancer and dealing with the psychological changes incurred by subsequent breast surgery was described as distressing. Most women commented that the implied pressure to cope from others

within society often lead to a pretence of coping. A few women admitted to pretending to cope and trying to act '*normal*'. Gina explains:

"I was okay as long as I appeared dressed and as if nothing had happened to me...So I think I really tried to pretend everything was okay, that I was normal".

(Gina)

Gina highlights that while struggling to feel '*normal*', the reality is these women do not.

It became evident women did not talk to others about their breast cancer and TRAM flap breast reconstruction experience.

Anne:

"I don't usually talk about my breast cancer. A lot of people who know me now would never know that I've had breast cancer, because I just don't tell them".

Stephanie:

"But in the actual situation of discussing this there's only very few people, very close core of people that knew my inner feelings or that I ever spoke about anything to. Because the rest are acquaintances, they know what happened but they don't have to know anything else".

Anne's TRAM flap breast reconstruction failed and she has since had further breast reconstruction with a prosthetic breast implant. She kept her experience secret from most people:

"Only my close family know it didn't work. People at my work, everyone knew I had breast cancer and knew I was getting a reconstruction. To this day only my friends, close friends and family know I've got an implant. They all think that I've got a TRAM flap and it worked. I haven't told anybody, there was no way". (Anne)

It was admitted by several of the women in this study that it was difficult for them to express exactly how their experiences had impacted on them psychologically and emotionally, therefore it was avoided. However, women expressed their plastic/reconstructive surgeon gave them the understanding and recognition they needed. Women went on to describe the intensity and importance of their relationship with the surgeon (see section 5.3.4).

It is evident that this experience is a complex one, where loss of a breast and its reconstruction does not just involve the physical self. These women illustrated that it greatly impacted on emotional and psychological well being, as the loss of a breast and its effects on self really did matter to these women. Not only did women feel others did not recognise how this experience mattered to them, they often did not initially realise

just how much it mattered to themselves. The struggle to have this acknowledged by those around them was expressed, along with an implied pressure for the women to cope with their situation. The surgeon who restored the breast provided one way of dealing with the consequences of the breast cancer diagnosis and gave the only complete recognition of the wholeness of the breast cancer experience.

5.3 “ADJUSTING TO A CHANGING BODY IMAGE”

It became clearly apparent throughout data analysis that the experience of these women having breast cancer, mastectomy and TRAM flap breast reconstruction was one of a process of adjustment. That is, a process of adjustment to a diagnosis of breast cancer, an altered body image, and subsequently an adjustment to the changes occurring in other areas of their lives secondary to breast reconstruction. This included changing relationship dynamics, changing life perspective and in most cases an altered lifestyle. All women stated these changes were for the better, with some identifying the experience of breast cancer and TRAM flap breast reconstruction was one of the best things to ever happen to them, due to the consequent facilitation of life changes.

The first phase of adjustment for these women was to the diagnosis of breast cancer (see section 5.2). For the five women who had delayed breast reconstruction, the next phase of adjustment was to the alteration in body image resulting from mastectomy (see section 5.2.2). For the women participating in this study, the adjustment to their TRAM flap breast reconstruction was typically different for those who underwent immediate reconstruction, compared with those having delayed reconstruction. Their difference in process of adjustment will be described. Barriers to the process of adjustment that these women encountered will also be identified, along with the support networks that were utilised to move through the process of adjustment.

5.3.1 Timing of breast reconstruction

Some distinct differences were found between immediate and delayed breast reconstruction groups regarding body image and subsequent self-esteem post TRAM flap breast reconstruction. Women who underwent delayed reconstruction described a greater and more rapid improvement in body image and self-esteem post breast reconstruction, while those having immediate reconstruction described initial impairment in body image and self-esteem that improved over time.

The benefit of deciding to go ahead with TRAM flap breast reconstruction was illustrated by some women stating that breast reconstruction does not just repair the physical deficit, but helps them feel '*whole*' and '*complete*' again. Stephanie, who had a delayed breast reconstruction, describes this the following way:

“It changed my body image absolutely because as soon as, even before the bandages and stuff came off, I could see that I was in shape, you know. I couldn't wait to rip off these bandages and just see exactly. And it was a little bit big...but it didn't matter. The symmetry was now right. You could stand in front of a mirror and you looked like you were supposed to look and automatically you feel a whole lot better. Your clothes are hanging on you nicely, you don't have to put anything on to complete your day, you just get up like you always did...You're just not missing anything, you are all complete again”. (Stephanie)

However, some women did not feel ‘whole’ as anticipated after their breast reconstruction and again unexpectedly discovered how much the experience of losing a breast and then having it reconstructed mattered to them. This was found mainly with women that underwent immediate reconstruction. Although Janet acknowledged the expected benefit of immediate breast reconstruction, she later went on to describe further emotional stress after TRAM flap breast reconstruction:

“Just the fact that I woke up and there was something there still...It does, I don’t know, psychologically make you feel better...But I think I was more upset about it after it (breast reconstruction) had been done rather than before”. (Janet)

Patricia, who also underwent immediate reconstruction, describes her unanticipated feelings post TRAM flap breast reconstruction:

“I feel like, not quite whole...I don’t think this makes up for your normal appearance by any means”. (Patricia)

“I wasn’t really wrapped...It was a good shape and realistically it was a damn good job, and I knew in my head that it was a good job, but yes, I wasn’t enthusiastic and I didn’t hate it...I just was like, you know, I could live with it at the time...I think the TRAM is in effect an effort to resurrect your body image, your self-esteem, to try and keep it at a reasonable level. I think it has to go down”. (Patricia)

This again highlighted that the entire experience is not just about the replacement of a breast, as the sequelae of mastectomy sometimes could not be rectified simply by the operation of breast reconstruction. Reconstruction of the breast did not necessarily immediately restore or retain everyone's self-esteem and body image. In fact in some cases the operation caused further unexpected detrimental impact.

Delayed breast reconstruction patients described a return to feeling '*normal*' and an elimination of the reminder of breast cancer. They reported drastic improvements in self-esteem and increased confidence. Stephanie's TRAM flap breast reconstruction experience was described as follows:

"I recovered much better physically and mentally after the reconstruction because it was wonderful to see this flesh that I used to keep patting and it was like all mine and pink...You've had this reconstruction and suddenly this confidence comes flying back, like 'Hey, I can be me again and get on with what I have to do'". (Stephanie)

Women described delight with the convenience of not having external breast prostheses, some reporting they felt '*whole*' and '*complete*' again. One woman described her TRAM flap breast reconstruction as a '*breath of fresh air*'. A small number of women reported a body image better than before they had breast cancer.

Along with this satisfaction with improvements in body image and self-esteem came feelings of gratefulness for what their breast reconstruction had given them.

For women having immediate breast reconstruction reports were variably different. Women reported they felt better that something was there. Some women described looking relatively '*normal*', but not feeling '*whole*'. Janet's immediate reaction to the breast reconstruction was described as '*awful*', '*ugly*' and '*a constant reminder of the breast cancer*'. However, she believes this has improved over time and now recognises the advantage of undergoing her TRAM flap breast reconstruction:

“Oh it's very awful really... You look at yourself and that's the first thing that you look at, you know, when you're hopping in the shower. I've this huge mirror in the bathroom... I look ugly, that's the first thing... All that's getting better... I can, you know, get dressed in the morning, put a bra on and look totally normal, or I can go for a swim and put my bathers on and look totally normal”. (Janet)

Patricia confirmed this by reporting she is becoming pleased with her result over time, emphasising the need for time to get used to the alteration of body image and become more comfortable:

“It's taken twelve months for ...me to get used to it and for me not to go 'Oh, I hate that nipple', or anything... That doesn't happen overnight... In the first few

months you're still sort of in this, you're in a sense of shock about the whole thing anyway...It's not the same as it was...It certainly doesn't feel the same to touch, and it certainly doesn't feel the same for someone else to touch, from the inside and the outside...It's quite an obvious difference...You're sort of initially living with the thoughts that it might get better or you might have something done...you're still getting revisions done...so you don't really know what the final outcome is going to be like". (Patricia)

Several women having immediate reconstruction described displeasure with certain aspects of their breast reconstruction, however were happy with the overall outcome. It was evident women identifying themselves as having a high body image (i.e. no scars, no stretch marks, slender physique) before breast cancer and breast reconstruction, experienced a greater alteration in body image and therefore further detrimental impact post TRAM flap breast reconstruction. Janet describes how her body image plummeted initially following her TRAM flap breast reconstruction:

"I was always slim, I didn't have any marks, so you know, I felt good about myself. And so I think having that, I did go through that sort of first initial months thinking 'Oh you know, I've got scars now, I've got this and that', and it was hard, you know. It was hard and I did feel yuck about myself". (Janet)

Women who underwent immediate breast reconstruction and verbalised a low pre-existing self-esteem, commented that TRAM flap breast reconstruction compounded to lower self-esteem further. Patricia was one of these women:

“I don’t feel good about myself generally anyway. Because I feel like every woman, I feel like I’m overweight, I need to go to the gym...If I was going to have a relationship with any man I really wouldn’t want to look like I do right now anyway apart from the TRAM. So the TRAM’s only an added part of that”. (Patricia)

Exceptions to these differences evident between delayed and immediate breast reconstruction groups were the experiences of Paula and Marie, however from opposing standpoints. Paula had a delayed reconstruction and described an unsatisfactory hospital experience from time of admission until discharge, plus an unsatisfactory aesthetic outcome. She acknowledged that it is difficult for her to separate her negative experience from her dissatisfaction with the outcome of her surgery:

“So it was all just a really unpleasant experience with a really unpleasant outcome...I’ve tried to separate the two but I’m not sure in the end that you really can...The way I feel about the end result is probably being coloured by...the experience and it’s very hard to come away from that”. (Paula)

Despite her dissatisfaction, Paula acknowledged advantages of her breast reconstruction, related to greater lifestyle convenience.

The other exception was Marie who underwent an immediate reconstruction and described an excited anticipation of the surgery pre-operatively. She went on to describe her experience stating her pleasure with the outcome. She feels her body image is better now than it was pre cancer diagnosis. She now has increased self-esteem and confidence, is more outgoing and even wears clothes she may not have considered wearing previously.

Whether experiences are good or bad, positive or negative, there was still a need to adjust to this alteration in body image and its effects on self-esteem. One thing that was agreed upon across groups was the immediate advantage to body image of the abdominoplasty resultant from the TRAM flap breast reconstruction. Many women stated it helped improve their self-esteem. In general, women describing better aesthetic outcomes also described better outcomes of body image. It also became evident that positive experiences throughout the surgical and recovery phases resulted in the description of superior outcome satisfaction.

Whether having an immediate or delayed TRAM flap breast reconstruction, all women noted improvements in their body image and self-esteem over time. Women stated feeling less self-conscious and more comfortable with their bodies as time passed. For women who had delayed reconstruction their self-esteem increased, primarily due to a

return in versatility of clothing, and therefore looking and feeling better about themselves. A small number of women highlighted they had underestimated the impact breast reconstruction would have on their body image. Despite this unawareness of the importance of body image to self, it was later illustrated to these women that the breast reconstruction experience did really matter to them. However, for some women, particularly those who had immediate reconstruction, there was now a need to adjust to their altered body image.

5.3.2 Situational factors influencing the process of adjustment

In addition to dealing with a diagnosis of breast cancer, mastectomy and breast reconstruction, all women had other personal issues or situational events that impacted on their reconstruction experience. These factors require further adjustment, therefore lengthening the time taken to achieve the process of adjustment.

As previously mentioned some women had pre-existing emotional issues they were motivated to deal with. These ranged from relationship issues, the death of a loved one, to family disputes. Two women reported experiencing suicidal thoughts related to the combination of the breast cancer diagnosis and other personal distress. They stated these thoughts were short lived due to consideration for loved ones.

Gina was eight and a half months pregnant when diagnosed with breast cancer. She underwent a mastectomy, delivered two weeks later and began chemotherapy two

weeks after the birth, later going on to have a delayed TRAM flap breast reconstruction. The situational factors of the emotional time of pregnancy and childbirth, the requirements of looking after a newborn while living with breast cancer, and suffering the sequelae of chemotherapy, added situational stress to her experience. Gina reflects on the situational factors that influenced her experiences:

“I suppose thinking back it could have been a positive thing, because it actually kept me busy and not thinking so much about myself. Whereas if I had nothing else to think about except my situation I probably would have been in the depths of despair”. (Gina)

Two women indicated a financial burden. One struggling with the expenses of chemotherapy, the other a single mum paying for extensive medical bills. This was illustrated as an additional stressor during the process of adjustment.

The simultaneous sequelae of chemotherapy also impacted negatively on the process of adjustment. Not only related to the body image adjustment regarding hair loss, but also the physical effects of treatment such as nausea and exhaustion. Although, Julia recognised keeping busy helped minimise the effects of chemotherapy:

“I used to hop on the plane (for work) at quarter to six and had my chemo at four o’clock...taking it (adjuvant therapy) off your mind virtually, I had no time to think about the chemo and what it was going to do to me”. (Julia)

Five of the ten women participating in this study suffered complications post-operatively. Two of those being minor and three classed as major (that is requiring rehospitalisation and/or surgery). Complications lengthened recovery time, sometimes by months, and were identified to impair aesthetic outcome. One woman described her complication phase as '*frustrating*'. Complications denoted an extended process of adjustment.

Nine of the women had undergone various revision procedures and indicated this improved aesthetic outcome. One woman describing it as '*icing on the cake*'. Although there are several situational factors that impaired the process of adjustment for these women, revision procedures were viewed as providing a distinct enhancement to the process of adjustment.

Women's experiences within relationships also impacted on the process of adjustment. With regard to intimate relationships with husbands most women commented it was never an issue. Their husbands had been supportive and accepting, while some women were experiencing apprehension and nervousness regarding acceptance of their body by their husband. It seemed that although husbands were accepting, women were still in the process of self-acceptance. This implied not sexual dysfunction, but sexuality dysfunction on the woman's part. One woman's husband rejected her body after mastectomy, leading to feelings of resentment towards him. However he reaccepted

her body sexually after breast reconstruction. This woman described the experience with her husband as having a negative effect on her process of adjustment.

5.3.3 Finding support throughout the process of adjustment

A variety of support mechanisms and resources were utilised by the women, with a recurring concept of the need to heal from both the physical and emotional consequences of the breast cancer and breast reconstruction experience.

One woman sought professional help with primary reference to the recent death of a loved one, and felt she received enormous help and support through her breast cancer experience from this source. Another woman adopted alternative therapies to get through the experience including Buddhist meditation, Reiki and psychic consultation. She reported gaining great comfort and insight into life as a result. A few women belonged to a religious faith. Whether they were already deeply involved or not, all women stated their religious faith was strengthened through their experience of breast cancer and breast reconstruction. Women described this faith as giving them immense support as it gave them something to hold onto and provided them with strength through spiritual empowerment. Janet tells of her faith in relation to her experience:

“I feel much closer to God. Because during those times I really cried out ‘God I really need you to help me. I just can’t do this alone’. And I really did absolutely feel the strength from that, from God. I really did...and I think that’s

just what gave me that assurance all the time, you know, I'm going to be alright, everything's going to be okay". (Janet)

Patricia tells of her empowerment through growing from her experience:

"It's very spiritually empowering when you've...hit the lowest point of your life. Often that's when you move very powerfully spiritually and I think I was in the middle of that". (Patricia)

When support networks were discussed, women belonging to religious organisations had huge support from the church, not only emotionally but also in terms of help with general activities of daily living. They all commented they found their religion a great support.

Several women explained having to cope because of children that are dependent on them, some women indicating a lack of support in this area. As Patricia explains:

"I think the fact that I've got three kids...I was still in that mode of I have to cope and I have to get through this, and they have to feel secure, so I have to cope and I can't let myself go to pieces". (Patricia)

Anne felt this may have helped her to cope by keeping her busy and therefore not having time to dwell on her situation:

“People depend on you, children depend on you. I probably think if it wasn’t for them, I wouldn’t say I wouldn’t have got through, but it gave me a normal life because I still had to do things for them”. (Anne)

A small number of women in this study commented on family members difficulty coping with the situation, as somewhat impeding their coping style. Linda explains:

“Saying ‘Hey, I’m not going anywhere’, and that sort of stuff, ‘it will all be okay’. Yeah, I suppose when you’ve got to convince other people, you convince yourself as well. And that was my thinking ‘I’m not going anywhere, my boys are too young’...He (husband) said if I wasn’t handling it as well as I was, he doesn’t know how he would have gone”. (Linda)

All women acknowledged the importance of support and talking to help share the burden. Some women recognised a challenge in the ability to accept help and support. Several women noted there was an issue with dependence during the recovery phase. In the hospital setting the dependence on nursing staff was described as ‘*undignifying*’ and ‘*humiliating*’ as these women were not used to feeling this helpless. Janet describes her hospitalisation post TRAM flap breast reconstruction:

“You feel so vulnerable...Oh it’s horrible...Particularly when you’re used to doing everything for yourself. I mean it’s most humiliating having someone to help you go to the toilet”. (Janet)

Also out of the hospital setting women described sometimes feeling like a burden to family and friends, one woman inferring this was perhaps due to societal pressures to be independent and cope.

Patricia:

“I’ve got quite a lot of friends and stuff, but I mean lots of people have got kids and stuff. They’ve got their own lives...You feel like you’re a burden on people...We’re sort of socialised into thinking...’you’ve got to be independent, you’ve got to cope’...That pressure that you’re sort of putting people out having to do stuff for you all the time”.

With regard to support from friendships there was variance in both directions. Some relationships formed closer bonds, while others became more distant. An appreciation of the constant support of close friends was frequently mentioned as resulting in the formation of stronger bonds. Other women described not an increased closeness in the relationship, but a change in the dynamics of the relationship. Stephanie believed that by her daughter living through the experience with her, they developed a closer bond of friendship. Their relationship had changed from one of mother and daughter, to that of

friends. She comments on this being distinctive from her relationship with her other daughter:

“She dressed it, and she you know, she used to shower with me, and show me, and look at it, she’d been through every fine detail with me...She was with me twenty-four hours a day...The actual relationship has changed in that I’m more of a mother to my eldest daughter, but I’m more of a friend to (youngest daughter). (Youngest daughter) and I are the best of friends... You know, we’ve got more of a total bond of friendship...So, yes, that if any relationship changed, that one did and certainly for the better, we had the best time”. (Stephanie)

Some friendships were distanced, not for any particular identified reason. Women attributed this to these friends not knowing how to handle the situation or what to say, therefore avoided the friendship. Anne explains her situation:

“I had some friends that I’d had for a long time, which I really don’t see now. Because when it happened some people are scared, they don’t know what to say and don’t know how to react. So these people I don’t see anymore”. (Anne)

Gina tells of some of her friends’ reactions to her initial diagnosis of breast cancer:

“They came to visit me in hospital and you could just see the dread on their faces, it was like they were saying goodbye...You could read their faces...They

hear cancer and they think death.. I was already sick with fear, people expecting me to die just added to that”. (Gina)

Several women expressed they felt it was because these friends did not understand the life changing results of these women’s experience as they had no concept of facing their own mortality. This was Gina’s belief:

“A lot of people don’t understand it, they don’t understand me. Because now I’m into Reiki, and I still read a lot but my reading has a lot to do with philosophy and faith and alternative therapies. And people who don’t understand that, they just think I’m away with the fairies...They think ‘oh she’s a bit crazy, don’t worry about her’. Because they have no concept of life and death and having to face that situation when it’s in your life”. (Gina)

Most women commented on people’s reactions to their situation, stating they would tell stories of others battle with breast cancer. All women found this a disturbing trait. Some exemplars:

Gina:

“And just out of the blue they’ll say ‘poor so and so, my best friend, she’s been diagnosed’ or ‘this person just had a recurrence’ or ‘gee this person I knew, she’s been seventeen years since her breast cancer and she’s just had a

recurrence, back on chemo'. And I'm thinking 'why am I being surrounded by all this?'. I don't want to know, I don't want it around me".

Barbara:

"Someone just rang me up and said 'Oh well, you know, if you've only got three or four years to live, then you should do this and that and something else'. And I sort of thought 'Have you written me off already? I haven't written me off'".

Anne:

"Somebody would come out with something and I'd say 'Are these people dead or alive? If they're alive I want to hear about it, if they're dead go away'...A lot of people don't let you forget about it as well you know, like they say 'Your looking well, you know, considering what you've been through'. You know it's nearly three years now, so I just ignore that".

Friendships displaying these characteristics were not pursued and no anger or resentment seemed to be held. It was just accepted by the women as part of the redefinition of their lives.

5.3.4 Surgeon's acceptance and recognition of the women and their situation

Although most women verbalised acceptance and support from their loved ones, the most support in terms of understanding that these experiences did matter to women was

identified to come from their surgeons. The surgeon's acceptance and recognition of the women and their situation was a focal point within many interviews. The plastic/reconstructive surgeon was identified as the person who recognised and reinforced that, yes, the breast cancer experience does matter. He seemed the one-person women could express that to and receive understanding from.

Several women described quite an intense, positive relationship formation with their plastic/reconstructive surgeon. Several women stated the support of their surgeon made all the difference at the time of the initial consultation. These women have a high regard for their surgeon, describing the surgeons as reassuring, informative, professional and most importantly focused on the women and their needs. The women described feeling relaxed, comfortable and at ease with their surgeon. It was evident from this group of women there is was a very trusting relationship between the woman and her surgeon. Marie describes her initial meeting with her surgeon:

“He seemed to be really focused on me and my problem and, you know, getting me better, which is really good...He was just so nice and just made me feel really relaxed and comfortable...to me that was really like a critical point... If he hadn't made me feel so good, it could have been totally different...He certainly made me feel that they (surgical team) were going to do the very best for me that they could and that's what was reassuring”. (Maria)

Through their interviews women had demonstrated a great appreciation for what their surgeon had given back to them with the TRAM flap breast reconstruction. The women had great admiration toward their surgeon. Stephanie highlights her gratitude towards her surgeon:

“He’s done such a great job, and he’s really given me, he’s just given me a whole new life. Which I know it’s hard to pinpoint one person and say, if someone had to say to me ‘Who was the person that made you feel so great?’, I would have to say that it’s him”. (Stephanie)

Some women said they *‘put their lives in his hands’* and left decisions up to what he thought was best for them. They would do as they were told under his guidance due to an immense amount of trust in this person. As Stephanie depicts:

“What also helped me a lot I really have to say is (surgeon’s name), because I had huge confidence in him so I basically never questioned him. If he said jump, I jumped, if he said sit, I sat, if he said eat, I ate... I just put my sort of life in his hands and he never had any restrictions. Even when it came to the other operations, the nipple reconstruction, he would tell me all the things and then say to me ‘Right, which do you want me to do’, and I would say to him ‘You do the one that you know is right for me’”. (Stephanie)

Although not all women are satisfied with the immediate outcome of their TRAM flap breast reconstruction and acknowledge imperfections, the esteem in which they held their surgeon did not alter. In some cases they even seemed to become passively defensive of their surgeon. Gina describes her surgeon's work:

"There is a slight difference, this one's smaller than the other side. The nipple isn't quite in the perfect position; it's not quite as prominent as the other nipple. But it doesn't matter, because I have such faith in (surgeon) and I know he did the best job possible. What more can I ask for?". (Gina)

One woman commented visits to her surgeon and their subsequent relationship had become part of her life. Several women noted sadness at the termination of the relationship and stated they did not want the relationship to end. Stephanie tells of her ending relationship with the surgeon:

"I've just had my last appointment with (surgeon) last week, and do you know what I said to him? 'What am I going to do'...I've been coming here for two years; I mean it's like part of my life. What do you want to fix next?' So it's almost like lets close the book now". (Stephanie)

Marie likens the relationship with her plastic/reconstructive surgeon to that of her obstetric experiences:

“I remember when I had my children, you know, you go and see your specialist right up until you have your baby and then you go for your six week check up and that’s it. And I remember thinking then, you got so used to seeing this person and suddenly, especially with a young baby, your sort of like cut adrift and you don’t go back to see that person ever again”. (Marie)

This relationship between the woman and her surgeon depicts the components of any relationship, in terms of formation, maintenance and then termination processes. The women’s search for support lead them to develop this unique relationship with their surgeon. The intensity of this relationship could be attributed to the surgeon being the person who could most help them through their process of adjustment by performing their reconstructive breast surgery.

Most women verbalised adequate support throughout their process of adjustment, however upon further discussion several women identified other people’s attempts at being supportive acted as a barrier to their coping style. There were a number of coping mechanisms and support networks utilised which helped women through this process of adjustment. Although no matter how well these support mechanisms assisted coping for these women, the key to the process of adjustment was time.

5.4 “REDEFINING NORMALITY”

Throughout the analysis of this study it was evident the attempted outcome of the process of adjustment was to return to ‘normality’ as defined by the women and expressed by Stephanie:

“You suddenly go from normal, whoever you are, to getting this life threatening terrible disease...and suddenly you feel like it’s all gone. Now you’ve got to start rebuilding yourself and yet your confidence is absolutely shattered”.

(Stephanie)

However due to the major and extensive life changes resulting from the entire experience of breast cancer and TRAM flap breast reconstruction, it was illustrated a return to the ‘normal’ these women once knew was not possible. Rather these women redefined what was ‘normal’ for them within the context of their new bodies. They re-explored their self-concept and re-evaluated their lives within the perspective of their family environment.

For most women, their concept of self was rediscovered and redefined. Not only does this theme involve the acceptance of a redefined self, but also the acceptance of this new self by others as previously discussed (see section 5.3.3). This theme will discuss the life changes experienced by these women and the consequences these changes have had on self, relationships and family. The overall outcome in all cases being the

positive redefinition of life to a better state of 'normal', derived from the positive and also negative aspects of the experience of breast cancer and TRAM flap breast reconstruction.

Women with delayed reconstruction described the body image disturbance of mastectomy as '*mutilation*', '*a total mess*', stating it looked different and was not right. Women felt '*abnormal*', some stating they could not have gone ahead with one breast, others confessing they were not coping with the body image disturbance caused by mastectomy.

The use of an external breast prosthesis was functional for some women, although inconvenient and embarrassing at times. For others the use of a prosthesis was described as a '*weird*' and '*odd*' experience. These women felt even though it may have looked fine to the outside world, it just was not right to them.

This desire to look and feel '*normal*' became the main motivation for deciding to undergo breast reconstruction. For some women, particularly those with young children, there was not only a need of normality for self, but immense consideration for the impact the portrayal of the 'abnormality' of mastectomy would have on their children. As was the case for Linda:

“Because I had the boys and I didn’t want to be a party trick for them. Like, we’ve got a pool in the backyard, didn’t want mum’s boob floating around in there”. (Linda)

Most women chose TRAM flap breast reconstruction as they had been advised or had the opinion, from seeing other women’s reconstructions, that it was the most natural looking type of breast reconstruction. This method was therefore identified as being capable of returning their bodies closer to *‘normal’*.

A further requirement of the adjustment process was recognised by the women to be the acknowledgement that breast reconstruction is not going to be a true replacement of the lost breast. The aim is the formation of a breast mound of a size, situation, shape, colour and skin texture that matches as close as possible that of the lost breast (Ward, 1981). However, TRAM flap breast reconstruction achieved some outcomes of ‘normality’ for these women. Some women stated they felt back to *‘normal’* and looked *‘normal’*. Stephanie tells of her sense of normality following TRAM flap breast reconstruction:

“You’re not self conscious at all because you’re just you, you are just now fully attached, you’re fully normal...I feel as far as the reconstruction goes, as I sit here now I just feel like me, whereas without it I could never have said to you I feel like me”. (Stephanie)

Women were once again able to feel comfortable in their clothes and resume their pre-existent levels of activity without self-consciousness or apprehension. This satisfaction with their redefined normality made women feel better about their body image. One woman stating she no longer felt *'freakish'*.

Revision procedures to the TRAM flap were identified to result in further improvement of the aesthetic outcome, enabling the resemblance of the reconstructed breast to become even closer to *'normal'*. Some women depicted minimal scarring as attributing to their breast looking more like a *'normal'* breast. Other women who were not happy with their scarring felt this impeded the aesthetic outcome of their new breast.

For some women redefining their normality in relation to their new breast took longer. One stating it was still different to the real breast; therefore her outcome had not met her expectations of normality.

The majority of the participants indicated how they feel about their body's changes day to day:

“If you asked me the same question tomorrow then I might say differently. But it depends on the day, if I'm buying clothes or I'm getting dressed to go out to dinner or something, and I can wear something that's a little bit tighter or with a slightly different neck, I think 'Yes, yes, that's good'. If I'm having a bad day

and my hair's not going well then you think the whole bloody lot's a pain in the arse". (Paula)

"I'd think sometimes 'Why is this happening to me', you know. And then other times I'd think 'Well it could be a lot worse'. So you've just got to get on with it". (Janet)

Not only was the normality of their body image redefined, but also their entire lives, as a result of the profound experience of breast cancer and undergoing TRAM flap breast reconstruction. Stephanie describes this:

"It (TRAM flap breast reconstruction) totally changed the world I live in. It changes every area of your life in some way". (Stephanie)

Several women described the experience as the best thing that ever happened to them. One woman summated her experience by reporting she had gained more than she had lost. There seemed to be a consensus that something so positive had in fact come from something so negative. The experience was viewed by many women as an inspiration in life, due to the reality check of cancer '*frightening the hell out of us*'. Women described a greater appreciation for life. There was a realisation that the meaning of life is about fulfilment and enjoyment. This led to a reprioritisation of less work, more play and greater emphasis and consideration for self. Several women said they worried

less about things they could not do anything about. The general concept indicated was that life is for living and cannot be put on hold.

Comparatively, Patricia was one woman who described minimal life changes as a result of the experience of breast cancer and reconstruction, stating she believes this is because she has been through previous traumatic experience with the loss of her husband and hence has already experienced grave emotional distress:

“I think for somebody else this could have been so mega, it would be mind blowing, and I think that I’d already been through all that mind blowing stuff...I was never scared and I had more inner peace about that, but that’s from my experiences in the last few years”. (Patricia)

A few women described that breast reconstruction changed them as a person also. Two women stated they felt they had become better people. Most women described themselves as more sympathetic, empathetic and compassionate, which lead to a willingness to help others going through breast cancer and TRAM flap breast reconstruction. These women expressed they felt they had something valuable to share that would help others. Women reported this made them feel good about themselves and increased feelings of worthiness. Julia tells of her time helping others in similar situations:

“I’ve visited at least a dozen or more women and young girls that have had breast cancer. And because I got over it really well, you know with no side effects with me, I can go out to these people and confirm that ‘it’s okay, it’s alright, you can get over it’, you know, ‘just do the things you want to do’...I think I’ve left an image in their mind that, you know, breast cancer is not a death bed, it can be fixed, you can get over it...I just had more confidence and having more sympathy with people”. (Julia)

However, one woman did not feel this way. She felt helping others would bring it all back, when she wants to move on and not be reminded of it.

The women summarised their experience as a transition period in life. All women had commented the experience had changed their perspective on life. Some felt they had become somewhat ‘*enlightened*’. Gina said:

“It’s not about living and dying almost, it’s more the quality of what you have. And to appreciate every day and every moment, and just the blue sky, and the green grass, and the flowers, and how blessed we are. We have everything”.
(Gina)

This changed perspective initiated a rethinking of priorities. Stephanie explains:

“Things get put into perspective for you. You actually don’t have to sit down and think ‘Well let’s try and figure this out’. It actually just, it sits there on a plate and if you don’t eat it, so as to speak, you’ve got to be a silly person. I mean, it just lightens up your world and it says ‘Wake up, why are you worried about all this non-sense for? Just live’”. (Stephanie)

Things that were significant, now seemed insignificant. Several women noted material importance decreased and family importance increased. Gina explained her reprioritisation:

“The most important thing now is me! Unless I feel good about me, how can I be good for anyone else? I think the family benefits from the changed me”. (Gina)

This sentiment of increased importance of self was reiterated by several women. Decisions are now being made with more consideration for self.

Stephanie:

“I do what I want to do, nobody gets in my way. It might sound almost like a little bit selfish, because you get to a point if I want to do something now, I’ll do it...But in prior times...you always kind of fitted into everywhere else. Now I don’t do that anymore. If you don’t want to do it with me that’s fine...I’m not

prepared to have all this, excuse my language, but all this like bullshit, you know”.

Several women added these changes in outlook were also adopted by their partners and families, due to a greater appreciation for life and how they spend their time. However, for some women their husbands were somewhat confused and adverse to this change. Greater socialisation of women saw some husbands '*left behind*'. In most relationships both parties accepted this, and the dynamics of the relationship were modified accordingly to continue harmoniously. For others the relationship had suffered and these women recognised the need to address this situation. Most partnerships were described as stronger relationships. This was attributed to the sharing of the experience and living through it together. Women highlighted some relationships improved from their pre-existing state due to the husband's greater appreciation for his wife.

It seems the outcome of the process of adjustment is such a positive one considering the negative effects the experience can have on a woman's life. Paula likens the reasoning of the TRAM flap breast reconstruction decision to that of parenting:

“I was just thinking, you know, people have lots of kids. You have more than one. Any woman in her right mind would have one...the second wouldn't happen; you just wouldn't do it twice. But you do because the outcome is a positive thing...Maybe the reason we do accept this (breast reconstruction experience) is because the outcome is a positive thing”. (Paula)

Thus we can see the process of adjustment and subsequent redefinition of normality is accomplished over time, through the experiences of diagnosis, mastectomy, reconstruction, recovery, adjuvant therapy, and the impact these experiences and pre-existing issues have on body image, self-esteem, relationships and ultimately quality of life. It is clear to see that redefining normality did not just refer to the body image alterations of breast cancer. It involved redefining the meaning of life and what they do with it, and redefinition of their relationships with others. All women stated the experience was a positive one for them. The redefinition of their normality had resulted in the discovery of a better state of '*normal*'.

5.5 Summary

The women in this study clearly identified the breast cancer and breast reconstruction experience to be an intensely profound one. Dealing with the diagnosis of a life threatening illness, (in the cases of those having delayed breast reconstruction) living with mastectomy, and undergoing the physically and emotionally punishing TRAM flap breast reconstruction, had the potential to, and in some cases did, throw the women's lives into turmoil. The physical effects of these experiences consequently affected the psychosocial areas of body image, self-esteem, and sexuality - in fact the woman's entire self-concept, particularly regarding family and relationship dynamics. Therefore, adjustment to these inflicted changes was required. This adjustment was equally as complex as the sum of its indicators. The women adjusted through

redefinition of what 'normality' meant for them. For most, TRAM flap breast reconstruction was a positive step in the adjustment phase, however for others it incurred further need to adjust. Despite this, and the recognised influencing factors of this process of adjustment, all women identified positive adjustment over time.

The first theme, "Loosing a breast matters" highlighted women's recognition of the unexpected impact loss of a breast had on self. The women felt there was a need to have others recognise this impact, however this was minimally achieved. Contradicting this was women's struggle for individuality in terms of being identified as more than a breast.

The second theme, "The process of adjusting to a changing body image" identified differences between women who had immediate and delayed TRAM flap breast reconstructions. In general, those undergoing delayed breast reconstruction demonstrated a more positive and rapid adjustment than those undergoing immediate breast reconstruction. Aesthetic outcome and pre-existing body image were identified to be factors affecting the process of adjustment. Barriers to the process of adjustment were also identified, including situational circumstances at the time, adjuvant therapy and complications. The women expressed the importance of support mechanisms, particularly with regard to changing relationship dynamics and subsequently changing circles of support. The women identified positive and profound relationships with their plastic/reconstructive surgeons, as these men were able to recognise and accept the immense impact of losing a breast.

The third theme, “Redefining normality” was identified to be the aim and outcome of the process of adjustment. The redefinition of normality was not only a process regarding breast reconstruction, but also involved the life changing experience of living with breast cancer. All women in this study, despite few negative reports of some aspects of their experiences, reported major life changes and a positive redefinition of self.

Exploration of these findings and their implications will be discussed in Chapter Six.

CHAPTER 6

DISCUSSION

This chapter will discuss the findings of this research regarding issues for women undergoing TRAM flap breast reconstruction post mastectomy, drawing on the analysis of the women's experiences and current literature. The aim of this chapter is to discuss the findings of this research, so that health care professionals and others will gain a greater understanding to assist women's transition through this experience.

Recommendations for improved support, guidance and education for women undergoing TRAM flap breast reconstruction will be outlined. Limitations to this study will also be noted.

The experiences described by the women in this study, as depicted in Chapter 5, highlight the all encompassing experience of breast cancer and breast reconstruction. Although the long-term effects of various forms of cancer on quality of life have shown to result in similar life changing outcomes (Carpenter et al, 1999; NBCC, 2003), the experiences of these women living with breast cancer emphasised the significant impact on aspects of body image, self-esteem and overall self-concept. The Clinical Practice Guidelines for the Psychosocial Care of Adults with Cancer (NBCC, 2003) recognised that certain issues experienced by cancer survivors may be more applicable to those diagnosed with cancer of a specific origin. The authors reported that body image and sexuality are in particular pertinent issues for women with breast and gynaecological

cancers. In a review of cancer literature, the authors of these guidelines found much of the literature regarding body image was related to women living with breast cancer.

The profound impact of the diagnosis and treatment for breast cancer experienced by the women in this study may further be attributed to the connotations of intimacy associated with the breast and its removal. The breast has long been identified as an integral component of a woman's self concept, encompassing the areas of motherhood, sexuality and feminine identity (Grossman, 1976; Derogatis, 1986; Sawaya, 1994). The women in this study often referred to the lost feeling of '*wholeness*' after removal of their breast. Yet when assessing body image in breast cancer patients Hopwood (1993) highlighted that women's descriptions of their sexuality involved more than simply having a breast. This has been expressed in earlier research, with an Australian study recognising the complexity of issues a breast cancer survivor faces beyond that of losing a breast, distinguishing body image as one of those major issues (Reaby & Hort, 1995).

Body image is clearly one of the concerns at the forefront of dealing with a breast cancer diagnosis. In many circumstances the shock associated with a diagnosis of breast cancer results in body image being perceived as a secondary issue at this time. For a small number of women, however, body image has been found to be a primary consideration in the treatment choice (NBCC, 2002). This demonstrates the place body image assumes within a woman's self-concept. The Clinical Practice Guidelines of Information, Counselling and Support for Women with Breast Cancer (NHMRC, 2000)

recommended body image issues be viewed as including the person as a social being, not just related to the physical aspects of existence. Therefore it is evident the holistic experience of breast cancer and subsequent surgeries may be intensified due to the more intimate nature of the breast and its overall impact on a woman's core self-concept.

The three themes derived from this research will be discussed within the context of their sub-themes.

1. "Loosing A Breast Matters".

- Recognising the impact of the loss of a breast.
- I am more than a breast.
- Struggling to gain acceptance.

2. "Adjusting To A Changing Body Image".

- Timing of breast reconstruction.
- Situational factors influencing the process of adjustment.
- Finding support throughout the process of adjustment.
- Surgeon's acceptance and recognition of the women and their situation.

3. "Redefining Normality".

Further discussion will focus on the complexity of the breast cancer and breast reconstruction experience, with a central focus on the impact of TRAM flap breast reconstruction on self-esteem and perceived body image for women with breast cancer.

“LOOSING A BREAST MATTERS”

The theme “Loosing a breast matters” illustrated the psychosocial impact of mastectomy. However, for women who underwent immediate breast reconstruction issues related to losing their breast were also expressed after breast reconstruction surgery. Not only did this impact involve the woman’s self-concept, but the perceptions of others and the woman’s response to these perceptions.

Whether undergoing mastectomy with or without immediate breast reconstruction, the women identified they underestimated the psychosocial impact their experience would have on them. It has been well documented that the psychological impact of a cancer diagnosis is significant (NHMRC, 2000; NBCC, 2003), regardless of prognosis. Whether coming to terms with a life threatening illness, or dealing with the physical, emotional and social challenges related to surviving cancer, psychosocial impact is an unavoidable part of the breast cancer diagnosis (NBCC, 2003). Approaches to lessen this impact and improve women’s quality of life have increasingly been the focus of research over the last five years.

Women in this study reported initially *undervaluing the significance of body image and therefore the impact of losing their breast* (see section 5.2.1). The definition of body image used to guide this study's framework refers to the conscious and subconscious aspects of body perception (Stuart & Laraia, 2001). It is perhaps the subconscious aspects of body image that are not contemplated when considering the loss of a breast. At this time a woman's focus may be on survival and dealing with the immediate day-to-day consequences of her diagnosis. Only when women are immediately faced with this loss, do subconscious aspects become prominent, with a realisation of the significance of the impact on their body image. For the women in this study the meaning of body image was expressed as feeling '*normal*' about their bodies. Related issues of symmetry, form, everyday function and sexuality were encompassed in the concept of a satisfactory body image for these women. A study by Cohen and colleagues (1998) also illustrated the defining importance of body image to women living with breast cancer. Body image was a social expression of who they were, a way of being in the world beyond the realm of physical appearance, and an expression of existence following the threat to their mortality.

All the women in this study described experiencing feelings of psychological distress throughout their breast cancer experience related to facing their own mortality, feelings of loss and imposed body image concerns post surgery. Regardless of their pre existing expectations, losing a breast mattered a great deal to these women. It was a source of immense psychological distress and impacted on their entire lives. Breast reconstruction became a means to

ameliorate this burden and improve quality of life for these women. Several studies suggest depression can be twice as prevalent for women suffering breast cancer than the general female population (Fallowfield et al, 1990; Royak-Schaler, 1991). Zabora and colleagues (2001) study reported the rate of psychological distress within cancer patients ranges from 20-66%, compared to a national average of 17% in the general community (Australian Bureau of Statistics, 1998). McDaniel and colleagues (1995) identified major psychological issues for women with breast cancer to include body image disturbance, depression and anxiety. These authors argued the significance of these issues were often under-appreciated and under-treated. For the women in this study, particular exacerbation of anxiety was expressed during checkups due to the fear of recurrence of the breast cancer (see section 5.2). Several studies have identified this fear of recurrence to be a prominent concern and cause of psychological distress in up to 50% of breast cancer survivors (Jenkins et al 1991; Hall et al, 1996).

The sub-theme '*I am more than a breast*' reflected the women in this study's experience of the contradicting feelings associated with the loss of their breast, resulting in confusion and difficulty in expressing their views and concerns. Women identified strongly with their breast, although wanted their experience to be recognised as being about more than the loss of a breast (see section 5.2.2). This contradiction arose from the struggle encountered by women to gain acceptance, not only from others

but also from themselves. This reflects the experience of these women as being an external struggle influenced by the values of society and also an internal struggle with self. Society, as defined by the women in this study, encompasses family, friends and the broader community within which they live.

The literature describes the conflict experienced by breast cancer survivors, particularly relating to the balance between dependence and independence, and grief at experiencing great loss with joy at reclaiming life. The Clinical Practice Guidelines for the Psychosocial Care of Adults with Breast Cancer (NBCC, 2003) highlighted this contradiction regarding loss versus life may result in feelings of isolation and a sense of being poorly understood. The women who underwent delayed breast reconstruction expressed this contradiction. These women described difficulties dealing with the emotional consequences of mastectomy. As explained by Gina, there was a need to balance the repulsion she felt towards her body, with expected feelings of gratefulness to be alive (see Gina's quote, page 102). This led to some women feeling guilty about their difficulty dealing with mastectomy, and a sense of failure in deciding to reconstruct their breast, while being resentful of the personal cost required to secure this.

These contradicting feelings added confusion during the process of adjustment for these women. While trying to accept their situation and wanting this to be acknowledged, women did not want to be perceived simply as a 'breast'. Perhaps the focus on the importance of breasts, through media, film and other influencing mediums within

society, makes this body part or the absence of it, the focus of a breast cancer sufferers' identity. The women in this study believed the concentration on the breast ultimately detracts from the whole experience of breast cancer and breast reconstruction, yet seek to replace the lost breast, again adding to the contradiction of their experience.

These contradicting feelings were a focal point for these women in their *struggle to gain acceptance* from society. While there have been no studies that have specifically explored societal attitudes towards breast reconstruction surgery, a recent psychosocial/sexuality study undertaken by the NBCC (2002) commented that a woman's reactions to her breasts and attitudes to related issues raised, is strongly influenced by the portrayal of women in society. Women participating in this study described a heightened awareness of this portrayal following their breast surgery. They perceived a negative societal attitude towards breast reconstruction, in that it implied breast reconstruction to be '*superficial*' and '*cosmetic surgery*'. The women described a perception by others that breast reconstruction was a minor procedure, not a necessity. As this study has highlighted breast reconstruction involves much more than the physical restoration of a breast, but incorporates vast psychological and emotional issues associated with the loss of a breast. The procedure of TRAM flap breast reconstruction, as previously detailed in the literature review (see section 2.4), involves lengthy, intricate surgery and a prolonged and physically strenuous recovery.

The consensus from the women who participated in the focus group of this study, was that breast reconstruction is seen by society solely as an aesthetic improvement, and

implies vanity on the part of women who choose to have this procedure. Women were made to feel TRAM flap breast reconstruction was not essential as it was not 'life preserving' surgery and was therefore optional. However, for these women this surgery was necessary, and in some cases imperative to improve their quality of life. For these women the importance and value of this surgery was not recognised or valued by society. In some cases 'society' includes close family and friends.

The women described feeling that others perceived breast reconstruction as indicative of failure to adjust to the impact and consequences of breast cancer. The women appeared to initially experience a sense of failure and guilt associated with the decision to undergo breast reconstruction. The women described how the views of others placed pressure on them to be seen to be 'coping'. Ultimately this led to the women pretending that they were coping and not openly talking about their internal struggle (see section 5.2.3). This increased pressure to cope with their situation evidently impaired the process of adjustment for these women. Several authors have identified that the decision to have breast reconstruction can be associated with gaining a sense of control over the situation (Clayton & Waller, 1996; Astin et al, 1999). The study by Astin and colleagues (1999) reported this attempt to control what can be an uncontrollable situation can lead to burdensome feelings of responsibility, blame and guilt for women.

Although the women felt undergoing breast reconstruction would be seen by others as indicative of their inability to cope, implying a failure on their part, breast

reconstruction became an important means for them in adjusting to the sequelae of breast cancer and mastectomy. The women's struggle to gain acceptance regarding the decision to have a breast reconstruction often meant they felt the need to justify their decision. This was achieved through the expression of worthiness for breast reconstruction according to age (see quotes on pages 109-110). Women felt they were still young enough to be 'eligible' for breast reconstruction. This poses the question; at what age would these women no longer be considered eligible for breast reconstruction?, and whose decision would this be, is it the surgical team or the woman herself? The general consensus of the women in this study was that women in their forties and fifties still deemed themselves worthy, but they would not if they were in their sixties or seventies. Although one woman who was now in her sixties defensively believed she was still worthy. Perhaps women's 'eligibility' increases as their age increases. The concept of 'worthiness' in itself is a challenging one. Women felt the need to place a value of 'worthiness' upon themselves to justify their decision to undergo breast reconstruction. It later became evident that coming through the experience of breast cancer can increase women's feelings of worthiness. All of the women in this study, due to their experiences, are positive advocates for breast reconstruction. The impact of breast cancer is identified to be significant for women of all ages (Northhouse, 1994; Sawaya, 1994). However, some studies suggest younger women experience more concerns related to heightened sensitivity to body image alteration and higher investment in body image, leading to further risk of psychosocial distress (Northhouse, 1994; Al-Ghazal et al, 1999).

Once the decision to have a breast reconstruction was made, the next hurdle women experienced was associated with the recovery phase. Women again identified pressure from family and friends to breeze through recovery and be independent, therefore leading to a reluctance to seek help during this physical recovery stage. The need to be independent was evident within the hospital setting and after discharge from hospital, and was recognised by the women to have the potential to compromise both physical and emotional recovery. How much this was influenced by the women's view that breast reconstruction surgery was not 'justified' is not clear.

Several women stated the pressure to be seen as 'coping' lead to a reluctance to express to others their feelings related to their experiences, as outlined previously. The women in this study explained their suppression of feelings by commenting they felt society's lack of understanding would not result in the provision of support and empathy needed, and may further the view that women were not coping, perhaps instigating a greater sense of failure. This pretense of coping was demonstrated by several women, who reported hiding their feelings from others. Women's experiences of mastectomy and breast reconstruction were not generally discussed with people who had not closely been through their experience with them. The Clinical Practice Guidelines for the Psychosocial Care of Adults with Cancer (NBCC, 2003) identified that inhibiting the expression of feelings is associated with feelings of shame and admitting difficulty coping. Servaes and colleagues (1999) suggested this suppression of feelings can be an attempt to contain feelings in order to maintain 'acceptable' social relationships. Their study comparing breast cancer survivors to a control group, found the patient group

showed more ambivalence over emotional expression, and more restraint, however accompanying this were greater levels of anxiety. Several studies have noted the avoidance of discussing emotional issues can lead to increased distress (NBCC, 2003). This was also evidenced by the reports of the women in this study. Their psychological distress was manifested by feelings of loneliness and isolating themselves from the outside community, often leading to self diagnosed bouts of depression. Discussion of their experience was undertaken with few close family members or friends.

The problem related to the perceived views of society regarding breast reconstruction and the effects of these perceived views on women choosing to undergo breast reconstruction, is cyclic in nature and needs to be broken. Broader society's understanding can only be improved by women sharing their experiences, yet women feel they can not truly express their feelings related to these experiences openly. Although women choosing to undergo breast reconstruction is only approximately 20% of the women requiring mastectomy in Australia, this number is increasing. It is the task of health care professionals to raise awareness of breast reconstruction within society, in order to establish its place as a fundamental part of the treatment of breast cancer.

“ADJUSTING TO A CHANGING BODY IMAGE”

The experience of undergoing a TRAM flap breast reconstruction is one of transition, as illustrated by the women in this study. During this transition women had to adjust to a changing body image. Timing of breast reconstruction was discovered to be an influencing factor on this process of adjustment. It was also recognised by the women that several external factors influence this transition period and ultimately individualise the experience. Support from both health care professionals and family and friends was expressed to be of paramount importance throughout the breast cancer and breast reconstruction experience.

Timing of breast reconstruction was an important variable in the process of adjustment. Distinct differences were identified when exploring the experiences of women who had immediate and delayed breast reconstruction (see section 5.3.1). Women undergoing delayed breast reconstruction experienced improvement in body image and self-esteem post breast reconstruction (see Stephanie’s quote on pages 117-118). While those having immediate breast reconstruction described an initial decline in body image and self-esteem, subsequently improving over time (see Patricia’s quotes on page 118-119). This may be explained as women having delayed breast reconstruction have already experienced the loss of a breast, which ultimately became motivation to undergo breast reconstruction. However, women having immediate breast reconstruction are experiencing that loss immediately post breast reconstruction. Although women may have the form of a breast, it is still not the same as the original breast in many ways. The breast reconstruction experience therefore becomes part of the loss as opposed to

the replacement. This is not to advocate delayed breast reconstruction, but to highlight that we cannot assume women having immediate TRAM flap breast reconstruction do not experience loss.

The obvious difference in the staging of adjustment between the two groups relates to the women's expressed focus on feeling '*normal*'. As identified by the women in this study, those undergoing delayed breast reconstruction move from feeling '*normal*' (pre cancer diagnosis), to '*abnormal*' (after mastectomy), and then return to '*normal*' (post TRAM flap). Contrastingly, women having immediate breast reconstruction initially experience a single transition from '*normal*' (pre cancer diagnosis), to '*abnormal*' (post TRAM flap), with a gradual improvement towards '*normal*' experienced over one to two years post operatively. Despite this, those women who had immediate breast reconstruction verbalised overall satisfaction with their outcome. Perhaps cognitive dissonance plays a role whereby expressing grave dissatisfaction would prevent them from moving forward past their trauma, therefore an exaggerated degree of satisfaction assists this dissonance (Reaby et al, 1994).

These differing experiences highlight that breast reconstruction is not necessarily a 'fix it' solution to the impact of mastectomy. For those undergoing immediate reconstruction consequences similar to that experienced by those living with the sequelae of mastectomy can still be experienced. One study hypothesised that low satisfaction could also be attributed to the complex nature of the TRAM flap operation, and the need for revision procedures to achieve a personally acceptable aesthetic result

(Harcourt et al, 2003). There is a need to look further into both short term and long term benefits of immediate breast reconstruction.

The findings of this study contradict the view of several authors who argue that those who have immediate breast reconstruction do not suffer the distress of losing a breast (Noone, 1985; Bostwick, 1995; Clayton & Waller, 1996; Cogwell et al, 1996; Neill & Briefs, 1997; Al-Ghazal et al, 2000). The women in this study who underwent immediate breast reconstruction expressed grief related to the loss of their original breast, similar to the feelings experienced by women who had lived with mastectomy. Both groups at differing stages of the process of adjustment talked about feeling 'whole' and experiencing self consciousness and decreased self confidence. Some authors argue that delayed breast reconstruction assists women to adjust to a changing body image (Schain, 1985; Winder & Winder, 1985; Harcourt & Rumsey, 2001). However, it became evident the women participating in this study chose to undergo breast reconstruction as they were unable to adjust to their altered body image secondary to mastectomy. The women who underwent delayed breast reconstruction described greater appreciation of their reconstructed breast, as has been previously reported (Schain, 1985; Winder & Winder, 1985; Harcourt & Rumsey, 2001). The benefits in the long term may well be the same in both groups. This is an area in need of further research.

There were exceptions to the differences identified between immediate and delayed breast reconstruction outcomes. These were related to educational and support factors.

Paula's negative description of her hospital stay was identified by herself to be primarily responsible for her perceived negative aspects of her breast reconstruction experience. Paula acknowledged it was difficult to separate the negative experiences of her hospital experience from her satisfaction with the outcome of her breast reconstruction surgery. For Marie, while having an immediate breast reconstruction, she still experienced loss due to her breast removal, however reported a very positive experience and greater satisfaction with her outcome. She attributes this to the education and support given by the surgical team.

The variations in the women's emotional experience leads to further questions for future study. These include, to what extent do pre-existing personality traits and attitudes influence experiences and act as outcome predictors? Research has been completed related to control issues and psychological distress. Although control is deemed a healthy part of psychological function, it has the potential to become unhealthy (Astin et al, 1999). Astin and colleagues (1999) study found women who expressed a high desire for control, yet demonstrated few positive control actions showed the poorest adjustment. Women who expressed a high desire for control and achieved greater positive active control showed the best psychological adjustment. This represents another balancing act for women regarding a healthy level of control over their own health. The capacity to be flexible within a situation of uncertain and sometimes uncontrollable dynamics appears to be important to psychosocial outcome.

All the women undergoing immediate breast reconstruction recognised a decline in their self-esteem post-operatively, regardless of the pre-existing levels of self-esteem reported. Women who described themselves as having a high pre-existing self-esteem, reported a significant drop in self-esteem due to the perceived imperfections of their bodies secondary to breast reconstruction (see Janet's quote on page 122). Women in this study who, from their descriptions, identified a low pre-existing self-esteem viewed the change to their body image resulted in a further decline in self-esteem (see Patricia's quote on page 122). It has previously been documented that women who have a high investment in their body image are at increased risk of experiencing impaired psychosocial adjustment (NHMRC, 2001). A study by Hart (1996) found a pre-existing positive body image enables greater tolerance for emotional distress, while a negative body image may be exacerbated by the alteration caused by breast surgery. Assessment of women's functioning self-concept, including body image and self-esteem, prior to undergoing breast reconstruction may be useful in predicting and organising post-operative support requirements within specific situations.

Apart from the personal aspects affecting how the women dealt with their experience of TRAM flap breast reconstruction, *finding support throughout the process of adjustment* was another challenge faced by the women in this study. Several women in this study reported experiencing changes in their relationships due to the breast cancer and breast reconstruction experience. Some women described personal growth and therefore closer relationships, while others described deterioration and disintegration of some friendships. The women perceived that relationships were distanced as people did not

understand the cancer experience or were frightened by it. The women explained the concept of cancer was immediately associated with death, and this misrepresentation made others uncomfortable and unaware of how to react towards them. Strengthened relationships were attributed to the sharing of experiences with others and receiving immense emotional support from them.

When discussing the issue of intimacy with partners, most women stated their husbands were accepting of their new bodies and sexual intercourse was not obviously affected. The women still described feeling self conscious regarding the exposure of their bodies, despite reassurance from their partners. Importantly, how women felt about their bodies impacted on their overall sexual experience and sense of sexuality. Although the women did not directly report sexual dysfunction, in discussing their experiences sexuality dysfunction did become apparent. Women reported this situation improved over time as they became more comfortable with their bodies. Barbara's partner rejected her body after mastectomy, and consequently she reacted with feelings of resentment toward him. After breast reconstruction her partner became more accepting of her body sexually, this sending her the message that her value to him was influenced by having two breasts.

The women in this study described the recounting of friends and families stories of others cancer experience as distressing (see pages 133-134). Perhaps others tell these stories in an attempt to express understanding of the situation through some connection. This may also be a subconscious and deliberate act, almost in the form of a blocking

strategy, in an attempt to distance themselves from a situation they do not feel they can handle. It seems this story telling impacts on the women by devaluing and depersonalising their experience. The women found a lack of understanding from these people, as they seemed to be moving the focus away from the women's breast cancer experience. It was as if family and friends did not or could not share the women's experience and emotional distress.

One relationship strongly expressed by several of the women in this study was regarding women's relationships with their plastic/reconstructive surgeons (see section 5.3.4). The women in this study described relationships with their plastic/reconstructive surgeon that were very important to them. Endearment and admiration was attributed to the surgeons caring for the women and about their situation, not solely on the technical aspects of the surgery. Surgeons were held in very high regard by the women both professionally and personally. Women were extremely grateful for what the surgeons had provided for them and the changes this had made to their lives. The surgeons were ultimately viewed as having 'rescued' the women by restoring their altered body. This had a profound effect on the women's emotional wellbeing. The surgeon reconstructing the breast did what others could not – understood and helped rectify the problem being faced. In fact, these clinicians stood out as they were giving back, as opposed to the outcome of other clinicians encountered through the cancer experience who took away (for example oncologists and breast surgeons). TRAM flap breast reconstruction was advantageous compared with the negative consequences of mastectomy and adjuvant therapy. The plastic/reconstructive

surgeon was therefore associated with a positive outcome of a negative cancer experience.

This union had the dynamics of a relationship, including formation, maintenance and termination. Women expressed sadness at the termination of this relationship. Surgeons had been viewed as friends and the relationship was of great importance to the women. One quality this relationship did not hold was reciprocation. It was not evident that the surgeon's view of the relationship was reciprocated, as feelings towards the women were not shown to be of the same intensity. The intensity of this relationship may be related to the intimacy associated with the breast. This may involve an aspect of the surgeon fulfilling a role of male acceptance and understanding. Feelings may have been intensified as the surgeons were perceived to be the only people to wholly understand the women's situation. These findings contrast those expressed in the sexuality/body image study that found women felt health care professionals were too busy with clinical aspects of care that they do not deal with body image and sexuality as important issues. However, not all the women in that study had the further experience of breast reconstructive surgery.

One concept previously identified by Weiss (1974) (as cited in Dragsett & Lindstrom, 2003) that outlines the dynamics of this relationship between the women and their plastic surgeons is the theory of social provision. Weiss describes social support as consisting of several different components. Firstly attachment, whereby a person gains a sense of emotional closeness and security. Secondly, reassurance of worth. The

opportunity for nurturance, refers to displaying a sense of responsibility for the well being of others. Reliable alliance describes a situation where a person can count on assistance under any circumstances. Finally, guidance from trustworthy individuals who can provide advice and expertise. The relationship these women described displays all these characteristics. Through these attributes women feel they became close to their surgeon. The surgeon made the women feel worthy of breast reconstruction and showed concern and nurturance for the well being of these women. There was an immense amount of trust and reliance demonstrated upon the surgeon.

The women in this study highlighted the areas of support required to be spiritual, emotional, familial and also physical in nature. The same breadth of holistic concerns have been identified in other studies (Wyatt & Freidman, 1992). Although several women in this study stated what others thought of them did not matter to them, they later went on to describe events where it did. It was unclear whether this an attempt to convince others, or perhaps to convince themselves also. Women expressed that people around them were supportive, yet identified experiencing a lack of support. This may highlight differences in what is supportive behaviour, and the mismatch between the type of support offered and needed. This may also highlight the isolation these women can experience. Support is a concept that has received limited focus, yet Hart (1996) postulated the woman's environment and support system can be the most accurate predictor of how well a woman will cope and adjust to breast cancer.

The variety of *factors demonstrated to influence the process of adjustment* for the women in this study clearly evidenced the complexity of the experience of a woman undergoing TRAM flap breast reconstruction after mastectomy (see section 5.3.2). It is well recognised that women dealing with breast cancer survival may have pre existing issues influencing their experience and increasing the complexity of their current situation. These may include previous life experiences as well as a range of medical, social, practical or emotional issues (NBCC, 2003).

Financial worries were found to add pressure to the women and their families. Women recognised the need for greater awareness of available resources to alleviate financial burden. Adjuvant therapy was found to hinder recovery from breast reconstruction. Although this situation cannot be avoided, unless breast reconstruction is delayed, further support within the home may help alleviate this burden.

Post-operative complications were found to prolong the recovery period and negatively influence aesthetic outcome, resulting in a delayed process of adjustment. There is a need to educate women regarding possible complications and their outcomes, and to reassess their need for support requirements during the recovery period. Revision procedures were seen by the women to enhance the outcome of TRAM flap breast reconstruction. Further progression in the process of adjustment was made as a result. Women may be unaware of the length of the entire experience, from the initial consultation with the surgeon to the completion of revision procedures two years or

more later. The provision of information in a number of different formats is crucial for women.

“REDEFINING NORMALITY”

Redefining normality was the aim and anticipated outcome of the process of adjustment. Although this redefinition was a forced consequence of the need to undergo mastectomy for breast cancer, all women expressed a positive outcome of this redefinition (see section 5.4).

Women identified the need to redefine normality, as the '*normal*' they once knew before their breast cancer diagnosis and breast reconstruction experience was no longer able to be maintained. The women in this study also realised that ultimately the breast was never going to be the same. More than the physical, however, their lives had changed as a result of the experience they had been through. The Clinical Practice Guidelines for the Psychosocial Care of Adults with Cancer (NBCC, 2003) recognised all forms of cancer potentially threaten the lives of survivors, often resulting in an altered lifestyle.

Redefining normality did not just involve aspects of body image related to breast surgery, but included redefinition of relationships, family situation, lifestyle and entire self. The challenge faced by the women in this study was to maintain harmony of the redefined self within the context of self and family. Women reported the changed

perspective on life lead to reprioritisation and altered lifestyle, which ultimately improved their lives. The changed outlook on life is commonly attributed to the diagnosis of breast cancer and having to face mortality (NHMRC, 2000; NBCC, 2002), however many women in this study attributed the improvement in life to the advantages of breast reconstruction surgery. Similar reports related to appreciation, lifestyle reprioritisation and focusing on self have been verbalised by women participating in other studies. (Carpenter et al, 1999; NBCC, 2002). A study by Neill and colleagues (1998) concluded a similar thematic focus of women “seeking normality”. Heindrich and Ward (1992) have previously postulated that people may adjust to illness through a process of redefining who they are. Undergoing breast reconstruction following mastectomy has been identified as a process that assists in the return to normalcy (Nissen et al, 2002). Though this was a redefined concept of ‘normal’. As indicated by the women in this study the key to the process of adjustment was time, regardless of the support networks and coping mechanisms utilised during the experience. Not only is it important for women to develop this redefinition, it is also necessary for others to recognise and accept this new image and often changed person (Hart, 1996; NBCC, 2003).

Throughout the interviews and focus group, several references were made comparing the experience of breast reconstruction to the obstetric experience. Coping after the major surgery of TRAM flap breast reconstruction was compared to having a caesarian section. The implied pressure to cope following breast reconstructive surgery was compared to the expectations of a ‘glowing’ mother after caesarian section (see

Patricia's quote, page 111). The women's relationship with the surgeons was compared to the intimate relationship with an obstetrician, and the sudden termination of that relationship (see Marie's quote, pages 137-138). Also, upon discussion of women dealing with and accepting the punishing, timely process of breast reconstruction, the experience was compared to having children. As stated by Paula, the negative aspects of the experience were worth the positive outcomes, similar to child birth and the rewards of parenting (see Paula's quote, pages 147-148). Women perhaps viewed their process of adjustment and redefinition of normality as a metaphorical rebirthing of self.

CONCLUSIONS:

There are several significant conclusions to be drawn from the findings of this study that have applications within the context of nursing care. Being diagnosed with breast cancer and undergoing TRAM flap breast reconstruction is a significant and life changing process with immense psychological, social, emotional and physical repercussions. The need for support before, during and after this time is paramount. This is not only due to women underestimating the impact of losing a breast, whether it is reconstructed immediately or at a later time, but also due to women's perceptions of societal views towards their experience. Women who undergo TRAM flap breast reconstruction simply are not receiving enough support. The psychological impacts of breast cancer are now well recognised. Although the support women require involves

psychological wellbeing, a greater focus on the physical, financial and social realms associated with recovery is needed.

Society's views of breast reconstruction and lack of understanding, as described by the women, inflicts pressure to cope leading to feelings of guilt and failure, along with suppression of emotions related to the breast reconstruction experience. This indicates a need for broadened education to increase the awareness of breast reconstruction and associated issues within society. This is an area all health care professionals can influence.

The experience of undergoing mastectomy and TRAM flap breast reconstruction is a process of adjustment over time. The differing stages of adjustment between women having immediate or delayed TRAM flap breast reconstruction showed greater immediate satisfaction among the delayed breast reconstruction participants. However, chronologically, whether dealing with mastectomy then breast reconstruction or dealing with the sequelae following immediate breast reconstruction, outcomes are similar. This area would benefit greatly from further research with a larger sample size, to explore and analyse the growing trend towards immediate breast reconstruction.

Despite the need to improve support associated with breast reconstruction, the overall experience of TRAM flap breast reconstruction is a strengthening process, whereby women can meet the challenges faced. Overall the experience

is described as positive, despite the hardships encountered. This is ultimately achieved through the women redefining what is 'normal' for them. This does not in any way lessen the significance of the experience, as different circumstances act to dramatically individualise this experience. Therefore it is imperative each woman's experience is assessed and supported appropriately.

LIMITATIONS:

As a qualitative study a small number of participants were recruited, with a relatively short follow up period since operation of less than two years. This limitation was due to the time constraints of being an honours research project. While allowing for in-depth exploration of the women's experiences these results are not generalisable. The sample of this study was taken from a private hospital, with no representation of those within the public health sector. It remains unclear whether this factor may influence findings. Although the majority of TRAM flap procedures in Western Australia are undertaken in the private health sector, further research incorporating both sectors is required. A further limitation relates to the lack of tools used to measure the variables of self-esteem and body image being investigated. Further research would benefit from a mixed method, prospective study design, with a larger sample size and greater follow up period. This would allow for more complex and in depth

analysis of the diversity of staging of the process of adjustment to reconstructive breast surgery.

RECOMMENDATIONS:

Education: There is a need for greater education of women who choose to undergo TRAM flap breast reconstruction. Pre-operatively, women require more knowledge of the procedure itself, the recovery period involved and the possible complications and their consequences on recovery. Body image, self-esteem and sexuality issues should also be addressed as important issues in the education process. Education needs to continue in the post operative period to cover aspects of emotional impact, complications, recovery and support. Regular follow up of women's progress during the immediate and sometimes prolonged recovery phase should occur, and/or an education resource person should be available to address women's concerns, whether physical or psychosocial.

Family and significant others can be forgotten in the education process. It is important to educate family members, particularly in the areas of recovery and psychological impact for the woman, whether this is done individually or at the time of patient education. Society in general also needs to be educated about

breast reconstruction in order to raise awareness of breast reconstruction and its outcomes.

Support: Although women praised the support they received, they described a great lack of support, not only from health professionals but family and significant others also. This is why women undergoing TRAM flap breast reconstruction may also benefit from the education of family members. Support from health care professionals is crucial during the immediate pre and post-operative phases.

In terms of psychological support, needs may be better identified by pre-operatively screening patient's psychosocial adjustment. Monitoring of women's progress should occur throughout the process of adjustment to their changing body image so that changing educational and support needs can be identified and met. This follow up would be most beneficial to occur throughout the one to two year estimated time period of adjustment. Further support is required in the areas of physical support, perhaps in terms of domestic assistance, and financial issues, where available options should be explored. All required and available resources should be made aware to the woman undergoing TRAM flap breast reconstruction.

The educational and support needs of women undergoing TRAM flap breast reconstruction may best be met by extending the current education received.

The nursing role should be dedicated to the implementation of thorough and continuing education and support.

- ◆ Breast reconstruction of all types should be made more available and accessible to women with breast cancer who require mastectomy. Community awareness will assist this cause, however, health care professionals dealing with patients at the time of a breast cancer diagnosis should ALWAYS advise breast reconstruction as an option.

- ◆ Greater availability of breast reconstruction within the public sector is required. The majority of TRAM flap breast reconstructions are performed within the private sector, and of those performed in the public sector, delayed breast reconstruction is the most common option (Leanne Simpson and Joy Fong, personal communication, June 2003). This poses a dilemma for women who do not have private health cover and therefore may not be able to undergo breast reconstruction or have the timing of reconstruction they would like. This raises related equity issues that need to be addressed.

Future Research: The best outcome for the future would be a cure for cancer. Despite the possibility of this outcome breast cancer issues will unfortunately need to be addressed and dealt with for many years to come.

Areas that would benefit from further research as derived from this study include:

- ◆ The difference in outcome between immediate and delayed TRAM flap breast reconstruction patients.
- ◆ Identification of the educational needs of women undergoing TRAM flap breast reconstruction.
- ◆ Identification and provision of support needs for women undergoing TRAM flap breast reconstruction.
- ◆ The interventions and practice of health care professionals caring for women having TRAM flap breast reconstruction.
- ◆ Exploration of the dynamics of the relationship between the women undergoing TRAM flap breast reconstruction and their plastic/reconstructive surgeons.
- ◆ The impact of this surgery on family and significant others of women undergoing TRAM flap breast reconstruction.
- ◆ Further comparative studies between the TRAM flap procedure and other currently practiced forms of breast reconstruction on psychological and physical outcomes.

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APPENDIX 1

Surgeon's Cover Letter

Dear _____,

A member of nursing staff at the Mount Hospital, Olivia Hill, is undertaking research into women's experiences of having reconstructive breast surgery. An information sheet that outlines the details of the study and the contact details for participation are enclosed. If you are interested in participating in this study or receiving further information please complete the forms attached and return in the enclosed envelope.

You are under NO OBLIGATION to agree to participate in this study. Your decision to participate or not, will in no way impact in any care you receive from myself or the Mount Hospital. None of your personal details have been provided to the researcher.

Yours sincerely,

Mr _____

APPENDIX 2

Information form A

Study Title: What is the impact of TRAM flap breast reconstruction on self-esteem and perceived body image for women with breast cancer?

Researcher: Olivia Hill, RN, RMHN

Supervisor: Associate Professor Kate White

My name is Olivia Hill. I am a registered nurse at the Mount Hospital, currently undergoing a research project on TRAM flap breast reconstruction.

With Dr _____ permission I am writing to invite you to participate in my study regarding self-esteem and body image issues, relating to your experience of TRAM flap breast reconstruction.

The purpose of this study is to gain a deeper understanding of the psychosocial effects undergoing a TRAM flap breast reconstruction has on a woman's self-esteem and body image.

It is proposed this research study would give further insight into the experiences of women undergoing TRAM flap breast reconstruction. Not only is it anticipated this research may become a further information tool for women considering the procedure, but also assist in increasing awareness of the nursing skills required to provide adequate support and education to women before, during and after their hospitalisation for TRAM flap breast reconstruction.

Your participation would involve an interview with the researcher at a time and place that is comfortable and convenient for you. The interview will include a series of open-ended questions relating to your experiences of TRAM flap breast reconstruction, and will take between 30-60 minutes. Any personal details or identifying information will be removed from the data.

The second part of my study involves a focus group session. This will involve a group of women who have also undergone TRAM flap breast reconstruction and myself, undertaking a discussion session on the pertinent issues raised in the interviews. You may choose to participate in the interview, the focus group or both. You do not have to participate in both. Any form of participation would be greatly appreciated.

Interviews and focus group sessions will be tape-recorded. They will be transcribed by a qualified transcriber who will sign a confidentiality agreement. Original tapes and transcripts will be secured at the university premises in a locked office for a period of 5

years after publication of the research study, at which time they will be destroyed. The only people having access to the information given will be myself, and supervisor to the research, Associate Professor Kate White.

The perceived benefits to you in participating may include the opportunity to talk about your experiences within a supportive setting. In addition, information from this study will assist in developing a further information source for women considering TRAM flap breast reconstruction. You will be helping to further inform the practice of nursing, by assisting nurses to develop better education and nursing care for future TRAM flap patients.

Participating in this research by discussion of your personal experiences may cause emotional distress. In the event that this should occur, the interview would be stopped immediately. You would be given the option of continuing another day or withdrawing from the study. You may choose to withdraw your participation from this study at any time and this will have no impact on your relationship with your surgeon or any health service.

Please note this study has been approved by both Edith Cowan University and the Mount Hospital. Any person with concerns in relation to participation in this study at Mount Hospital should contact Dr Geoffrey Dobb, Chairman of the Mount Hospital Ethics Committee on 9483 2841.

Please find enclosed a consent form and stamped self-addressed envelope. Submission of contact details and signed consent is required as soon as possible, at the latest by , so I can commence my research.

Your participation in any form would be greatly appreciated. If something is unclear or you have any queries, please do not hesitate to contact me;
Mobile: 0407770946
E-mail:

Yours sincerely,

Olivia Hill

APPENDIX 2

Information Form B

8/9/03

Dear _____,

Once again, I would like to thank you for participating in my study titled, 'What is the impact of TRAM flap breast reconstruction on self-esteem and perceived body image for women with breast cancer?' The valuable information gained from the sharing of your experiences will be used to help educate others.

I am writing this letter in regard to the previously proposed focus group. The purpose of this group discussion session, is to clarify and further expand on issues discussed in the interviews, within a group setting. The group will consist of myself, a research officer from Edith Cowan University, and the other participants (9). Once again, the session will be tape recorded.

I have arranged this focus group session to take place at the **Mount Hospital** seminar room on Saturday the **4th of October, 2003**, at **10 am**. It is anticipated the session will last for 1-2 hours. Light refreshment will be provided.

Please return the form attached, stating your availability, in the self addressed envelopes as soon as possible. I will again be in contact to notify you of confirmation closer to the date. Please do not hesitate to contact me with any queries; ph:0407770946. Hope to see you there!

Yours sincerely,

Olivia Hill

APPENDIX 3

Consent Form

Researcher: Olivia Hill, RN, RMHN

Supervisor: Associate Professor Kate White

Research Question: What is the impact of TRAM flap breast reconstruction on the self-esteem and perceived body image for a woman with breast cancer?

I have been given clear written information about this study and any questions I had have been answered to my satisfaction.

I have been informed of the possible risks and benefits of participating in the study.

I am aware my participation will be confidential and any personal identifying details will be coded and secured at the university premises for a period of 5 years after publication, at which time they will be destroyed.

I understand ethical approval for this study has been given by both Edith Cowan University and the Mount Hospital.

I understand my participation is voluntary and I may withdraw from this study at any time.

Participant's signature

Date

Witness signature

Date

Written explanation of this study has been given to the participant and I have sought her understanding for informed consent.

Researcher's signature

Date

APPENDIX 4

Interview Schedule

- Thankyou for agreeing to participate. The purpose of this interview is to explore your experiences of breast cancer, mastectomy and reconstruction.
- Firstly- demographic questions.
- To start, could you tell me how the diagnosis of breast cancer made you feel?
- Was breast reconstruction discussed with you as an option following mastectomy?
- What were the deciding factors for you in choosing to have a breast reconstruction?
- How would you describe the impact of mastectomy/TRAM flap on your body image?
-prompt and explore for further detail.
- How has this changed over time? (explore role identity).
- Could you explain how this experience has affected your self-esteem?
-prompt and explore for further detail.
- How has this changed over time? (explore role identity).
- Can you tell me how these life changes we have discussed have affected your personal relationships?
-prompt and explore related issues of sexuality and intimacy.

FINAL QUESTION; Describe to me how you feel your life in general and yourself as a person has changed as a result of your experience with breast cancer, mastectomy and reconstruction.

Are there any other areas of your life that you feel breast cancer and your surgery has affected that we have not discussed?

-prompt and explore for further detail.

WIND-UP; Thankyou for sharing your experiences with me. It seems an overwhelming and profound experience, and I believe that by women sharing their experiences it can benefit health professionals, both doctors and nurses, by giving us an insight into how breast cancer diagnosis and surgery made you feel. I hope this further understanding can enhance the care we give to women experiencing breast cancer in the future.

PROMPTS; Could you tell me more about that?

How did that experience make you feel?

Explore: education, recovery, complications, revision procedures, coping mechanisms

APPENDIX 5

Focus Group Interview Schedule

- Introductions.
- Outline the purpose of the focus group: to further explore issues as identified in the individual interviews, related to the breast cancer and TRAM flap breast reconstruction experience.

“Normal” is a very hard concept to define. What did normal, within the context of this experience, mean to you?

It seems undergoing mastectomy and TRAM flap breast reconstruction affected everyone’s body image and self-esteem. How did your pre-existing body image and self-esteem impact on your experiences?

In terms of deciding to reconstruct your breast and having a TRAM flap, what mattered to you? What was important in impacting on you?

How hard was it to let people know how this experience was impacting on you?

How did others around you make you feel regarding what you were going through?

Was there any person in particular who understood what you were going through? Explore Dr/Patient relationship.

What helped you through the experience, and what didn’t help?

Were there any other issues or events either related to the breast cancer and reconstruction experience or not, that affected your outcome either positively or negatively?

Tell me how you feel the experience has impacted on you and your families overall. Explore the concept of positive outcomes to a negative experience.

Is there anything you feel could have been done to improve your experience?

What advice would you give to other women who may be considering TRAM flap breast reconstruction?

What recommendations would you give to health care professionals about assisting women through this experience?

APPENDIX 6

Edith Cowan University Ethical Approval



EDITH COWAN
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ABN 54 361 485 361

29th May 2003

Human Research Ethics Committee

Ms Olivia Hill (Student # 0990948)

Dear Ms Hill

Code: 03-78

Project Title: *What is the impact of TRAM flap breast reconstruction on self-esteem and perceived body image for women with breast cancer?*

This proposal has been reviewed by members of the Human Research Ethics Committee.

I am pleased to advise that the proposal complies with the provisions contained in the University's policy for the conduct of ethical research, and your application for ethics clearance has been approved.

Period of approval: **From** 29th May 2003 **To** 31st January 2004

With best wishes for success in your work.

Yours sincerely

Kim Gifkins
EXECUTIVE OFFICER
Phone 9273 8170
Fax: 9273 8661
Email: research.ethics@ecu.edu.au

Attachment: Ethics Monitoring Form

cc. Associate Professor K White, Supervisor
Ms S Kern, Executive Officer, HDC