UNDERSTANDING WOMEN’S EXPERIENCES OF THEIR BODIES AFTER UNDERGOING A MASTECTOMY AND NOT CHOOSING RECONSTRUCTION

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Thiloshini Devlall

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ABSTRACT

The aim of the research was to explore women's experiences of their bodies after undergoing a mastectomy due to breast cancer treatment and choosing not to have reconstruction. A qualitative study was carried out to gain a deeper understanding into women who took on a counter-cultural approach of choosing to live without breasts in a society that views breasts as the epitome of womanhood and a symbolic representation of femininity. Purposive sampling was used to meet two criteria, that is, to recruit the women who underwent mastectomies because it was part of a treatment plan to remove the cancerous tumours from their breast/s, which entailed losing one or both breasts and secondly who chose not to have reconstructive surgery after the mastectomy. In-depth interviews revealed a range of shared experiences of having breast cancer, undergoing a mastectomy and living without breasts. Data analysis was conducted using the phenomenological approach. Three leitmotifs emerged from the data: (1) Pressure for a "normal" body; the leitmotif highlighted the pressure the women experienced to conform to having two breasts. (2) Experiencing the body as transitional. Many of the women described various transitions that occurred from the time of being diagnosed, going through treatment and living with one or no breasts. (3) Exhibiting agency, the women described the various things they did to help deal with the changes they encountered. The research identifies that in the face of social pressure, perceptions of the body are transitional and that exhibition of agency is crucial amongst breast cancer survivors.

DEDICATION

To my amazing husband for standing by me and encouraging me to follow my dreams.

To my two wonderful boys for their constant love and affection.

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CHAPTER ONE: INTRODUCTION AND LITERATURE REVIEW

The female body encapsulates both the biological entity of being a woman and the culturally symbolic essence of womanhood. In other words, a woman's breasts have a biological function to lactate as well as socially and culturally her breasts are seen as sensual, the mark of her womanhood and the essence of her femininity. So, for a woman who becomes ill, in particular, develops a tumour in her breasts and has to have them removed, the ramifications and her experiences of being ill are not just biological but entwined within this socio-cultural ideology of how breasts are seen in society. Before I discuss breast cancer and the existing research into breast cancer survivors and their experiences as well as the aims of my current research, it is important to lay the bedrock for the theoretical foundations of embodiment.

Embodiment

There is no denying that the body is a biological organism, made of cells, nervous system, bones and tissue. However, the body is not just a biological phenomenon but can also be seen in socio-cultural terms. As Lupton (1998) highlights "the ways in which we understand and experience our bodies are mediated through social, cultural and political processes" (pg. 122). For example, in today's western society, thin bodies are seen as being attractive whereas in other societies larger bodies are seen as attractive. It may seem somewhat contradictory to argue that the physical body is shaped by psychological, social and cultural factors. After all, people go through natural lifecycles such as birth, death, sickness and pain. However perceptions about these events as well as understandings and beliefs thereof, vary amongst social and ethnic groups (Lupton, 1998; Cregan, 2006; Barry & Yuill, 2012). Societal norms and values shape the way one experiences their own body and as a result the body is experienced as both natural and a product of its social environment (Bordo, 2003; Shilling, 2008). This is because we both are and have a body; we are embodied beings.

In a fundamental sense, the body is our way of being in the world. Embodiment is a synchronized experience of cognitive awareness and material reality of the individual. The individual's feelings, behaviours and thinking are rooted in his/her bodily interaction with the world (Merleau-Ponty, 1962; Davies, 1997; Carey, 2000). According to Merleau-Ponty (1962, pg 146)

> *"The body is our general medium for having a world. Sometimes it is restricted to the actions necessary for the conservation of life, and accordingly it posits around us a biological world; at other times, elaborating upon these primary actions and moving from their literal to a figurative meaning, it manifests through them a core of new significance: this is true of motor habits [sic] such as dancing."*

In other words, the individual through his body and with his body interacts with the world. An individual is an embodied being, not simply someone who possesses a body but rather refers to the experience of living through the physical body (Shilling, 2004; Barry & Yuill, 2012; Shilling, 2012). However, our experiences of embodiment are more than just the individual's biological interactions with their socio-cultural spheres. Our experiences are influenced and shaped by shared social and cultural understandings (Merleau-Ponty, 1962; Burr, 1995; Cromby & Nightingale, 1999; Butler, 2003). These socio-cultural understandings of the body are underpinned by societal and ideological categorisations of gender, race, class and so forth. As a result the body is seen in terms of colour such as being white or black, male or female, rich or poor.

Furthermore, the ideological constructions of gender, race and so on, not only bring about understandings of embodiment, but also influence cultural practices regarding the body (MacLachlan, 2004). Cultural practices regulate the manner in which the body is understood and engaged with. For example, in the Maori culture the head is considered "tapu" or sacred and so there are certain cultural regulations regarding the manner in which the head is to be treated and engaged with.

Bordo (1993, pg 165) takes it a step further and suggests the body is rendered as "a powerful symbolic form, a surface on which the central rules, hierarchies and metaphysical commitments of a culture are inscribed." Bordo's proposal that culture is engraved on the body is somewhat narrow as an understanding of embodiment in its entirety because cultural norms, practices and ideologies do not enforce the way we experience our bodies, Instead it is a dyadic relationship though which individuals resist, reflect, and mediate their interactions with society (Davis, 1997; Butler, 2003; Shilling, 2008, 2012). However, this is not to say that the existing cultural understandings of embodiment are not influential and instructive. Many individuals experience their embodied states in relation to prevailing socio-cultural understandings relating to their bodies. The convolution of these social understandings, ideologies and practices towards embodiment can be seen through gender.

Gender is described as a social classification of traits applied to the male and female body. These socially constructed traits are generally categorised as masculinity and femininity respectively (Oakley, 1972; Howson, 2005; Cregan, 2012). In other words, socio-cultural meanings and practices of what it means to be male and female are inculcated within the feminine and masculine qualities. For example, in various societies the exhibition of masculine traits is seen through being strong, rational and logical whereas feminine traits are expressed through being passive, gentle, emotional and nurturing (Diprose, 1994; Mosse, 1996; Tong, 1998; Gregan, 2012). In keeping in line with masculine and feminine qualities, men and women are often subjugated to certain prescriptive roles. For example, historically, after World War II women were expected to return to home making, which was in keeping with their gender appropriateness although they flew planes, worked in factories and did all sorts of ‘men’s work’ throughout the war (Roberts, 1984). Also, with medical diseases, in particular relating to the male and female organs, it was permeated by gendered notions (Cregan, 2012; Connell, 1995). For example, in ancient Greek medicine, hysteria was first thought to be directly associated to the uterus, pathologizing both the organ and the women (Laqueur, 1992). Similar associations are made to this day in relation to Premenstrual Syndrome (PMS), that is, that women are at the mercy of their moods just because of their biological composition (Cregan, 2012). Furthermore, the ability for women to give birth and breast feed their infants have further re-enforced the feminine notion that women are nurturing and emotional, which has been naturalised into understandings of the female body (Brownmiller, 1984; Yalom, 1997; Young, 1998; Cregan, 2006). In addition, woven within the threads of this socially constructed notion of femininity is the objectification of a woman's breasts.

Through the centuries, breasts are viewed as the epitome of womanhood and have socially and culturally been inscribed to represent what it means to be maternal as well as it is seen as an object of desire that evokes love, beauty and eroticism (Yalom, 1997; Young, 1998; Bordo, 2003). Such socio-cultural representations of women's breasts have been reflected in mediums such as art, literature and fashion (Rakow, 1986; Young, 1998; McGannon, Berry, Rodgers, & Spence, 2016). In addition to breasts, being the essence of womanhood, pressure has been placed throughout history for a woman's breasts to be a certain size, shape and texture. Historically, the idealized breast was pointy, akin to a Barbie doll (Young, 1998). In many western societies the ideal shape of a women's breasts are to be perky and not sag, to be firm and for both breasts to be directly proportionate in size to each other (Young, 1998). This representation of the ideal breast is further re-iterated through mediums of media, art and literature (Bordo, 2003). These pervasive and powerful representations of women's breasts in Western culture create normative processes, which women constantly confront. As Jaggar &

Bordo (1989, pg 14) comments, “the contemporary aesthetic body for women in Western societies has led to an obsessive pursuit, which has become the central torment of many women’s lives.” Such objectification of the breast, its shape and size often causes a woman to idealise a certain representation of what a breast should look like and as a result desires that same breasted experience.

In other words, society’s perceptions of a woman’s breasts are often internalised on an individual level, which in turns results in women going for Breast Argumentation to getter bigger breasts or better shaped breasts. Oberg and Tornstam (1999, pg. 630) state that “subjectivity is a negotiated process whereby the individual draws upon cultural resources for making sense of who they are and whom they become.” I argue that within this process exists this undercurrent of pressure that is pervasive among women in obtaining breasts that are in keeping with societal idealisations of what the perfect breasts should look like.

The question then arises what about those women’s experiences of their bodies when they have to loose their breasts within this same western socio cultural plethora that views breasts as a representation of womanhood. Do they face pressure to confirm through reconstruction after their mastectomy? Before looking at current existing body of research into the experiences of breast cancer survivors and delving into the aims of my research, the biological underpinnings of what breast cancer is all about and the treatment modalities that are available must be sought.

Breast Cancer

About 3000 women are diagnosed with breast cancer each year in New Zealand; over 50 women are diagnosed every week. Around 600-650 women die each year from breast cancer (Ministry of Health, 2000-2010). Breast cancer starts when cells lining the breast lobules or ducts grow out of control. These cells usually form a tumour that can often be seen on an x-ray or felt as a lump (Kumar, 2011). Women and men can both get cancer, although it is rare in men. There are two types of breast cancer, the non-invasive and invasive breast cancer.

Non-invasive breast cancer is called ductal carcinoma in Situ (DCIS), which are abnormal cells contained within the ducts of the breast. Invasive breast cancer is categorised into early breast cancer and locally advanced breast cancer. Early breast cancer means the cancer has spread from the ducts and lobules into surrounding tissue. Most breast cancers are found when they are invasive (Dyson, 1989). Locally advanced breast cancer is when the cancer has spread to areas near the breast such as the chest. Finally, secondary breast cancer, known as Metastatic breast cancer, which refers to cancer cells that have spread to other parts of the body such as bone, liver or lungs (Kumar, 2011). This is also called advanced breast cancer. The symptoms of early stage breast cancer can often go undetected (Baum, Saunders & Meredith, 1994).

There are some common signs of breast cancer, a hard lump developing in the breast or armpit, typically painless and occurring on one side only. Also, a change in the size or shape of the breast, including indentation, ‘growing’ (particularly prominent) veins or skin erosion would be another symptom (Fallowfield & Clark, 1991). In addition, skin changes such as hardening, dimpling, bumps, redness/heat or an orange peel like appearance. Furthermore, changes in the nipple such as retraction, the secretion of abnormal discharge or a rash around the nipple area (Fallowfield & Clark, 1991). There are various methods used in the diagnosis of breast cancer.

Several tests are commonly used to find out if breast change is due to cancer, such as a breast examination, mammogram and a biopsy, if an abnormal or unusual tissue is felt in the breast (Baum, Saunders & Meredith, 1994). Breast cancer treatment options vary depending on the stage of the cancer, its size, position, whether it has spread to other parts of the body and the physical health of the patient (Fallowfield & Clark, 1991) Current treatments for breast cancer include surgery, radiotherapy, and chemotherapy, hormonal and targeted therapies (Fentiman & Hamed, 2006). These therapies may be used alone or in combination depending on the stage of the disease.

Surgery is the main treatment option for patients whose breast cancer has not spread to other parts of the body and is also an option for more advanced stages of the disease. The types of breast cancer surgery differ in the amount of tissue that is removed with the tumour and the tumour's characteristics. Some of the most common types of surgery include, breast conserving therapy or lumpectomy which involves the removal of the cancerous area, the surrounding tissue and in some cases the lymph node, whist aiming to maintain a normal breast appearance after surgery (Majure, 2000). A total mastectomy is performed in an attempt to further cancer prevention (Majure, 2000). This surgery involves the removal of the entire breast, without the removal of lymph nodes (Kumar, 2011).Surgery can also be followed or preceded by radiotherapy and/or chemotherapy, either sequentially or in combination (Baum, Saunders & Meredith, 1994). With the removal of the breast or breasts, women are given the option of breast reconstruction.

Breast Reconstruction

Breast reconstruction is an arduous procedure carried out by a plastic surgeon to restore and replace the breast or breasts after the original breast or breasts have been removed due to a mastectomy (Piasecki & Gutowski, 2006). There are two types of breast reconstruction offered, implant procedures and tissue flap procedures. The implant procedure is a made of a silicone shell filled with saline, which is attached to the women. With this procedure there are health risks such has the silicone leaking from the implants as well as separation and implant exposure and infection (Ferguson, 2017). The more common procedure, the tissue flap procedures, uses tissue from the abdomen or back (most common) or the buttocks or thighs (less common) to reconstruct a breast. Two types of methods, pedicle flap and free flap, are used. In a pedicle flap procedure, the tissue's blood supply remains intact, and is transferred beneath the skin to the chest area, where a new breast mound or pocket for an implant is formed. In a free flap procedure, the flap of skin, fat, blood vessels, and muscle tissue is severed from its blood supply totally and detached from its original place, and complex microsurgical procedures are used to reattach the tissue flap to new blood vessels near the chest. This procedure takes longer to complete than a pedicle flap procedure (Serletti, 2006).

There are four main tissue flap procedures are performed: the TRAM (transverse rectus abdominis muscle) flap, which uses tissue and muscle from the lower abdominal wall, which may be transferred as a free flap or a pedicle flap. The DIEP (deep inferior epigastric perforator) flap uses skin, fat, and minimal abdominal muscle tissue, and it uses a free flap approach (Serletti, 2006). The latissimus dorsi flap procedure, transfers skin, fat, muscle, and blood vessels from the upper back as a pedicle flap, tunneling the tissue under the skin to the front of the chest. Finally, the gluteal flap is a free flap procedure that uses skin, fat, blood vessels, and gluteal muscle tissue from the buttocks to create the breast shape (Fentiman & Hamed, 2006). Some of the risks associated with tissue flap procedures are excessive scar tissue, bleeding, extreme pain post surgery, death of the whole or part flap and also problems at the donor site (Edlick *et al.,* 2005; Manne *et al*., 2016).

Despite the numerous health risks breast reconstruction poses, many women still choose to have reconstruction. Research shows that after a mastectomy, women worried about their femininity, feeling anxious about intimate relationships, and, for some, increased psychological distress (Al-Ghazal, Sully, Fallowfield & Blamey, 2000; Rowland *et al.*, 2000; Amir & Ramati, 2002). Also research showed that women felt abnormal and unattractive because they felt they no longer fitted into the perceived ideal of being feminine without a breast or breasts. They had experienced feelings of not being whole and many explained that they had become more aware of their physical appearance (Avis, Crawford & Manuel, 2004; Arroyo & Lopez, 2011). Others experienced their bodies as objects after the mastectomy (Lindwall, 2004) and felt it was severely wounded and mutilated (Parker & Scullion, 1996; Piot-Ziegler, Sassi, Raffoul & Delaloye, 2010). For some women, they thought that their breasts looked cosmetically unacceptable (Arman & Backman, 2007).

In an attempt to look the way they did before the mastectomy, women opt for breast reconstruction. Reconstructive surgery gives women the perceived option of feeling normal and looking good. There is research that showed the positive effects of having reconstructed breasts. For example, research shows surgical reconstruction is offered to women as the last step in regaining a sense of complete womanhood, enabling a sense of optimism to bringing the body back to normal (Nissen, Swenson & Kind, 2002). Others argue that women having breast reconstruction show superior outcomes because they have not lived with the loss of a breast (Bostwick, 1995; Clayton & Waller, 1996). Studies report better psychological and sexual outcomes among women selecting breast reconstruction compared with women selecting mastectomy (Al-Ghazal, Sully, Fallowfield & Blamey, 2000; Manganiello, Hoga, Reberte, Miranda & Rocha, 2011).

However, there is a gap with many of the studies around reconstruction and mastectomy, it does not take into consideration the wider social context and its influence on the women and the decisions they make to have reconstruction or not. I have already discussed that breasts are not just biological but also socially constructed and that a woman's breasts are seen as a symbolic representation of femininity and womanhood. So for women to have no breasts, it would impact on how they see themselves because social norms have created this ideology that to have breasts is to be feminine. For example, research showed that women felt that having reconstructed breasts helped them feel feminine again (McKean, Newman & Adair, 2013). So, the perception that may be prevalent amongst women is that to have reconstructed breasts is to be feminine again, which yet again feeds into the socio-cultural ideology that influences and shapes how women experience their bodies. Even though women have reconstruction to make them feel more feminine, research shows that women after having their breast reconstruction were dissatisfied with their surgical outcomes (Reaby, 1998; Denford, Harcourt, Rubin & Pusic, 2011; Rubin, Chavez, Aldeman, & Pusic, 2013). Women also showed regret after choosing reconstruction (Sheehan, Sherman, Lam & Boyages, 2008). Even with reconstruction, research shows women struggle with feeling whole again after their breasts have been removed.

Despite research suggesting that reconstruction might not necessarily be the solution to living without breasts, there seems to be so much pressure on women to have a breast reconstruction. Pressure placed on them to look a certain way and also a lot of pressure that comes from the surgeon. Pitts-Taylor (2007) argues that to "presume that pathology can be read on the surface of the body as a visible sign of the truth of its interiority puts pressure upon subjects of cosmetic surgery to assert their normalcy … by accepting a pathologizing view of their bodies" (pg 184). For surgeons having no breasts is seen has an illness that needs treatment and the treatment is reconstruction. Sandell (2008) argues that plastic surgeons felt that women who do not choose to reconstruct, are incomprehensible since they do not choose to be "cured" from "one-breastedness." They felt that offering reconstruction to women was a way of making them complete again as women and aiding in bringing the bodies back to normal (Kasper, 1995; Ferguson, 2000; Crouch & McKenzie 2000; Nissen, Swenson & Kind, 2002; Broom, 2005; Crompvoets, 2006). Research also showed that surgeons felt that women who did not choose reconstruction were under informed or misinformed (Mock, 1993; Reaby, Hort & Vandervord, 1994; Hart *et al.,* 1997; Sandell, 2008). This came forward in the way surgeons took upon themselves as an important task to inform patients about reconstruction, both directly to patients through media and web sites, and indirectly through other doctors who meet breast cancer patients. The argument was that if only women were more properly informed of the benefits of reconstruction, more women would choose this (Mock, 1993; Reaby, Hort & Vandervord ,1994; Hart *et al* ., 1997; Sandell, 2008). There are quite a few studies done on surgeons placing pressure on women to have reconstruction. However there was not enough research around what the women are saying about the pressure they face in the patient-doctor interaction. Furthermore there was not enough research on the time frame given to make a choice, which can place women under immense pressure.

In making the breast reconstruction choice, the patient evaluates the importance of the benefits of each surgical option and her own values and inclinations against the medical risks linked with each procedure (Manne *et al.,* 2016). The decision process is complicated by the stressful circumstance of being recently diagnosed with breast cancer and the compact timeline for decision making (FallbjPrk, Frejeus & Rasmussen, 2012; Tan, Kok, Ganesh & Thomas, 2014; Murray, Turner, Rehan & Kovacs, 2015). There is not enough research on pressures that women face in making a decision about reconstruction.

Also research shows that when people experience illness or any sort of psychological distress, transitions do take place (Arman & Rehnsfeldt, 2003). A transition is defined as “a passage from one life phase, condition, or status to another” (Chick & Meleis, 1986, pg 239–240). Transitions occur when one’s self-identity is threatened during disruption, such as becoming ill and there is a need for restoration of identity and redefining of one’s self (Bailey, 1999; Banister, 1999). It is not an event, but rather the inner signs of difference that can be explored, which include self-redefinition that people go through

(Bridges, 2004). It is a process that occurs over time. Research seems to suggest that the transitions are uni-directional and linear (Glacken, Kernohan & Coates, 2001; Martin-McDonald & Biernoff, 2002) with a beginning and an end (Elmberger, Bolund & Lutzen, 2002; Bridges, 2004). However, I agree with Meleis (2010) who argues that transitions are more intricate and convoluted process; it is forward and backward movement especially in women with chronic illnesses.

There are several papers that look at the transitions that occur in people, for example, transitions from health to illness (Elmberger, Bolund & Lutzen, 2002; Arman & Rehnsfeldt, 2003). Other studies looked at specific diseases and the transitions that occur such as people living with HIV infection (Thurber, 1992), spinal cord injury (Selder, 1989) or having dialysis (Martin-McDonald & Biernoff, 2002). There has been some research done looking at transitions of breast cancer survivors.

Breast cancer survivors share the universal experience of transitioning from wellness to becoming a person with cancer, beginning and ending cancer treatments, and going forth again to continue living as survivors of this disease (Hewitt, Herdman & Holland, 2004). For an estimated one third of the hundreds of thousands of women diagnosed each year, cancer-related distress can be significant and affect their psychological well-being for years after diagnosis (Zabora, Brintzenhofeszoc, Curbow, Hooker & Piantadosi, 2001).

However, they do not stay in a state of psychological distress but rather transition.

Lally and Underhill (2012) looked at women's transitions over a 2 year period and looked at the psychological adjustment thought processes and behaviours over the two years from diagnosis to treatment and after treatment. Over the period she saw women who were struggling, transition to searching for meaning in the diagnosis rather than postulate causative factors for the breast cancer. The diagnosis was credited with bringing about positive changes about which these women were proud of such as helping them find a greater purpose and appreciation for life and family, growing in their relationship with God, and becoming a better person (Lally & Underhill, 2012). It can be even suggested that transitions can even take place with women who have to deal with the pressure of not having a breast reconstruction, the transitions that take place from not choosing reconstruction to living their lives with just one or no breasts. More research needs to be done in this area.

Part of the ability for individuals to transition can be attributed to their exercise of agency. Agency stands for the:

> *"Freedom of the contingently acting subject over and against the constraints that are thought to derive from enduring social structures. To the extent that human beings have agency, they may act independently of and in opposition to structural constraints, and/or may (re)constitute social structures through their freely chosen actions"* (Loyal & Barnes, 2001, pg 507).

A Foucauldian perspective states that individuals observe and monitor their own behaviour and “become active participants in the monitoring of their bodies” (Howson, 1998, pg 223). They not only are influenced by socio cultural norms and values but they challenge and confront those norms and values. Rather than being controlled by society, individuals exhibit agency in how they feel and think about themselves and others. There exists a dyadic relationship between individuals and society, both shaping and influencing each other.

Part of exhibiting agency is individuals are reflexive, that is, they are always living simultaneously in the past, future, and present, and adjusting the various situations of everyday living in a reflective manner (Giddens, 1991). They continuously engage with patterns and repertoires from the past, project hypothetical pathways forward in time, and adjust their actions to the demands of emerging situations. Moreover, there are times and places when individuals are more oriented toward the past, more directive toward the future, or more evaluative of the present; they may switch between (and reflexively transform) their orientations toward action, thereby changing their degrees of flexible, creative, and critical response toward structuring contexts. The reflexivity of self can extend to the human body as its part of an action system rather than a passive object (Giddens, 1991). The body becomes more central to the individual's reflexive identity. The body becomes more and more integrated in social life and is often quite central to the individual's self-actualization, which implies increased awareness of the body and the transitions it is going through.

Also, agency can be exhibited not only through being reflexive but through the support of others, agency is encouraged and achieved.

Research shows that the interaction between family and friends and breast cancer survivors play a crucial role in bringing about change in patients (Schumacher, 1995) Although interactions varied amongst groups of families, the support and care greatly helped patients (Meleis, Sawyer, Im, Messias & Schumacher, 2000). Also, part of exhibiting agency and aiding in transitions is developing new skills and behaviours to manage new situations (Kralik, van Loon & Visentin, 2006).

Meleis, Sawyer, Im, Messias and Schumacher (2000) talk about the mastery of skills that assist in the transition and how developing or engaging in skills helps bring about changes. However, there is a lack of research in showing how developing skills or engaging in tasks can assist in exhibiting agency. When women who undergo mastectomies and lose their breasts, they may experience the challenges of negotiating between culturally dominant notions of having breasts versus not having breasts. Tensions between a previously “whole” self and a new altered self-emerge. In the face of the pressures of choosing reconstruction, and fitting into the normalcy of society, some patients choose not to conform. They choose to not subject themselves to an ideology or construct that propagates gender stereotypes that see breasts as marking womanhood. Part of saying no to reconstruction is exercising agency, but there is not much research done in this area as yet. Agency is an important concept in breast cancer survivors and further research is needed.

There was a clear lack of research on women who chose not to have reconstruction and therefore I decided to look into this area. My current research aimed to provide more understanding into women’s experiences of their bodies after a mastectomy, and not choosing reconstruction. There are three key aims I wanted to gain understanding into:

Firstly, women who did not choose reconstruction and made an active choice to live without a breast or breasts in a society that sees breasts as the essence of being female and therefore for them to not choose reconstruction, is for them to almost act counter culturally and therefore I wanted to gain deeper understanding into their experiences of the pressures they faced in not choosing reconstruction, and in a way not fitting into the norm of what a woman should look like.

Secondly, I aimed to further explore the transitional process that may occur when women had to face pressure of not having a breast reconstruction, the transitions that take place from not choosing reconstruction to living their lives with just one or no breasts.

Finally, I wanted to look in detail to the exhibition of agency in the face of pervading socio-cultural norms and values. In other words, the various avenues the women engaged in to be counter cultural in choosing to live with one or no breasts.

CHAPTER TWO: METHODOLOGY AND METHODS

METHODOLOGY

Phenomenological Analysis

The aim of my research was to understand women's experiences of their bodies after a mastectomy and not choosing reconstruction. The best approach in achieving this aim was to use Phenomenological Analysis (PA). Before I explain my rationale for choosing this methodology, and discuss the methods used, I will discuss the epistemology and theoretical perspective that underpins PA.

Firstly, it is underpinned by a social constructionist epistemology. Gergen (1985, pg 266) says "social constructionism views discourse about the world not as a reflection or map of the world but as an artefact of communal interchange." According to this epistemology, meaning is being constructed from our active interaction and engagement with the world. It is a collective and social process, through which individuals collaboratively construct and uphold meanings (Moghaddam, 2002). Also, according to social constructionism there is such great diversity in the manner in which human lives are organised and their behaviours patterned. It highlights the plasticity of human behaviour and the possibility for reconstructing psychological and social realities in various ways. As a result human nature is seen in a continuous state of change (Burr, 2003). In addition, social constructionism sees language as shaping an individual's thoughts and perceptions. In other words, “language is not a transparent lens that we use to see the world as it is. Rather, the language is warped and coloured lens that determines what we see the world looks like to us” (Moghaddam, 2002, pg 15). It means that categorisations and differentiations that are part of the grammar for a particular language makes it more likely to take on one set of directions rather than others. For example, an Inuit has seven different words for snow, whereas an English speaking New Zealander has only one word for snow, as a result the experiences of snow for both groups of people are very different.

Social constructionism epistemology becomes the bedrock for the theoretical perspective, Hermeneutic Phenomenology (HP). The key focus of HP is on lived experiences of people, that is, they look at what people actually do when they engage in everyday tasks and are concerned with meaning and interpretation of these activities within a historical and cultural context (Packer, 1989). HP acknowledges that there are distinct characteristics to the meaning of human action (Packer, 1989).

The first characteristic is that human action is perspectival. From one point of view an action has one meaning but from another point of view, it has another meaning. However, each action is seen mostly in only a few alternate ways, correlating to the contexts of its occurrence (Packer, 1998). For example, the action of giving someone flowers may be a peace offering or a bribe but not usually a threat or making a dental appointment (Packer, 1998).

Secondly, human action is not seen as separate entities but rather as a holistic character. According to Heidegger's ready to hand mode of engagement, we are in this mode when we are actively engaging in everyday tasks, such as mailing letters or talking to friends. He says we carry out activities with an awareness that is holistic, that is, our activities are network of interrelated tasks and he says understanding a particular act is not possible without understanding the context within which it occurs (Packer, 1998). According to HP, a person's history or background, includes what a culture gives a person from birth and is handed down, presenting ways of understanding the world. In other words, people have pre-understandings, which are the meanings of a culture that are present before we understand and become part of its historical background. Pre-understanding is not something a person can step outside of or put aside, as it is understood as already being with us in the world. Heidegger went as far as to claim that nothing can be encountered without reference to a person's background (Martin & Sugarman, 2001). This notion is supported by Weber (cited in Hughes & Sharrock, 2007) who says that meaning is found as we are constructed by the world while at the same time we are constructing this world from our own background and experiences.

There is a transaction between the individual and the world as they constitute and are constituted by each other. Packer (1985, pg 1087) argues that any attempt to eradicate the background and treat human action as an "object like entity is a methodological error because it would remove the conditions for genuine comprehension of the phenomena being studied. Our interests, involvements, our habits and cultural practices play a crucial role for the entities and events that we create and experience around us."

To summarise, the object of study according to HP is concerned with human experience as it is lived and that consciousness is not separate from the world, in Heidegger's (cited in Packer, 1998) view, but is a formation of historically lived experience. Also, HP seeks to understand the participants' perspectives. It is a historically situated approach, regarding explanation as first and foremost the giving of an account that is sensible in the way it addresses current interests and concerns and it does not a search for timeless and ahistorical laws and formal structures (Packer, 1998; Martin & Sugarman, 2001; Langdridge, 2007).

Based on the tenets of a social constructionist epistemology and the theoretical perspective of HP, Phenomenological Analysis was used. In my research, it was important to choose a research design that supported the underpinnings of a social constructionist epistemology that values language and highlights the plasticity of human behaviour and the theoretical perspective of HP that shows that participants can not be treated as objective individuals but as subjective and their experiences are shaped and formed by their socio-cultural norms. My aim was not to provide an objective hypothesis devoid of outside influence but rather it was all about understanding a particular group of women and their lived experiences. It was subjective and acknowledged the importance of cultural influence. The socio constructionist epistemology and the theoretical underpinnings of HP, form the basis for using Phenomenological Analysis (PA) as a valuable methodological tool.

Through the use of language in PA, it allowed in uncovering the women's intersubjective experiences, from experiences of desires, feelings, motivations, belief systems through to how these manifest themselves or not in behaviour and action. It was quintessential to see their experiences were seen through cultural and socio-historical lens of the participants. PA allowed me to look at what was experienced and the way it is experienced. It examines the particular experiences of individuals in a given situation thus exploring not what is (reality), but what it is perceived to be (Langridge, 2007). Also, PA allowed me to focus on the women who had mastectomies, and their meaning making and interpretation around this event. It sought to discover, state and analyse the meaning of women's lived experiences. In other words, phenomenological analysis looks at how individuals perceive the experience, feel about it, judge it and remember it, how they make sense of the experience and share it with others (Langridge, 2007). To summarise, using PA, I could engage in an in-depth exploration of the personal and lived experiences of the women and was able to look at how they made sense of their experience.

There have been various researches especially done in health psychology that has used PA as it helps perceive and make sense of lived experiences of illness (Brocki & Wearden, 2006; Eatough & Smith, 2008; Reid, Flowers & Larkin, 2005). Also, it is a popular choice when looking at breast cancer survivors' experiences. For example, Lindwall and Bergbom (2010) used PA to describe how Swedish women experience their altered bodies after breast cancer surgery. Stark (2010) employed a phenomenological approach to explore the meaning of creating art for four women with a diagnosis of breast cancer. She sought to look at the experience of women with breast cancer who create art, specifically through painting, sketching or drawing. Using phenomenological research allowed me to achieve that which I set out to do and that is to understand women's experiences of their bodies after they had mastectomies and chose not to have reconstruction. Next, I will discuss the methods I used, and then I will discuss my participants that were chosen, the ethical considerations, data collection and finally data analysis.

METHODS

Participants

I initially emailed the Communications Administrator at a particular breast cancer organisation to introduce myself and the project. They agreed to assist me by sending an email with my information sheet (see Appendix One) to all their members. Upon receiving the email, women that were interested contacted me. I received fifteen responses from all over the country. I chose women that were over the age of 18 years old, who had mastectomies and had no reconstruction. As well participants needed to be based in Auckland and not to fair afield, furthest point was Hamilton. In total, eight women were identified and agreed to participate. Six to eight participants are an appropriate number for a phenomenological study. This number provides for enough cases for the researcher to look at the similarities and differences between the participants and that the researcher is not overwhelmed with the amount of data being generated (Smith & Eatough, 2007). Next, I will discuss the method used in data collection.

Data Collection

I used a one-to-one semi structured interview method to collect data. A semi structured interview meant I could have a set of questions in place to ask the participants. It was prior to the interviews that I constructed an interview schedule. It was important to begin by considering the range of issues to be explored within the broad remit of my topic being researched. With reviewing literature, I identified a number of key issues that formed the overarching structure to my interview, which I asked during the interviewing process.

The reason I chose semi structured interviewing was because it allowed for consistency across all the interviews, by using the same set of questions in all the interviews. However, at the same time it allowed for flexibility in the order I asked them as well as I was freer to probe other interesting areas that arose during the interview. Also, with semi structured interviewing the participant becomes an active agent in how the interview goes and it creates space for the participant to tell their story, which allows to enter the social and psychological of the participant as far as possible (Smith & Eatough, 2007).

All interviews were conducted by me, and each interview took place in the participant's homes or on university premises. Before the interviews started there was some small talk while drinking coffee in order to develop a relaxed atmosphere (Kvale, 1996). I then went over the information sheet with the participant, and reassured the participant that the interview was confidential, pseudonyms was used when transcribing and writing up the research to protect their identity, I also pointed out that they could withdraw one week from the time the interview was conducted. Also at the end of the interview I asked if there was anything they said during the interview that would not like me to transcribe or write about. I also pointed out that the interview was to be taped and transcribed. Once the information sheet was discussed the participant signed a consent form (See Appendix Two), the interview and recording then began.

Each interview was conducted as a conversation, and I ensured that each person interviewed was comfortable. I began with an open question that allowed for the participant to share her experience: “Please tell me about your experience of when you first found out you had breast cancer.” During the interview other questions were asked such as tell me about how you perceived your body at the time of the mastectomy and how you perceive your body now. Similar questions around thoughts and feelings surrounding their bodies were asked. Also, they were asked about reasons for not having a reconstruction. My main role was to encourage the participant to continue talking, using certain techniques as discussed. Such as open-ended questions that were used to provide participants with ample opportunity to express their feelings. Also tracking the conversation, which showed interest and encouraged participants to speak by closely following the content and “can you please tell me more about …?” I had to determine whether questions had been misunderstood and had to clarify matters if necessary. Clarifications and exemplifications from daily life experiences were requested in order to deepen the understanding when it was needed (Schneider, & Whitehead, 2016). Also, as much as verbal communication is essential, non-verbal communication influences the interviewing process.

I watched my own body language as well as my participants’ body language. At times, in the interview there were silences as participants tried to hold back the tears whilst talking about their experiences. During those moments I allowed for the participant to regroup by keeping quiet and allowed them to continue to talk when they were ready. Finlay (2006) argues the importance of the researcher paying particular attention to a participant’s movements and general demeanour. It involves both behavioural reading of gestures and an appreciation of the embodied relationship between researcher and participant.

She also says that self-awareness is needed, that the researcher needs to examine their own bodily experience throughout the research process. Finlay (2006) has stressed the need to attend to issues of embodiment in the interview process. She highlights the absence of the body in much phenomenological research, in spite of the existential foundations at the heart of the phenomenological psychological perspective. It was important to be both reflexive during and after the interview process. Reflexivity is the term used in which researchers are aware of and reflective about the ways in which their “questions, methods and very own subject position (as white/black, middle class/working class, heterosexual/homosexual, insider/outsider, etc.) might impact on the psychological knowledge produced in a research study" (Langdridge, 2007, pg 58).

At the end of each interview, I would go and listen to the recording and look at ways I could have done it differently. Also, during the interview I was very reflexive of my own actions and comments. Some of the questions I asked myself was why am I carrying out this study? What do I hope to achieve with this research and what is my relationship to the topic being investigated? Do I empathize with the participants and their experience? As Langdrige (2007) argues reflecting the choices and questions the researcher makes and brings is as much as the experience of the participants talking about their experiences. Once the interviews were conducted they were then transcribed.

Transcription is a vital part of a phenomenological study when data has been collected through interviews (Langdridge, 2007). My focus in transcribing was to produce a transcript that provided me with a verbatim account of the interview. I included 'ums' and 'ahs' in my transcription. Also pauses during the interview was noted with three dots (…) as well as other expressions such as laughter and tears were noted in brackets when transcribing. I tried to get it as close as possible to the recorded interview. Before discussing the analysis of the transcriptions, I would like to discuss the ethical considerations in this research.

Ethics

Ethics approval to conduct this research was granted by the Massey University Ethics Committee. Ethical issues were considered prior to the research and through the research process. The following ethical issues were considered:

Consent- Participants were initially given my information sheet by the breast cancer organisation as well as I went through the information sheet again with them at the beginning of the interview, after explaining the information sheet I asked them to fill in the consent form. On my information sheet I noted the purpose of my research, the expected duration and information on the interview process. I also gave them the opportunity to withdraw from the study at any point and assured them that pseudonyms were to be used when transcribing as well as in the write up to ensure their true identity remains confidential. Contact details were on the bottom of the sheet. It is important that participants are given enough information regarding the study and their involvement in order to enable them to provide informed consent to take part in the research (Edwards, Lilford, Thornton & Hewison, 1998).

Confidentiality and anonymity- All information gathered from the participants remained confidential. This position was made clear to the participants and nothing was made public. This is in keeping with the ethical terms of confidentiality, which means that any information that the informants divulge is not made public or available to others (Lobiondo-Wood & Haber, 1998). In order to ensure anonymity, that is, the protection of the informants in a study so that even the researcher cannot link the subject with the information provided (Lobiondo-Wood & Haber, 1998). I ensured that the pseudonyms were used during the write up and transcription stage. Also, the contact information on the consent forms, interview tapes and transcriptions were all stored separately. Consent forms were stored in a locked drawer at home. The tapes were stored in a locked cabinet in my home office. Coded transcriptions were stored electronically on my password secured laptop.

Distress and harm –Due to the sensitivity of the topic of my research, participants could become distressed during the interview process. It was important for me to protect the participants from physical and mental harm. Although physical harm is unlikely to happen, mental harm is something that must be considered. The ethical guidelines state that, the risk of harm must not be greater than that which a person may experience in everyday life (Langdridge, 2007). So in order to mitigate the risks of distress on the part of my participants, I provided them with a list of counsellors (Cancer Society Auckland, Breast Cancer Society and Maori and Pacific Support Services**)** to whom they can refer if they need to after I interviewed them. These services suggested were free of charge, as participants were not expected to incur any costs in participating in my project. The contact numbers were on a piece of paper which was disseminated to all participants after the interview.

Data Analysis

Data analysis was done to preserve the uniqueness of each participant's lived experience while permitting an understanding of the phenomenon under investigation. I began by immersing myself in the data with reading and re-reading the transcriptions as well as made and comments on the left-hand margin on anything that appeared interesting or significant. I did repeat this stage twice in order to ensure I adequately captured the meaning of what was going on in the text. I then took the comments from each transcript and wrote it on another piece of paper, so that I could generate categories and then the categories were then grouped into higher order categories. I ended up with about 6 categories, and so I then photocopied each transcript, and cut out quotes from the transcript that pertained to each category and stuck it on an A3 paper for each participant. I then spread all the A3 paper on the room floor, which contained each participants voices and experiences so that I could clearly see all the data and how it came together.

The aim of grouping data was to reduce the number of categories by collapsing those that are similar or dissimilar into broader higher order categories (Burnard, 1991; Downe-Wamboldt, 1992; Dey, 1993). However, Dey (1993) points out that creating categories is not simply bringing together observations that are similar or related; instead, data are being classified as 'belonging' to a particular group and this implies a comparison between these data and other observations that do not belong to the same category (Graneheim & Lundman, 2004; Hsieh & Shannon, 2005). Through interpreting of the data before me, I further reduced the categories to three main categories. They were, pressure for a “normal” body, experiencing the body as transitional and the exhibition of agency. Although there were other leitmotifs, these three seemed to be the overarching bigger issues that arose from the data analysis.

CHAPTER THREE-FINDINGS AND DISCUSSIONS

The quintessential purpose of this section is to provide a detailed presentation and discussion of findings based on three leitmotifs that were identified in the data: (1) Pressure for a "normal" body (2) Experiencing the body as transitional. (3) The exhibition of agency.

Pressure for a "normal" body

Findings revealed there are two types of pressure the women experienced, the pressure the surgeons put on the women to have breast reconstruction and pressure the participants placed on their own selves to fit into society after having their breast or breasts removed. Both forms of pressure exist in order for the women to succumb to normality, which is having two breasts that symbolically represent womanhood and femininity which have been inculcated into women through socio-cultural norms and values. First, I will look at the pressure surgeons put on the women.

Pressure from the surgeons

The women explained the surgeons imposed their opinions on them, that is, the surgeons were biased to reconstructive surgery. Rebecca said, "The surgeons were pushing for it, and they were quiet upset when I did not want to do it." Another woman, Esther shared a similar experience whereby the doctor presented information that was more biased to having a reconstruction and just assumed Esther would have a reconstruction.

> *He just assumed I would follow the track of having a reconstruction. I said what if I don't have a reconstruction and he said, "Ahh" and I said can I have a look at some photos. And he already had his brag book out showing me what he could do and I said can you show me somebody who has not had a reconstruction and he said I don't have any. And I think I might not have one and that point. So we booked it for another week after that and in that time, I went online, googled women photos of women who have had mastectomies and I said I can handle that. So saw dreadful jobs but some really nice ones too. So I said no reconstruction.*

It is clear that the disseminating of information by the doctors were very one-sided. Instead of presenting both the pros and cons of reconstruction and giving the women a balanced view, reconstruction was forced on them. This finding is supported by other research, which states that many surgeons deliver pro-reconstruction information to breast cancer patients and fails to gives the patients a balanced view of reconstruction (Reaby, 1998; Finlayson, MacDermott & Arya, 2001; Ananian *et al.,* 2004; Jagsi *et al.,* 2014). In my research, the participants were not given much choice by the surgeon. Another participant says:

> *At the time when I saw the, he was a male and he never gave me the option of having a mastectomy without reconstruction. He almost assumed I would have reconstruction, and I was 41 so I wasn't older. He assumed that I was younger and not*

> *menopausal that I would want a breast.*

It is clear that the surgeon completely ignored the option of not having reconstruction. This finding is reinforced by other research such as Delbanco *et al..*, (2001) whose studies show that the reconstructive decision is often made without considering the patient's thoughts about her specific desires and needs. Doctors tend to minimize the patient's desire to be involved in the decision-making process (Butow, Harrison & Choy, 2007; Halkett, Arbon, Scutter & Borg, 2007; Kleeberg, Feyer, Günther & Behrens, 2008) and as a result doctors ignore the participants' voices in the decision making.

From the surgeon's point of view there could be various reasons as to why they were pushing for reconstruction. My research did not cover the surgeons' perspective however the participants in the study voiced their suggestions as to why they thought surgeons would push for reconstruction. The participants felt the surgeons wanted to fix them, also they thought that maybe if the doctor was female she would have showed more understanding, and that money seemed to be another motivation. Firstly, I will discuss the surgeons need to fix what they thought was broken. Rebecca says

> *Also, there is no particular reason to do it. The surgeons were pushing it, and they were quiet upset when I didn't want to do it. They said oh well, I had a patient who had breast cancer and they had reconstruction and she said to me now I can get up and look in the mirror and not*

> *think about my breast cancer. And I thought that is pretty silly because whether you have reconstruction or not, is not going to change the fact that you had breast cancer. Umm..there is a lot of myths around reconstruction. I'm actually a doctor, and the medical profession, like to say or well you got breast cancer, never mind we can give you a reconstruction and they want to feel like they helping you. They want to feel like they doing something.*

It is interesting to note that Rebecca was able to give insight into the medical profession as she is also a doctor. The participant takes a different stance as compared to her fellow colleagues and says that some doctors are focused on helping fix what they conceive as abnormal. From Rebecca we get a sense that the doctors saw being without breasts as something wrong which needs to be rectified. According to Bensing *et al.,* (2003) interactions between patients and doctors do not exist in a vacuum but are influenced by other issues. From the doctors perspective, for women to have no breasts in a western society is contradictory to societal norms that highlight the need for two breasts, which represent beauty and sensuality of a woman. So for doctors, the answer to this abnormality is to provide reconstructed breasts. When surgeons offer reconstructive surgery, it can be argued that it ‘‘pressures people...to become what Foucauldian thinking calls ‘docile bodies’...pliable bodies to be shaped infinitely so as to conform to a set of standards called normal and beautiful’’ (Hall, 2011, pg 24).

Suggesting reconstruction can be said to propagate the socio cultural norms of what it means to be feminine. In other words, it can be argued that to be forced to have reconstruction, is to be pressurised into propagating the gender stereotype of breasts as key markers of womanhood and femininity and to be without breasts is to not be fully feminine. As Price Herndl (2002, pg 154) argues to "cosmetically create normality is a sign that one is giving in to the cultural demands for a specific femininity."

Secondly, the participants thought a female doctor may have a different perspective. Esther says:

> *He probably just assumes that women just want a reconstruction. I'm not sure if a female breast surgeon might feel the same way.*

Esther felt that had the surgeon being female she may have had a different approach. She might have thought that a female doctor may have been more understanding and empathetic. This may reflect what patients expect women doctors to speak like and be interested in, based on gender stereotypes (e.g. women are more interpersonally oriented than men) (Hall, 2003). Comparing male and female doctors can be argued to propel gender stereotypes, however it cannot be negated. Hall (2003) states that gender is the most studied characteristic of health professionals in the patient-doctor interaction. According to research although doctors share a body of knowledge and professional ethos, there are different working styles between male and female doctors. Female doctors value psychosocial aspects of health more than men do, and tend to operate more strongly from a biopsychosocial rather than biomedical paradigm (Manderson, 2003). A meta-analysis by Hall (2003) demonstrated that female doctors spend more time with patients, and demonstrate more partnership building and positive verbal and non-verbal behaviour. So, it would seem that gender does impact the doctor-patient interaction and if the doctors were female they might have placed less pressure on choosing a reconstruction and exhibit more understanding.

Finally, participants wondered whether getting more money for reconstruction was a motivation for pushing for reconstruction.

> *Sarah says, "I went through the private medical system, so I thought maybe he makes more money doing the private reconstruction instead of just doing a simple mastectomy."*

The women felt that if the doctor did a mastectomy as well as a reconstruction he will get more money and therefore when giving information instead of being concerned about his patient and what was best. It seemed like the surgeons were selling a product (reconstruction) in order to make more money. In addition to participants feeling pressure from the surgeons for reconstruction they place pressure on themselves to look normal.

Social pressure on women

At the point of diagnosis women had to decide whether to have a mastectomy as well as reconstruction at the same time. It was making a decision about two major operations at the same time. For many women their focus was on being diagnosed with breast cancer, and being told they have a tumour in their breast or breasts. So the initial reaction was that they needed to get the tumour out of their bodies, as a result their focus was on having the mastectomy rather than how they would look after the mastectomy. Irene poignantly described how survival was at the forefront of her decision making.

> *The biggest issue for me was survival, so what happens when you diagnosed is that you get a huge amount of information. I can't begin to tell you how much information that they make you to understand and I thought I am going to make three objectives. In every decision I make has to be going through those three decisions*
>
> 1) *Go for survival*
> 2) *Get the best people*
> 3) *And be open to possibilities*

The top priority on Irene's list was survival and she used these three steps in every part of her treatment as well as when it came to the decision of having reconstructive surgery. Irene described how she came to her decision.

> *So before surgery I considered having a reduction because I am quiet big breasted. So I considered having a reduction on the other side because I felt having a large prosthesis was going to be hard work in the bra and heavy to carry around and so I thought I would have a reduction on the other side and that will mean my prosthesis is smaller and it will make life easier and the normal plastic surgeon was not*

> *available. And so I met the plastic surgeon who was going to do the reduction on the other side and I said to him how many surgeries of these have you done because a surgeon should do about 30 a year to be proficient and he wouldn't answer my question about how many he had done and how many he had done in a year. So I thought number two, get the best people. Then does number one, having a reduction improve my survival? No. Can I get the best person? No. So I decided against the reduction, the day before surgery I said no, I don't want the reduction.*

For many women, survival was the priority and so to even consider going through another major operation like reconstruction did put pressure for the women to think about the implications of reconstruction and what it meant for them. Esther explained the short time frame in which decisions she had to make placed huge pressure on her.

> *It all happened really fast, really quickly from feeling the lump to being booked into surgery happened within a week. I don't think it should be such a rush, because he end up making a lot of decisions in a very short period of time. I wanted time as to what the options where in as far as surgery goes, it was a Wednesday and I was to have surgery that Monday and I said I can not make such a major decision so quickly.*

For Esther, making major decisions within a short time frame was too much to handle and therefore took more time to think about and research her options. Under pressure it is easier for the patient to conform to the doctor's viewpoint given the short time frame because the doctor is the holder of power and authority within the relationship therefore to the patient the doctor might know best. However, in this case Esther unbalanced the scales of power by researching reconstruction and taking more time to decide for herself rather than giving into the doctor's bias on having reconstruction.

Women did feel pressure to choose reconstruction as reconstruction offered the women the choice to look "normal" with giving back the breasts they had lost. Participants expressed that it was not an easy decision to make. The decision making process placed pressure on them to choose reconstruction or not in a very short space of time. Research by Hart, Pinnell-White, Egro and Losken (2015) showed that women prefer more time and information than is provided before making the decision. Breast reconstruction can be a complicated decision made under stressful circumstances, and women do not always feel well prepared. The dialogue between me and the participant Yvonne highlights the dilemma and struggle the participant had to face in making a decision about having reconstruction.

> *Yvonne- I have to admit that reconstruction is important to me as well.*
>
> *Interviewer--So do you think, not having reconstructive surgery and just having a mastectomy does that impact on how you see yourself?*
>
> *Yvonne-Yes, I struggle with this...even when we were deciding about the mastectomy. Alot of my friends mean well, they use to say nobody is going to know. Only you know and I have been told alot of the time that the breast is other than breast feeding it does not serve any*

> *significant big purpose but that also makes me question, Am I that vain to be thinking about loosing a breast but I think that it is fair that I think about it. It is part of my body for as far as I can remember and even though my friends have told me it didn't serve any purpose, loosing it is not going to make you function any less, like loosing a hand...true...but I feel like a loss... struggling with that I was naive to think it would be all straight forward.*

Yvonne reveals the complexity and difficulty in making a decision about reconstruction and mastectomy. In addition to the pressure of having a short time frame to make decision, and the pressure placed on women due to the complexity of making the decision, the choice of having a reconstruction provides an escape of facing the loss of the removed breasts (Bostwick, 1995; Clayton, & Waller, 1996). When the decision of not having reconstruction is made, women have to deal with the emotions and thoughts surrounding the removed breast or beasts.

In my research, all the participants chose not to have reconstruction and part of not choosing reconstruction was facing the loss of not having a breast or breasts. They explained a deep sense of loss and grief they experienced for the removed breast or breasts due to the cancer treatment. Irene poignantly describes when she had to have her breasts removed, she named them.

> *I said I am extremely attached to my nipple… she was quite dismissive and said we all like that. And I thought it took me hours of thinking to come up with that and to come to this conclusion and she just dismisses*

> *it like that… and so I said I will have the mastectomy if you can't save my nipple, then there is nothing else that counts. So I named my breasts ... so this is Sarah …the one who stays... no Sarah is the one who left and Patience is the one who stayed…. also has a pair, hey... so to name them is too individuate them… so by individuating them you can loose one and not the pair.*

Irene's description shows the attachment she had to her breasts. For Irene, to lose her breasts, is to lose apart of her. In order to deal with the loss, she named them so that she would still have one to hold onto. Naming her breasts helped her cope with the loss. She named them so to separate them and in doing so remind her that she still has one left. One woman, Lisa, likened the loss of her breast to the loss of her dad.

> *In a sense there was a grieving process you have to go through, the only thing I can really compare it to. Like when my dad died, I grieved over him that is the only thing I can compare it to.*

This comparison gives insight to her intensity and pain associated with a losing her breast, which was part of her body, a part of who she is. It also depicts the attachment she has had to her breast. Research done by Maguire and Parkes (1998) supports the similarity of loss experienced between loss of a body part and loss of a loved one. People with either of these losses were preoccupied with feelings of loss; bereaved people were missing the lost person and the amputees were missing the loss of physical attractiveness or the physical functions that could no longer be carried out or both.

Going through the grieving process after a mastectomy is good, it is through the journey of grieving that breast cancer survivors come to accept and come to terms with the loss. It is part of the healing process (Fallowfield, Hall, Maguire, Baum & Hern, 1998; Pillai-Friedman & Ashline, 2014). For many of the women the possibility of reconstruction might have placed pressure to give in to the option of having two breasts, to not have to deal with the loss (Clayton & Waller, 1996; Neill & Briefs, 1997; Al-ghazal *et al.,* 2000). However, I argue that grief is important, it is important to acknowledge that loss. Breasts are important part of a woman's body and so to have them removed, require time to reflect and deal with the removal or loss of the breast or breasts. Lisa and Rebecca together with many other women, point out the need to go through the negative perceptions and grieving process. They acknowledge the need to face and confront the issue of grieving rather than avoid it.

Maguire and Parkes (1998) support the notion that women who have had mastectomies need to confront the loss of their breast or breasts. According to Maguire, Tait, Brooke and Sellwood (1981) confronting the loss will reduce the prevalence of psychological problems. Furthermore Batista da Silva *et al.,* (2013) state that through confronting breast cancer and its treatment, women bring about positive change.

In addition, to being pressurised into having a reconstruction in order to avoid dealing with the loss, reconstruction offers the option of having breasts to fit into society. Having no breast or breasts, in a society where two nicely shaped breasts are seen as a symbolic representation of femininity and womanhood, puts pressure on women to consider reconstruction. Reconstruction is seen as an ideal option to have breasts again and to be normal. Research has demonstrated that women's reasons for choosing breast reconstruction were primarily appearance/femininity and emotional concerns (Korvenoja, Smitten, Asko-Seljavaara, 1998; Shekhawat *et al.*, 2015). However, all the participants in my research chose not to have reconstruction and in doing so, they spoke about how initially they struggled with this choice and how they grappled with how they saw their bodies. They felt abnormal, ugly and unattractive. They felt like they did not belong in society. One woman Lisa described, when she first had her breasts removed, she felt *"like she kinda joined the circus*." This statement implied a sense of now belonging to a different group of people, people that are not part of the norm. Likewise, Louise says:

> *I lost a lot of confidence and initially, when I first had the operation, I was lacking confidence and felt quite like a leper to be honest.*

For Louise, using the comparison of a leper had demonstrated how marginalised she felt in society without breasts. Similarly, Yvonne felt different compared to woman with both breasts. Her quote demonstrates how abnormal she felt with just one breast.

> *It is the feeling of not being a normal person. I know I have prosthesis, I can escape but its more feeling not normal, like there rest of the people.*

Yvonne's quote reveals her need to wear prosthesis in order to escape the abnormality she may feel within society with just one breast. She had a desire to look like other women with two breasts, because of the societal norms tied to having two breasts. Yvonne felt this tremendous pressure to fit in to a society that looked at two breasts as a symbolic representation of femininity. The ability to not fit into society creates this shame that the women felt. Many women described how they would hide in the swimming pool or in the change rooms ashamed of what they looked like after having had the mastectomy. One participant Irene says:

> *I think now for me at that time I really struggled in the swimming pool. I go swimming Monday, Wednesday, Friday at the local indoor swimming pool and I always try and find a corner so that I can get dressed in the corner and alot of the women in the pool are very beautiful and body conscious and they very skinny and they always take the corners. Those corners should be left for women with mastectomies...clear out…Irene laughs...you know it's like...actually there are tiny little changing rooms...and far away from the shower...so how you get from the shower to the changing room without any togs on.*

Similarly, Miriam described the shame felt at the swimming pool.

> *The area were the mastectomy was taken was quite tender. So I was aware of it for quite a while. The actual looking at myself in the mirror was quite difficult. Yeah, I didn't like what I saw but I knew I had to just get on with it. I guess my attitude to it changed over time; it did as I became less embarrassed to change in public, that sort of thing. At first I used to hideaway in a changing room or something or make sure I didn't have to change in public.*

Both Irene and Miriam, describe how ashamed they felt in the swimming pool and changing rooms having only one breast. They felt like they did not fit and both expressed feelings of embarrassment to change in public. They felt pressurised to be a certain way and because they had no breasts, they felt ashamed of their bodies. My findings were supported by other studies that looked at how women negatively viewed their bodies after having a mastectomy. For instance, Arroyo and Lopez (2011) demonstrated how marginalised and different the women felt within society having no breast or breasts. Furthermore, numerous caucuses of research support my research in how women struggle with feelings and thoughts of unattractiveness towards their bodies after a mastectomy (Ganz, Greendale, Petersen, Kahn & Bower, 2003; Fobair, Stewart, Chang, D'Onofrio, Banks & Bloom, 2006; Freysteinson, Deutsch, Lewis, Sisk, Wuest & Cesario, 2012). Women had feelings of altered femininity and sexuality, not being whole and many explained that they had become more aware of their physical appearance (Avis, Crawford & Manuel, 2004). The women experienced their bodies as objects (Lindwall, 2004) which were severely wounded and mutilated (Piot-Ziegler, Sassi, Raffoul & Delaloye, 2010). For some women, they thought that being without two breasts looked cosmetically unacceptable (Arman & Backman, 2007).

However, the issue with many of the studies stated is that they presented the women's experiences of their bodies as fixed and constant. There was no mention of change or transition. My current research showed that the women after making a decision not to have reconstruction, went through grief and negative thoughts and feelings about their bodies to loving a accepting their bodies. The participants made a transition in how they experienced their bodies.

Experiencing the body as transitional

My findings highlighted how women moved from a place of feeling inadequate to a place of making peace with themselves without a breast or breasts. In this research, the women talked about transitioning and not seeing themselves in a negative light all the time. Going beyond experiencing negativity, disdain and conflict regarding their changed body, and grieving over the removed breast, women transitioned to a place of feeling and thinking positively about their bodies.

In order to reach the end of the negative transition, the women acknowledged the importance of passing through the negativity. Lisa highlights the need to go pass through he negativity.

> *Often when bad things happen it's really important that you acknowledge that it is hurting and you don't like it and you move on from there. I think sometimes people are so busy being positive that they almost scared to acknowledge that this is not a good thing that is happening.*

Similarly Rebecca spoke about the necessity of first going through the negative feelings and thoughts about the body without a breast or breasts and dealing with the grief to then transition to having positive feelings and thoughts about the body without a breast or breasts.

> *It's hard to get a positive outlook without going through drama. People say your immune system improves if you're positive. You can't just sit there going I am positive today. It doesn't work. You actually got to do the negative stuff, feel bad and work through all that stuff, which is hard… which is hard ... like I think each year for quiet a few years when it was around a certain time, it wasn't a time of diagnosis, but for me it was chemotherapy was the worst. Pretty much for none months or a year, I pretty much couldn't do anything. I just only really basics of everyday living, and the same for a year after that and nobody could see any different, but everything is different and you can't particularly do stuff and your brain doesn't work properly and you can't really relate to people properly and its huge and then that is quite hard to come back from that as well. So the emotional stuff for me was all mainly around those things.*

The participants demonstrated the need to work through the negative to transition and change to experiencing the body in a positive way. Lisa and Rebecca both highlight the need of going through the negative to get to the positive. It is a process that does not happen over night but over time. Deborah says:

> *If you interviewed me two or three years ago, I wouldn't be as measured, it was very emotional. I cried but I did have peace through*

> *the process. I had been given a supernatural peace but there were times of sadness there.*

Research by Lally and Underhill (2012) supports my findings that breast cancer women experience transitioning from wellness to becoming a person with cancer, beginning and ending cancer treatments, and going forth again to continue living as survivors of this disease. Research highlights the women's experiences of psychological adjustment with their illnesses (Nosarti, Roberts, Crayford, McKenzie & David, 2002; Badger, Braden, Mishel & Longman, 2004; Millar, Purushotham, McLatchie, George & Murray, 2005; Henselmans *et al.,* 2010), positive transitions started to take place as the women defined positive meaning in the diagnosis and felt deserving and open to making changes in their lives, there was recognition of changes in life perspective and hope for future changes to better their life and health (Hall, 1981; Lally & Underhill, 2012; Meleis *et al.,* 2000). One participant, Miriam, profoundly describes how she changed how she saw herself through disregarding the pressure that society placed on her as a woman to have two perfectly shaped breasts.

> *I guess my attitude to it changed over time, it did as I became less embarrassed to change in public, that sort of thing… I also got strong within myself and I think there was and still is a lot of personal growth going on. You don't stop growing up you know. I felt it was very important after a few years to love your body again. The real person inside is much more important and if you can love yourself that is really important 'cos that gives you confidence in your everyday*

> *dealings with the world and actually it shouldn't limit you to the way you think about yourself.*

As discussed earlier, many of the women after the mastectomy experienced negative feelings and thoughts about their body as well as loss. From the quote, Miriam experienced some personal growth. She transitioned from feeling embarrassed about her body to loving it again. Similarly, research by Fishbein (1992) and Kane (1992) demonstrated that through empowerment and personal growth positive transitions take place. Similarly, Deborah states that she changed how she looked at her diagnosis and how she experienced her body.

> *And I feel if you have been on this journey it shouldn't be wasted. You can say yes I have had this experience but I am not defined by it. I guess when I look at my chest wall, I don't see it speaking of death but I see it speaking of life. That the scars speak of life, the chance to have a longer life here. So I am grateful for that… No matter what the challenges are if we have hope in this God who loves us and obviously I believe in Jesus dying on the cross and if we have hope in this God who loves us and if we have hope in this God who loves us, who redeems us from the parts of ourselves that need redemption. He gives us a new identity and in that place of new identity your body shape, size is still significant but it's not the end the be all and end all. You have an identity within a family of God. I don't sit here thinking I can't wait till I get to heaven to have a perfect body*

Like Miriam and Deborah, many women in the research acknowledged the need not to let the dominant ideologies of society regarding breasts dominate how they thought and felt about their bodies. Both women showed that did not let socio-cultural norms determine how they felt about their bodies. They took control of their emotions and exhibited resilience and dignity when dealing with their mastectomy. Research shows that when a successful transition has occurred, emotions are managed (Johnson *et al.,* 1992, Linson, 1987), there is a sense of dignity (Robinson & Pinkney, 1992), personal integrity (Myton *et al.,* 1992), and relationships are restored or promoted (Robinson & Pinkney, 1992). In a sense, the participants were exercising their agency in order to bring about transition. They did not let societal norms determine how they felt and thought but rather were exhibiting agency.

Exhibition of agency

There seems to be a pervading socio-cultural norm that looks at breasts as a symbolic representation of womanhood. In light of this, reconstruction would have provided the perfect opportunity for women to fit back into society by having their breasts reconstructed. However, all my participants chose not to have reconstruction. As a result, many of the participants expressed their views on how they felt having only one or no breasts. They also spoke about how they did not let society's opinions influence how they felt about their own bodies. Although socio-cultural norms influenced how they experienced their bodies, they exhibited agency in choosing not to succumb to pressures of having reconstruction. There were two choices that participants made that were counter cultural and demonstrated agency. The first choice was not to have a reconstruction and the second choice was to actively engage in activities that made them feel good about themselves. I will begin by discussing the first choice of not choosing reconstruction.

For many of the women the reason they chose not to have reconstruction is because although they loved their breasts and experienced grief over the loss of breasts, from a practical point of view they did not find much purpose in having them.

Rebecca says:

> *So its not having something that can function, like if you lose your hand then it would be good to have a pretend hand to do something or if you lose another part of your body, if it does something, its good to have a replacement one but your breast physically they can't do anything other than look like a breast.*

Similarly, Irene shares the same viewpoint, Irene says:

> *It's very clear for me a breast is a vital organ to a baby, not to anyone else. It's a vital organ, only baby needs breast, only to a baby, so no baby, no vital organ. so for me why would I sacrifice a muscle, functional muscle for a non-vital organ...I couldn't understand why would I give up a part of my anatomy that worked to create something that doesn't work. From a functional perspective, I was very functional. Breasts function is to produce milk to survive, to help the baby. Aesthetically I would rather have a muscle that I could use… I am really lucky as the breast is not a vital organ and I don't have a third of my lung cut off, it doesn't effect my breathing, it doesn't effect me.*

> *There are other cancer surgeries if you have sarcoma of the leg and if you loose a leg. How terrible is that because its all about your mobility and you cant move around, if you have cancer of the tongue and you loose the tongue, you loose its function...so on other occasions I feel very privileged that the amputation that I had was off something that didn't interfere with the rest of my functional life.*

Both participants described how they viewed the breast in light of making the choice of having reconstruction or not. Both said that the breast was not a functional organ and as it was only aesthetic they chose to loose it. For many participants they said that reconstruction involved using a functioning muscle to construct a breast. Esther says:

> *But my main reason for not having one was one I didn't want to... umm... put my muscles at risk just for a breast and have an implant anyway. Also, why affect my back muscle, latissimus dorsi muscle, why would I want to impair function just for a breast. To me function was more important than looks. Being able to use my muscles, having good posture in my core was more important than looks. Being able to use my arms for sport, I was 41 at the time and had a few decades to do sporting activities and I didn't want to lose muscles.*

From the participants, it seems like breasts were apart of their bodies, they were emotionally attached to their breasts but at the same time they came to terms with loosing their breasts. To the participants, having breasts did not serve a major purpose and having reconstruction meant affecting another functional muscle, which they did not want to do. For the participants, their main concern was getting rid of the tumour, which meant cutting out a non-functional organ. This is not to say they did not feel emotionally attached to their breast, but they felt that they would rather survive than have more complicated surgery. My findings are supported by other research such as Holland, Montague and Archer (2016) showing that the women's drive to survive clearly influenced their initial decision-making process of not having reconstruction. Their participants felt that reconstruction added no value to them and that in many ways would have caused more issues. Research done by Flitcroft *et al.,* (2016) demonstrated that many women who chose not to have reconstruction, felt that the reconstruction was unnecessary and impractical. The women did not feel that reconstruction was essential to their physical or emotional well-being, and they wanted to get rid of the cancer and avoid additional surgery. Also findings by Manne *et al.,* (2016) demonstrated that women chose not to have reconstruction because of the surgical risks and complications.

In light of exhibiting agency, the women in this study chose to take a stand and not fall prey to the pressures of reconstruction, but rather critically looked at the value that reconstruction would have. It was weighed up and participants chose to say no. Saying no to reconstruction meant many of the women had to go through the grief of loss and the initially feeling of not fitting in. Societal norms equates a women's breasts to her being feminine and a woman, and so to be without breasts might make the woman feel like they are no longer like a woman. I have already discussed how the women did feel this way, but they transitioned and did not let society prescribe how they should experience the body. The statement Deborah makes is so poignant, she says:

> *"I can still be feminine and not have a breast."*

She did not allow the dictates of society to influence her, she was reflexive and exhibited agency. Many of the women, through exhibiting agency, came to a place of loving their bodies and not despising it. Rumsey (2004) supports this finding, that individuals who experience positive thoughts and feelings regarding their bodies do not let the negative evaluations of others and the sense of social acceptance dominate them. Furthermore, research shows that individuals who experience positive thoughts and feelings about their bodies often reject the cultural norms that promote unrealistic standards (Homan & Tylka, 2014). Part of moving from feeling negative to positive they engaged in various activities, which allowed them to exhibit their agency. Participants did not allow themselves to wallow but they made active decisions to engage in activities that allowed them to feel good about themselves.

These activities varied from individual to individual due to different individual and social experiences. For example, Lisa described how Pink Pilates and belly dancing helped her in loving her body again.

> *I went to Pilates, Pink Pilates. It was great, really good to do that and I met a lady there who teaches belly dancing. So I thought that is a really nice way to engage with my body again. Like quite a positive way, 'cos the thing with all these treatments is. Normally I don't get very sick very often, normally you feel sick you go to the doc and he makes you feel better. In this case I was feeling fine and I go to the doctor and I end up with surgery and I end up with chemotherapy and I end up with radiation therapy and it's all meant to make you feel better but it feels*

> *quite destructive while you going through it. It feels like you really getting hammered. So I thought belly dancing will be a fun way of moving again.*

From the quote we see that Lisa could experience her body in a fun and engaging manner again through belly dancing and Pilates. These activities helped Lisa love her body again despite societal norm and values. According to Tiggermann, Coults and Clark (2014) belly dancing provides an opportunity for women who differ from the societally thin or youthful ideal to reconnect with their bodies in a joyful manner. Importantly, belly dancing focuses on the functionality of the body and requires mental and physical presence in the body, giving rise to a sense of interconnectedness with the body.

In a different approach, Louise went to the Look Good, Feeling Better programs. Interestingly Taggart, Ozolins, Hardier and Nyhof-Young (2009) demonstrated that such programs helped women improve how they saw themselves through managing appearance-related side effects. Another participant, Esther, described how engaging in rigorous exercise had helped her.

> *I think if you are fit and strong and flexible you generally feel better about your body. If you are fit you know you can go for an hour and half fast walk, you can climb things, and do some press ups and triceps, stretching, co-ordination, balance as well. You will feel good about your body.*

For Esther, exercise played a huge role in helping her transition to feeling and thinking more positively about her body. Various researches have shown that engaging in exercise assists in feeling and thinking positively about one's body (Bordo, 2003; Murphy, 2012). In addition, support from loved ones helped the women exhibit their agency.

Through the love and support they received from their families and friends, the women were not afraid of being counter cultural. They chose not have reconstruction, just to fit into this idealism of normalcy of having breasts. Irene's quote reveals the insight into how Irene's partner's acceptance helped Irene exhibit agency.

> *I got a hundred percent acceptance who said I embrace you for who you are and not how you look. I love you 'cos I love you not because you have two breasts ….you can't have more acceptance than that...can you...so my partner has always been so positive about my mastectomy and I think that really helps.*

Qualitative studies demonstrate the pivotal role social support plays in helping patients (Uchino, Cacioppo & Kiecolt-Glaser, 1996; Berkman *et al.,* 2000; Bauer-wu & Farran, 2005). Studies showed that social support has found to be related to adjustment and recovery (Edelmann, 2000; Taylor *et al.,* 2003). Through breast cancer survivors perceiving body acceptance from important others (e.g., family, friends, partners), and feeling loved, special, and valued for authentic qualities not contingent on appearance, are crucial in assisting individuals. In addition to engaging in activities and having social support, reflexivity also helped a great deal in being able to exhibit agency.

Many of the women in the research were reflexive about how they perceived their bodies and chose not to let societal norms dominate how they saw themselves. They were reflexive throughout their recovery. They assessed where they were at and where they were going. They chose not to let not having breasts weigh them down but looked at the positives of their journey. Deborah says:

> *When I assess my body, I have learnt too see the scar as a sign of life and so it's given me an extended life. Yes it would be lovely to have my breasts back and I even believe in healing miracles but this is a journey that I am on. And other women haven't survived…*

Being reflexive is an important part of exhibiting agency. When Deborah reflected on what happened to her, she saw that her scars were reminders that she survived and beat breast cancer.

All my participants made an effort to deal with their mastectomised bodies. They came to terms with and accepted their post surgical bodies. Tensions between a previously "whole" self and a new, altered self emerge when faced with a discourse that projects identity as strongly connected with the essence of womanhood. They challenged and engaged with gendered modalities, structures, and conditions of their embodied being-in-the-world. Many of the women through various activities and social support exhibited agency and did not let society prescribe how they should think and feel about their bodies. Many women were expected to feel "physically handicapped" both because of a patriarchal society that exults in breasts and because regaining symmetrical breastedness is taken one and the same as regaining what is feminine, but that was not the case. This research showed the participants ability to be their own individuals in the face of societal pressures.

CHAPTER FOUR: CONCLUSION

The aim of my research was do provide a deeper understanding into women's experiences of their bodies after a mastectomy and not choosing reconstruction. The research provided insight into the pressure that the women faced, also the transitions they went though and the agency they exhibited. Firstly, my research highlighted how women perceived the pressure placed on them by the surgeons. In addition the women also felt pressurised due to the short time frame given to make decisions, they also felt pressure through the decision making process and they felt social pressure to have a reconstruction to avoid feelings of abnormality and loss because reconstruction has been portrayed to be the solution in fitting into a society that marks the breasts as a key feature in a woman's femininity. Research showed that women chose not to have reconstruction and did experience negative feelings and thoughts about their bodies. However, this research shows that the women did not stay in a negative place.

The women transitioned and although the change was convoluted, they all came to terms with their bodies. Although reconstruction may offer a solution, it is not the only solution. My research highlighted that the women worked through the negativity and came to a place of loving their bodies again and seeing themselves as beautiful and feminine. They showed that through exhibiting agency, and saying no to reconstruction they reached a place where they loved and accepted their bodies. There has been a lot of research done on how transitions can be achieved; however there was a lack of research around agency in such transitioning. My research showed that the women chose to not give into this notion of fitting in through reconstruction, but acted counter culturally by choosing not to have reconstruction. They exhibited agency by engaging in all sorts of activities to assist in changing how they saw their bodies, they also were reflexive about the process. Finally the love and support they received, without having breasts made them feel they can stand up and be counter cultural in a society that portrays breasts as the epitome of womanhood.

This research shows that plastic surgeons do need to be more aware of the patient's orientation. It also shows that it is important for doctors to listen to their patient's voice and not impose their own understandings, such as the need for reconstruction in order to "fix" women with mastectomies. My research shows that it is so important to understand the fluidity of patients going through breast cancer process. It showed that although they may feel down at one point, it is not a permanent marker. They are in a process and it is vital has health care professionals to provide the support and care they need as they transition in coming to terms with how they think and feel about their bodies before the mastectomy and after the mastectomy. My research also highlighted the need has health care workers to help women find ways and outlets of expression that allow them to be free from social control, to be counter cultural and to find ways to help them love their bodies after having a mastectomy.

There are a few areas I would like to do more research into that is, looking at women who choose to have reconstruction done. It would be interesting to gain an understanding of the other side of the coin. As well as it would be interesting to interview doctors and gain their perspectives on reconstruction.

To conclude, this research has provided valuable insights into women who do not choose reconstruction as well as provides valuable information to health care workers in assisting women who have had mastectomies and chose not to have reconstruction.

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APPENDIX ONE

Understanding women's experiences of their bodies after a mastectomy.

INFORMATION SHEET

My name is Melanie Devlall and I am a full-time student in the MSC (psychology) programme at Massey University, Auckland. I am conducting a research as part of my degree requirements, under the supervision of Professor Kerry Chamberlain. My project aims to explore the experiences of women who have undergone mastectomies and chose not to undergo reconstructive breast surgery.

I am interested in learning about how you perceive your body, in particular your thoughts and feelings surrounding your body image.

As a member of the Breast Cancer Aotearoa Coalition, your participation in this study would be greatly valued and appreciated. I invite you to take part in an interview with me for approximately an hour long, to be held at a time and place convenient to you. I understand I am asking you to share information of a very personal and possibly distressing nature and assure you that I will endeavour to endure that your participation in this project is a positive experience for you.

The interviews will be audio-tape recorded and transcribed verbatim. All information provided by you will be treated confidentially and only my supervisor and I will have access to your contact and identity details. The transcriptions will be accessible only to my supervisor and myself, and used solely to inform this study. Pseudonyms will be used in my transcription as well as the report in order to protect your confidentiality. All data will be stored for a period of at least five years and then disposed of.

Please note that you are under no obligation to accept this invitation. If you decide to participate, you have the right to decline to discuss any particular topic, withdraw from the study up to one week after the interview, ask any questions about the study at any time during your participation, provide information on the understanding that your name will not be used in any reports from the study, and ask for the audio-tape to be turned off any time during the interview. At the end of the interview, you will be given the opportunity to reflect on what you said during the interview, and ask me not to include or transcribe any material that you decide. A summary of the project findings will be emailed to you when it is concluded. Please contact either Professor Chamberlain or myself if you would like any further information about any aspects of the project.

Melanie Devlall	**Professor Kerry Chamberlain**
Telephone: 0210339786	Telephone: 4140800 ext 41224
Email: t-devlall@hotmail.co.nz	Email:K.Chamberlain@massey.ac.nz

APPENDIX TWO

Understanding women's experiences of their bodies after a mastectomy

PARTICIPANT CONSENT FORM

I have read the Information Sheet and have had the details of the study explained to me. My questions have been answered to my satisfaction, and I understand that I may ask further questions at any time. I agree to participate in this study under the conditions set out in the Information Sheet.

Signature: .... **Date:** ....

Full Name - printed ....

Please provide your email address if you would like a summary of your findings from this research.

Email:____