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Experiences of gynaecological cancer and treatment of female survivors.

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Abstract

Until recently, clinical management of gynaecological cancer focussed almost exclusively on prolonging life. This resulted in improved diagnostic and treatment regimes that increased survival. Unfortunately, this comes at the price of various side effects that can have a vast impact on women's personal and social lives by introducing a variety of challenges and changes that necessitate adjustment. This qualitative study was carried out to gain insight into the challenges faced by women following gynaecological cancer diagnosis, treatment and effects as well as the changes implemented by them as a result of altered circumstances and perceptions. Purposive sampling was used to recruit women diagnosed with gynaecological cancer and who had undergone various treatments. Interviews revealed a range of shared experiences of the gynaecological cancer and highlighted the importance women placed on identity re-evaluation and reconstruction. Four themes emerged from the data: women's sense of female identity following gynaecological cancer treatment, threats to the identity experienced, protection mechanisms adopted by women to protect the self or identity as well as reconstruction of a new identity as a result of changed circumstances that was induced by cancer. While some of the findings were consistent with results of previous research conducted on identity re-evaluation and reconstruction of cancer survivors, it became clear that women with gynaecological cancer have to endure many unique challenges to their identity that needs to be addressed in future to lessen suffering endured.

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Introduction

How does one begin to describe the moment in your life when you hear 'you've got cancer!' These three words changed my life forever. My moment came when I was diagnosed. I then embarked on the largest, unplanned, unwanted, and most expensive journey of my life. My cancer diagnosis was a wake-up call that jolted me out of complacency and inducted me into a battle I neither wanted nor understood. (Ferrell, Smith, Cullinane, & Melancon, 2003, p. 1065)

How does it feel to receive a cancer diagnosis and to know that from that moment on your life will change profoundly? For some the diagnosis resembles their whole world caving in as this to them is a confirmed death sentence (Tower, 2008). Although many perceive death as a confirmed outcome of cancer this is not necessarily the case. Since 1960 the cancer survival rates for various forms of cancer has improved (Eiser, 2004). This was caused by advances in methods of early detection and treatment and have led to increasing numbers of individuals living with cancer for prolonged periods of time (Allen, Savadatti, & Levy, 2009). As a result, increasing attention has been placed by researchers and clinicians on the consideration and investigation of psycho-social issues faced by cancer survivors on a daily basis (Thewes, Buttow, Girgis, & Pendlebury, 2004). These issues influence quality of life, and is considered critical for the evaluation of new therapeutic protocols and for the development of disease management strategies (Carelle, et al., 2002). This emphasis on psycho-social issues, will only become increasingly important as we proceed in future (Patenaude & Kupst, 2005). In other words, an increase in the number of people who survive and live with cancer induced challenges that influence quality of life, resulted in research focussing more on this area in an attempt to alleviate suffering endured due to life alteration.

In order to try and understand as well as investigate this altered life, attention first need to be focussed on defining cancer. For this reason the next section will define cancer in order to set the context and background in which gynaecological cancer experiences take place. Then different treatments

implemented will be outlined to accentuate what is physically altered and the discussion will evolve into a description of the effects this alteration can have. Emotional change and implication as a result of alteration will then be addressed by discussing cancer and psychosocial treatment effects. After which the aims will be stipulated that rose from the discussion.

Defining cancer

This section will attempt to define cancer by not only emphasising how gynaecological cancer is unique and how it differ from other cancers, but by explaining and justifying the choice on this particular type of cancer. It will further highlight gynaecological cancer's prevalence and tendencies within the general population as further motivation for the cancer choice.

The diagnosis of cancer can be devastating and cause various psychological reactions including but not limited to: fear of death, disfigurement and disability or abandonment (Cancro, 1998). It leads to lifestyle changes that cause survivors to feel bewildered and overwhelmed not only physically but emotionally as well (Chan, et al., 2001). Although gynaecological cancer can share some of these experiences and can therefore be similar to that of other forms of cancer, it often is associated with other more unique sexuality, identity, reproductive and femininity concerns (Penson, Wenzel, Vergote, & Cella, 2006; Walton, Reeve, Brown, & Farquhar, 2010). For instance Holland and Reznik (2005) reports a reduction in quality of life in the area of sexuality and accentuates the need for more attention and research in this specific area. Gynaecological cancer is further associated with special adaptation needs relating to unique concerns, but sadly however, little attention has been provided to this area of survivorship (Molassiotis, Chan, Yam, Chan, & Lam, 2002). A need therefore exist for additional research that can identify and address quality of life and other concerns, as the number of gynaecological cancer survivors are increasing (Ferrell, et al., 2003). All these unique qualities of gynaecological cancer and shortcomings within current literature thus provided motivation for focussing the current research study on this particular type of cancer.

According to the New Zealand Ministry of Health (2009), 908 registrations of cancer of the female genital organs were registered for the year 2005. This primarily included uterine cancer (cancer of the corpus uteri) 383, ovarian cancer 301, and cervical cancer (cancer of the cervix uteri) 154 registrations. Although this can be perceived as a very small percentage of a total female population of 2,082,700 it is important to note that cancer of the ovary was the seventh highest number of registrations for females and that ovarian cancer registrations was the fourth highest number of female cancer deaths in New Zealand (Ministry of health, 2009). The Ministry mainly included uterine, ovarian and cervical cancer in this 2005 report but more types of gynaecological cancer exist and could manifest (Chamberlain-Wilmoth & Spinelli, 2000). For instance, gynaecology literature mentions uterine/endometrial, vulvar, gestational trophoblastic disease, cervical and vaginal as well as ovarian and fallopian tube when distinguishing between the different types of gynaecological cancer and indicate that various treatment regimes exist for this (Berek & Natarajan, 2007; Berkowitz & Goldstein, 2007; Bidus & Elkas, 2007; Holschneider & Berek, 2007; Lurian, 2007). As treatment involve multiple modalities it is not uncommon for women to cope with the recovery from surgery while preparing or experiencing chemotherapy and/or radiation therapy (Carter, Rowland, Chi, Brown, & Abu-Rustum, 2005). The next section will elaborate on this by focussing in specific on cancer treatment. It will outline what women endure physically and contribute to the understanding of effects that will later be described comprehensively.

Cancer treatment

Discussion of cancer treatment will focus around five different types of gynaecological cancers and will include: uterine, ovarian and fallopian tube, cervical and vulva cancer as well as gestational trophoblastic neoplasia.

The primary operative procedure for uterine cancer is a total abdominal hysterectomy i.e. surgical removal of the uterus and bilateral salpingo-oophorectomy which is the surgical removal of the ovary (Lurian, 2007; Marieb & Hoehn, 2007). Less reliance has been placed on radiation therapy in patients with uterine cancer as a direct result of the introduction of surgical staging, however, in patients who are medically unfit for surgical treatment radiation therapy alone can

be employed (Hacker, 2004b). The above mentioned treatment regimes are less favourable treatment options for young premenopausal women who wish to retain their fertility and for this reason more conservative hormonal therapy in the form of progestin and estrogens can be utilised dependent on various pathology qualities (Chamberlain-Wilmoth & Spinelli, 2000). In cases where the disease nature and/or progression do not allow more conservative management, chemotherapy can be used as a single or multiple agents or as a combination therapy with radiation and surgery (Cloutier, 2009).

Diagnosis of ovarian and fallopian tube cancer is often associated with an advanced progression of the cancer, this is due to the insidious onset and ovarian cancer mortality rates exceed those of both uterine and cervical cancer (Ferrell, et al., 2003). As a result of this, great emphasis is placed on the importance of thorough surgical staging as the subsequent treatment will be determined by the stage of the cancer (Berek, 2004b). Surgical treatment can therefore include total abdominal hysterectomy, bilateral salpingo-oophorectomy, omentectomy (resection or excision of the omentum) plus lymph node sampling, peritoneal cytological analysis and cytoreductive surgery to ensure that as much as possible of the tumour and its metastases is removed (Chamberlain-Wilmoth & Spinelli, 2000). Women with high risk low stage cancer are treated with a combination chemotherapy and in the case where women have advanced stage epithelial ovarian cancer, chemotherapy treatment should be individualised (Berek & Natarajan, 2007).

The stage of cervical cancer will influence what treatment regime will be followed and in general, early stage cancer can be treated with radical surgery or radiation, however, advanced stage cancer is best treated with chemo radiation (Bidus & Elkas, 2007). Like cervical cancer, vaginal cancer treatment will largely depend on the location and progression of the cancer as well as the presence or absence of the uterus and the main treatment protocol is radiation therapy although in some cases radical surgery is performed (Door, 2009). In radical hysterectomy the uterus, adjacent portions of the vagina, uterosacral ligaments, cardinal ligaments and bladder pillars are removed (Hacker, 2004a).

Treatment protocol for vulvar cancer is individualised and most early lesions can be managed with radical local excision, whereas more advanced progression of the disease is treated with chemo radiation followed by more limited surgical resection (Holschneider & Berek, 2007).

Gestational trophoblastic neoplasia are commonly treated with chemotherapy once tumour markers plateau (Berek, 2004a). Some women may desire surgical sterilisation in which case a hysterectomy may be performed with the mole still intact (Berkowitz & Goldstein, 2007).

Some of the treatment regimes discussed is clearly invasive, it does not only involve intoxication and removal of only expected problematic female reproductive organs, but include other adjacent organs and areas as well and one can only deduct that it will have effects of its own. So although advent diagnostic methods and treatment modalities for gynaecological cancer resulted in patient survival time gains (Rannestad, Skjeldestad, Platou, & Hagen, 2008), gains did not come without effects of its own and due to a variety of treatment toxicities during and following treatment many women experience a diminished quality of life (Penson, et al., 2006). The effect that some of these outlined treatment and toxicity can have on women will be highlighted next when cancer treatment effects form the focus of the discussion.

Cancer treatment effects

For the purpose of this discussion, attention will be focussed on two main areas of cancer treatment effects namely: biological- and psychosocial effects of cancer treatment.

Biological effects of cancer treatment

Local nerve supply and anatomical relations of pelvic organs are disrupted in hysterectomy and this common treatment for various gynaecological cancers may therefore adversely affect the function of these organs (Roovers, Van der Bom, Van der Vaart, & Heintz, 2003). Women with gynaecological cancer have reported various treatment related physical effects and include: hair loss, fatigue, nausea and pain (Ferrell, et al., 2003). Other effects reported is induced menopause, lack

of sexual desire and decreased vaginal elasticity, length and lubrication (Gotheridge & Dresner, 2002). Changes in reproductive, bladder, skin, bowel, hormonal, ovarian and sexual function has been reported as well (Holland & Reznik, 2005; Pearman, 2003).

Chemotherapy used as treatment for some forms of gynaecological cancer has a wide range of adverse effects and fatigue, nausea with vomiting, peripheral neuropathy, anorexia and myelosuppression has been reported (Lockwood-Rayermann, 2006). Women may further have to cope with decreases in cognitive function due to adjuvant chemotherapy, thromboembolic events due to cancer cells which may directly activate the clotting system, as well as the increased risk of osteoporosis as a result of the loss of estrogens due to some surgical procedures (McIntyre, 2009).

In a study which explored the experience of lower limb lymphedema following treatment for gynaecologic cancer, it was found that although lymphedema is considered a chronic condition which may develop after removal of or radiation therapy to lymph nodes, the reality of this condition came as a shock to women as insufficient information of its prevalence and seriousness was provided by health professionals (Ryan, et al., 2003). This study describes the major influence this condition can have on the female identity as many women make alterations to their wardrobe and an example is provided where previous attire is exchanged for larger sizes and designs which hide the problematic limb. The methodology of structured interviews used in this study can raise questions regarding the freedom of the women to share their full experience and it is further important to note that the study mainly focussed on vulvar cancer.

Opposing arguments do exist that gynaecological cancer survivors have few chronic treatment related physical problems (Matulonis, et al., 2008). This opposing study which explored long term adjustment of gynaecological cancer, only focussed on early stage ovarian cancer. Focussing on two separate types of cancers, vulvar and ovarian, complicates the matter as it is difficult to establish clearly if the presence or absence of chronic treatment related effects exists.

Menopause is the process by which biological fertility and endocrine ovarian activity cease entirely (Poniatowski, 2009). Surgical procedures such as bilateral oophorectomy, chemotherapy and radiation can induce premature menopause (Shifren & Schiff, 2007). The sudden onset of treatment related menopause is more symptomatic and have a greater impact on the quality of life of survivors than gradual menopause characterised by normal natural ageing (Young-McCaughan, 1996). Therefore another effect, related to treatment, that can have long term influences on survivors is menopause and its related infertility and is an issue for many young women diagnosed with gynaecologic cancer (Corney, Everett, Howells, & Crowther, 1992; Pearman, 2003). Radiation therapy which can cause sterility in high doses and chemotherapy that is toxic to the ovary are gynaecological cancer treatments that can further have a detrimental effect on female fertility (Carter, et al., 2005). Surgical procedures such as the hysterectomy can completely eliminate the woman's chances of ever creating a child with her partner and this can result in her feeling less of a woman and therefore affect her female identity (Moore-Schaefer, Cargo-Ladd, Lammers, & Echenberg, 1999).

In a message by a female cancer survivor it is explained that women have the increased burden of grief, that in addition to the loss of vital body parts women are mourning the loss of their reproductive ability (Becvar, 1996). This author wrote from the breast cancer survivor's perspective but similarities can exist between the two populations as both are characterised by the removal of cancer invested areas and include other treatment that can influence procreation ability. Another study, done by Moore-Schaefer et al. (1999) which explored living with gynaecological cancer during the child bearing years, found similar results, however, only included ovarian cancer survivors and generalisation of the findings to other gynaecological cancer survivors should be approached with caution. Infertility can cause a substantial amount of distress to survivors and can result in relationship difficulties, reduced quality of life, societal repercussions as well as have spiritual complications to the effect (Cullen, 2009). Women perceive fertility as pivotal to being female and the inability to have children indicate that they are old before their time and less attractive (Walton, et al., 2010). In a study which focussed on post treatment sexual adjustment following gynaecological cancer, it was found that for these women who perceive their fertility as pivotal to their

female identity, infertility as a cause of treatment resulted in a decrease in self-esteem, poorer body image and a lower sense of being feminine after removal of the reproductive organs (Juraskova, et al., 2003). Their work, however, mainly focussed on cervical and endometrial cancer and did not include all forms of gynaecological cancer. Some women's female identity is so radically influenced by their possible infertility that they consider the option never to marry as they view this inability as a burden on their partner (Molassiotis, et al., 2002). Although this study was conducted in Hong Kong only and cultural questions arise with relation to applicability to western cultures, it still remains valuable in creating an understanding into the experience of gynaecological cancer survivors.

The close connection that exists between biological treatment effects and emotions experienced became clear in the preceding discussion. It was regularly reported how biological cancer treatment effects caused certain emotional distress in women and femininity issues that arose was mentioned in specific. A more detailed description and discussion of psychosocial treatment effects will follow next, and this will include not only more effects but will elaborate on the connotation even more.

Psychosocial effects of cancer treatment

In order to discuss psychosocial cancer treatment effects, attention in this section will focus around six different themes. To initiate the discussion femininity will be presented and discussed. After this, attention will shift to the discussion of body image and appearance. Following this sexuality will be outlined and the relation between body appearance as well as attractiveness and sexuality will be highlighted. Isolation will then be discussed in terms of partner isolation and the need for support groups. Discussion will then revolve around gender role and to conclude the section, depression and anxiety will be presented and described.

Femininity.

The female body and body parts are loaded with cultural symbolism with different meanings, imposed and developed by age and different populations (Synnott, 1993). Historically conceptions of the meaning of femininity have been tied to women's bodies (Bayer & Malone, 1998). Maccoby (1998) attempts to

define femininity by providing some definitions. One definition defines femininity in terms of sexual orientation and accentuates the desirability to be attractive to men. In another definition, supplied by this author, attention shifts to the embodiment of the characteristics prescribed for the female sex roles in that particular society. Traditionally femininity was defined in terms of procreating ability and Catholic and Protestant moralists believed that motherhood ennobled womankind (Ozment, 1983). Characteristics and practices of what constitute femininity can vary by context, group and society, however, overarching features that individuals aspire to are prominent which cross-cut contexts, groups and perhaps societies (Schippers, 2007). The inability to fulfil femininity expectations can lead to questions about the individual's femininity (Watzlawik, 2009). In the next section attention will be given to some of these characteristics and practices of what constitute femininity and how this is relevant to survivors and their ability to meet these expectations.

Body image and appearance.

As mentioned earlier femininity can be defined in terms of sexual orientation and its close relation to the desirability to be attractive to men (Maccoby, 1998). The definition of what constitutes femininity is therefore described as a body with certain proportions and dimensions, as well as a female desirable in terms of masculine norms (Adelman & Ruggi, 2008). Western society media with its youth-centeredness advocate certain body sizes and shapes and any deviation from this norm can lead to women feeling insecure and anxious about the acceptability of their physical appearance (Chamberlain-Wilmoth & Spinelli, 2000).

A tendency in common consumer culture is to convince individuals that ascribed bodily qualities are plastic and that individuals can achieve certain desired appearances with effort and simple body work (Featherstone, 1991). Women are no longer given only verbal descriptions or examples of what femininity consists of, rules are conveyed through images which indicate what attire, body shape, facial expression, movement and behaviour are required (Bordo, 1993). It is therefore not surprising that a study conducted by Oberg and Tornstam (1999), which focused on body images among men and women of

different ages, found that over all age groups, physical appearance is more important for women than for men. Adelman and Ruggi (2008) accentuate this in their study on gender, identity and constructions of the body in contemporary Brazilian culture, by stating that women not only give preference to the standardised beauty and sexiness but, that it is placed at the highest position on priority lists and given a key position in their sense of identity and desires.

A study which focussed on attitudes to radical gynaecologic oncology surgery conducted by Nordin et al. (2001) found that young women considered not to continue living under circumstances characterised by the loss of femininity and attractiveness during cancer treatment. Although this study provide important information on attitudes in relation to the loss of femininity and attractiveness, it is important to note that the study population was limited to north London and caution should be taken when generalised to other populations. Various studies support this continued survivorship distress with relation to body image and appearance following cancer treatment (Andersen & Jochimsen, 1985; Wenzel, Donnelly, Fowler, Habbal, & Taylor, 2002), however, opposing literature (Wyatt & Friedman, 1996) indicate that somatic concerns which include bodily changes was prioritised by survivors as a lesser concern. This opposing study however focussed on all forms of female cancer, including breast cancer and makes no specific mention to vulvar and vaginal cancer. This has important implications as radiation and surgery treatment effects to the vulva and vagina can cause long term physical changes in appearance and lymphedema (Door, 2009) and can therefore influence study outcomes. The effect that lymphedema can have on body image and in turn on self-esteem and femininity is displayed in a study conducted by Ryan et al. (2003) that focussed on the experience of limb lymphedema after treatment of gynaecologic cancer. In this study women reported that under certain conditions they prefer not to wear compression garments, being well aware of the increased risk this can have on lymphedema, so that they can wear a nice dress again. According to the authors this indicates the women's continued attempts to regain the normal body and to wear normal feminine robes. Therefore, as mentioned earlier the women's inability to fulfil femininity expectations, namely to wear normal attractive dresses, can lead to questions about the individual's femininity and result in attempts to regain normality (Watzlawik, 2009).

Other femininity expectations closely related to body image which can influence gynaecological cancer women and cast doubt on femininity is weight alteration as well as hair loss and is reported in studies like Moore-Schaefer et al. (1999) where women comment on both weight gain and loss and the difficulty of finding suitable clothes for a body that changed shape in more than one way after cancer treatment and its effects. Here women further reported the devastating effect of hair loss and compared the baldness to a mark placed on a house that is quarantined when an inhabitant got invested with scarlet fever in the past. This strong association becomes understandable when it is considered that many women grow up with the perception that long hair is irrefutably feminine (Brownmiller, 1984). Hair is a powerful symbol of the self and part of the cultural definition of femininity (Synnott, 1993). Carelle et al. (2002) investigated patient's changing perceptions of the side effects of cancer chemotherapy and found that hair loss remained a major concern for patients.

In conclusion to body image and appearance, Wolf (1991) best explains appearance and its relatedness to deep sensitive areas of the female subjectivity by pointing out that beauty is intricately intertwined into the psyche and can be found where female sexuality mingles with self-esteem. The author further indicates that it is defined as an entity which is bestowed upon women from the outside on a continuous basis and that can be taken away at any given time. Therefore, by telling a woman that she is ugly one can cause her to feel ugly and act ugly and be ugly, at least as far as her experience is concerned. Therefore, physical changes due to hair loss brought on by certain chemotherapy, surgical scars and surgically induced ovarian failure symptoms, may adversely affect women's perceptions on attractiveness and sexual desire (Chamberlain-Wilmoth & Spinelli, 2000). This perception of own attractiveness and sexual desire affect female identity and can in turn influence sexuality as demonstrated in the next section and will be discussed accordingly.

Sexuality.

Psychosocial results of gynaecological cancer effects the very essence of the female being or identity as sexuality forms an integral part of not only who she is but how she relates to others (Werner, 2004b). For many women sexuality is not

merely the ability to engage in sexual intercourse but involves feelings of body appearance, procreation ability, femininity as well as the ability to function sexually (Chamberlain-Wilmoth & Spinelli, 2000). It can therefore be seen as an integral aspect of a women's personality that includes emotional, intellectual and socio-cultural components (Gotheridge & Dresner, 2002).

Diagnosis and treatment of gynaecological cancer can adversely affect a woman's self-image as scars and physical changes can be constant visible reminders, this affected self-image in turn forms an integral part of the female psyche and sexuality (Larrison, 2009). Primary surgical treatment such as a radical vulvectomy, discussed earlier, can be mutilating and often include removal of all labial tissue, the clitoris and the groin lymph nodes (Andersen, 1985). It is therefore understandable that some women are so concerned about their partners reaction to scars and if the partner will still find them attractive, that they advise partners to seek someone who can provide them with children and fulfil their sexual needs (Moore-Schaefer, et al., 1999). A study conducted by Townley-Bakewell and Volker (2005) which focused on sexual dysfunction related to treatment of young women further found that chemotherapy have the potential to cause chronic sexual dysfunction in young women. This study included only a breast cancer population but does stimulate questions about how the gynaecological cancer population will experience sexuality following treatment. Werner (2004b) focused on psychosocial effects of gynaecological cancer and found that feelings of inadequacy and guilt can drastically impair the need for sexuality. Various studies accentuate that sexual functioning can be disrupted following the diagnosis and treatment of gynaecological cancer (Andersen, Woods, & Copeland, 1997; Gamel, Hengeveld, & Davis, 2000). One opposing study conducted by Grumann, Robertson, Hacker and Sommer (2001) focused on sexual functioning in patients following radical hysterectomy for stage IB cancer and found that this treatment regime does not entail major sexual consequences. This study included only cancer of the cervix and included a very small sample size; conclusions must therefore be drawn with caution.

Irrespective of the ongoing dispute in the literature on the long term effects of diagnosis and treatment on sexuality or not, many women with gynaecological

cancer mention sexuality and femininity issues initially and report a decrease in sexual desire for a variety of reasons (Gotheridge & Dresner, 2002). Women under normal circumstances react positively to partner signals of sexual interest (Maccoby, 1998), reactions which may, as a result of treatment, no longer be shared by certain female cancer women. Therefore feelings of guilt can be experienced by women with gynaecological cancer due to their perception of an inability to satisfy the partners sexual needs (Molassiotis, et al., 2002). This in turn can have psychosocial implications as demonstrated in the next discussion on isolation.

Isolation.

For many individuals sexual functioning forms an important part of their well-being and general quality of life and any alteration in their sexual functioning can potentially result in emotional dysfunction and cause marital disharmony (Stead, Brown, Fallowfield, & Selby, 2003). Werner (2004b) supports this by pointing out that some women experience anger due to the fact that they perceive themselves as being different because of their inability to conceive, this can in turn influence her relationships overall and in particular with her partner and leave them feeling isolated. In a qualitative study that investigated subjectivity, family, gender and health services, it was found that although women diagnosed with gynaecological cancer indicated an increased need for moral support, the reaction in reality can be abandonment as the ability to procreate and motherhood is seen as central and the loss of this ability results in being useless as a woman (Pelcastre-Villafuerte, Tirado-Gomez, Mohar-Betancourt, & Lopez-Cervantes, 2007). This study included only cervical cancer women in Mexico and therefore focus on only one culture's traditional structure of a cancer that can be accompanied by certain stigma, and for this reason caution should be taken when conclusions is made to other world populations. However, the study can be valuable when other similar patriarchal societies are considered. For instance, one example of a study which accentuates this focus on reproductive health was conducted by Sevil, Ertem, Kavlak and Coban (2006) who focussed on the loneliness levels of patients with gynaecological cancer. The authors of this study found that in male dominated societies, such as their population group, women's

position in society has been reduced to the reproductive ability and therefore health of the female genital organs is considered crucial.

The gynaecological cancer diagnosis in itself can alter social aspects of life and can change the nature of, or even isolate women from energy, support and encouragement providing relationships (Lockwood, 2009). A further challenge is the fact that gynaecological cancer is a minority cancer and therefore fewer options exist with relation to peer support when compared to other forms of cancer (Ferrell, et al., 2003). The effect of gynaecological cancer on social life varies and women with more advanced cancer whose treatment extends over a prolonged period of time, can have a significant decrease in their relationships, this was found to be true for partners as well and some individuals indicated that relationships with friends diminished due to treatment needs of the women (Akyuz, Guvenc, Ustunsoz, & Kaya, 2008). Although partner isolation is interesting and worth being acknowledged as it forms part of an intricate social environment and network, it falls outside the scope of this particular study which focuses on the gynaecological cancer and treatment of women survivors. Another psychosocial treatment effect of gynaecological cancer closely related to isolation is gender roles and will receive attention next.

Gender role.

Gender role is defined as attitudes and behaviour which is considered appropriate for a particular sex in a given culture (Golombok & Fivush, 1994). Gender role beliefs indicate not only typical behaviour for different genders, but how they should behave and for this reason gender role beliefs can be perceived as being descriptive and prescriptive (Eagly, 2009). Gender role identity is in turn defined as the degree to which an individual identifies or displays societal prescriptions of masculinity or femininity (Mintz & O'Neil, 1990). Gender identity is therefore a different and broader concept and it can be argued that failure to adhere to society's prescribed gender roles does not necessarily imply uncertainty regarding the gender identity (Hoffman, Borders, & Hattie, 2000).

Baron and Byrne (2000) describes, in a discussion on the use of children stories in books and films to convey gender roles, how one of the usual female

roles is portrayed as being the mother who gives birth or to be sexually attractive to ensure procreation and bearing of offspring. Regardless of whether women actually decide to procreate, motherhood is perceived as pivotal to how women perceive themselves as well as how others define them (Phoenix & Woollett, 1991). Womanhood is strongly associated with motherhood and maturity, this according to some, indirectly imply that childless women are not mature and those who reject motherhood are not feminine (Hird & Abshoff, 2000). Contratto (1984) elaborates on this association even further by accentuating that the most important role of women since the early nineteenth century has been nurturing of children. History indicate that in the case where reproduction efforts was unsuccessful the individual woman were viewed as suspect (May, 1995).

Today all societies, irrespective of social structures, still value childbearing over childlessness (Jones & Brayfield, 1997). In some cases childless individuals are perceived as incomplete, immature, unhappy, lonely, child haters, career-orientated, selfish, maladjusted, unnatural and psychologically unstable (May, 1995). Childless women in particular are often considered to have the desirability to be like men (Hird & Abshoff, 2000). Only selfishness, according to Cameron (1990), is not associated with involuntary childless women as they are pitied because they lack the advantages of having children. Even feminism has had the contradictory effect of criticising the very activities they aim to legitimise by revealing ways that womanhood can be both oppressive and detrimental but at the same time bestow legitimacy on the work of raising children (Jones & Brayfield, 1997). A large amount of literature exists on this contradiction in feminism with relation to womanhood and procreating, however, although it is worth acknowledging a full discussion of it does not fall within the scope of this current study.

In a qualitative study by Moore-Schaefer et al. (1999) which focused on women living with ovarian cancer during childbearing years the participants indicated that having children was important to them and that an important part of the expected narrative for women was denied them. Werner (2004a) discussed life after choriocarcinoma and accentuates that she wished it was possible to fulfil her role as a woman and create a child with her partner. Both these studies (Moore-

Schaefer, et al., 1999; Werner, 2004a) indicate the importance women with gynaecological cancer place on the female role of childbearing and imply that by being denied that ability women experience a miss fit with societal prescriptions.

Reproduction have occupied a central role in both knowledge's of women as well as in the lived experience of women who are inevitably, at least partially defined in relation to the regulating ideal of reproduction and will continue to do so (Malson & Swann, 2003). Reproduction, however, is not a woman's only gender role, but also that of care taking (Lockwood, 2009). Often care provided by women extends beyond care to children and include care to elderly relatives, emotional and sensitive care to spouses and friends (Eagly, 2009).

Since the early nineteenth century psychological writers has been emphasising the need for women to be the primary care takers and argued that dire consequences would follow the neglect of this important role (Contratto, 1984). Although there has been some change in recent years with more men participating more fully in household tasks, it is still in traditional relationships women who manage the household and is responsible for the children while the man is responsible to provide for the households financial needs (Maccoby, 1998). A frequent reported complaint of gynaecologic cancer survivors is diminished energy and this can impact on traditional roles that society ascribe to women (Lockwood, 2009). Carelle et al. (2002) reported in a study on the changing perceptions of patients on the side effects of cancer chemotherapy, that patients stated that effects on family and the partner is the most severe side effect. This study did not only focus on gynaecological cancers exclusively and caution should be taken with generalisations to specific populations, however, it provides useful to report on ranking of cancer effects by survivors. Howell, Fitch and Deane (2003) reports in their impact of gynaecological cancer on the family, that older children and partners had to take on care giving and household roles as the women had difficulty to sustain their previous roles. The focus of these authors was only on ovarian cancer, which is often associated with invasion of adjacent areas which can influence treatment duration and outcome, but provides valuable information that can aid in the understanding of how gender roles gets redistributed within the family. In a study conducted by Akyuz et al. (2008) which focussed on the lived

experience of women with gynaecologic cancer and their partners, it was pointed out that this involuntary shift of female role responsibilities to spouses are not common in all societies. In this study the authors indicate that due to the traditional structure of some societies, house responsibilities are not taken over by spouses and that in some instances mothers and mother-in-laws are more likely to take up the responsibilities of the patient, this however depend largely on family ties. This study focussed mainly on Turkish traditional structures but convey important information about role reduction.

From the above discussion it is clear that not only women with gynaecological cancer, but society as a whole place great importance on gender roles and that adherence to these roles are greatly valued. It therefore make sense that in the event where women are unable to conform to gender roles, due to cancer treatment, psychological distress can be experienced of which anxiety is only one. Emphasis will be placed on two specific psychological distresses experienced by gynaecological cancer women when depression and anxiety is discussed next.

Depression and anxiety.

The cancer population has a high prevalence of physical and psychological symptoms and these symptoms can have an adverse impact on individuals (Portenoy, et al., 1994; Sevil, et al., 2006). These symptoms, such as stress, fear and anxiety, often is due to treatment regimes like radiation and chemotherapy (Akyuz, et al., 2008) which influence reproductive hormones and can make women with these cancers prone to develop anxiety and depressive disorders (Thompson & Shear, 1998).

The effects of these treatment regimes can extend into survivorship (Lowe, Ferrell, & Leong, 2007) and many patients report psychological and social effects at the end of their treatment, three months later as well as one year post treatment at which time they find it increasingly hard to share their concerns with others (Klee, Thranov, & Machin, 2000). It is for this reason that some women diagnosed with gynaecological cancer indicate that the need exists for psychological assistance (B. E. Miller, Pittman, & Strong, 2003).

A study which compared depression, anxiety and quality of life levels of women with epithelial ovarian cancer with women of the general population found that levels of both depression and anxiety were higher in the cancer population (Bodurka-Bevers, et al., 2000). Although this study provide valuable results in terms of the deviation of cancer individuals from the general population its main focus is on one cancer type, ovarian cancer, and does not provide any comparisons between different gynaecological cancer types and the general population. Women were further recruited form a single Gynaecologic Oncology Centre and generalisations are therefore even more complicated.

This introduction emphasised the complicated nature of gynaecological cancer survival. It further accentuated that the experience is characterised by the intricate interplay between various important effects that can have a profound impact on many lives. An impact that due to more effective early diagnosis and treatment tools influence an increasing amount of women daily. Current preferred treatment regimes were discussed which proved to be invasive and to cause devastating effects. It not only influences women physically, but resulted in major psychosocial effects that impacted significant others in relationships.

Physical effects detrimental to sexual functioning (premature menopause with related effects), procreation ability (removal of reproductive organs), mobility (peripheral neuropathy) and physical appearance (hair loss, weight alteration, lymphedema as well as surgically induced scarring), were outlined and this resulted in questions relating to how women experienced and made meaning of all the different physical effects of treatment.

The introduction further highlighted the relation that exists between physical effects and psychosocial effects. Femininity was explored in terms of traditional and historical conceptions and it was demonstrated that overarching femininity features change according to context. As a result of this questions were raised that focussed on how women with gynaecological cancer perceive and make sense of their own femininity following treatment effects.

Body appearance alterations were described and discussed by accentuating the importance of attractiveness and the influence this can have on self-esteem,

self perception, identity as well as on sexuality. As body alteration is a common result of treatment of gynaecological cancer, questions were raised on how women experience this particular biological cancer treatment effect and what it means to them, or in other words, how this affects the identity, how they make sense of it and live with the effects on a daily basis.

Closely related to this was isolation and here the influence of body appearance and sexuality became apparent again. The effect that biological body changes can have on relationships was discussed and questions were raised about how women experience and cope with isolation issues as a direct or indirect result of their gynaecological cancer diagnosis and treatment.

Attention then shifted to gender roles ascribed to women in society and the impact diagnosis and treatment can have on these roles, were explored. It became clear that one of the major roles affected was motherhood which is greatly valued in society. This resulted in questions about the experiences of women in this area. In other words how women perceive themselves following the loss the reproductive ability. How this affected the female identity.

Finally depression and anxiety were addressed in this population and its prevalence in women with gynaecological cancer was highlighted. This in turn raised questions of emotional experiences following diagnosis and treatment, how this impacts everyday lives of women as well as how each individual cope with anxiety and depression. In order to attain answers to all questions raised research aims were constructed to enable the exploration of each area of questioning and will be discussed next.

Research aims

It has been emphasised that femininity encompass a vast amount of intertwined constructs which is by itself are not always observable traits, and that instead these intricate constructs that consists of many different traits cannot always be easily defined (Watzlawik, 2009). Some studies attempt to accentuate this problematic nature of defining femininity and its related constructs by indicating that the definitions, although noble attempts, exclude various minority groups (Schippers, 2007). Gynaecological cancer survivors are such a minority

group (Ferrell, et al., 2003) and perhaps Hoffman et al. (2000) provides an alternative by indicating that there is some value in not focussing on the extent to which an individual's characteristics corresponds with traditional prescriptions but, rather on questioning what it means for that particular woman. Each woman and her gynaecology cancer, as well as her family and social network are unique (Lockwood, 2009) and will result in different and personal experiences (J. Miller, 2005). Experiences which are according to some literature (Akyuz, et al., 2008) in need to be researched so that an in-depth understanding can be attained of each aspect of gynaecological cancer's effects on women.

For this reason the current research study will attempt to gain an in-depth understanding of gynaecological cancer, treatment as well as effects and aim to:

- Try and understand how women experience and make meaning of the physical effects of their treatment.
- Find out how women perceive and make sense of their own femininity and female identity following treatment.
- Learn what body alteration means to women with gynaecological cancer as well as how they understand it. In other words how they make sense of and adjust to body alteration as well as effects and continue to live with it every day.
- Explore how isolation is experienced and coped with as a direct or indirect result of diagnosis and treatment effects.
- Investigate how women experience loss of the ability to conform to socially prescribed roles and how they not only perceive themselves as a result of this but how this affects their identity in general.
- Attempt to understand how cancer diagnosis, treatment and effects influence various relationships of women.
- Establish how women emotionally experience cancer diagnosis, treatment and effects and finally

- Ascertain how women experience depression and anxiety as a result of their diagnosis, treatment as well as effects and manage to cope with it on a daily basis.

The study will therefore attempt to enable a better understanding of cancer- and treatment effects in various parts of women's lives from the perspective of those who have had the experience of the phenomena.

Summary

In this introduction section gynaecological cancer was outlined and described. Cancer was defined in order to set the context and background in which gynaecological cancer experiences take place. Different treatments implemented were then outlined to accentuate what physical alterations occur and the discussion evolved into a description of the effect alterations can have. Emotional change and implication as a result of alteration was addressed by discussing cancer and psychosocial treatment effects. After this the aims was stipulated which rose from the discussion. In the next section the underpinning philosophy for this study will be presented and the philosophy of phenomenology will be introduced as a methodology for understanding the gynaecological cancer experience.

Methodology

The purpose of this section is to provide a clear overview of phenomenology as a research perspective and approach as well as to provide a rationale for selecting it as a methodology. Before commencing this discussion however, a brief and general explanation for the selection of the broader qualitative approach will be provided.

Qualitative research

Camic, Rhodes and Yardley (2003) provide an analogy which successfully demonstrates the clear difference between qualitative and quantitative research that influenced the decision between the two approaches for this study. In this analogy quantitative research is compared to the process of producing a map of a place. The map conveys with precision the location of this place and its relation to other places with regards to distance and proximity. Qualitative research on the other hand is compared to a video recording of the same place. This recording reflects what it is like to be at this place as well as the changing perspective of the observer. In this analogy the authors carefully points out that even though the map is extremely useful it neglects to provide a perspective of what it is like to be at the place. Marecek (2004) elaborates on this idea of what it is like to be at the place even more by indicating that qualitative research is more interested in how human action and meaning are constituted by the continuous flow of socio-cultural life. It is therefore idiographic as it aims to understand the meaning that an individual attaches to everyday life experiences (Schurink, 1998). Or in other words, the aim is to understand the meaning of a given phenomena from the perspective of the individuals who experience it (Dalton, Ellias, & Wandersman, 2001).

The research questions of this research, as outlined earlier, are to gain understanding of how women experience gynaecological cancer, what it is like to be diagnosed with it, and how women experience their treatment and effects. A qualitative research approach in this sense will be more suitable due to the *how* and *what* nature of the questions asked. In other words it will be better equipped to provide an understanding of what it is like to be diagnosed with gynaecological cancer.

As stated earlier, gynaecological cancer is different in the sense that it has sexuality, identity, reproductive and femininity issues and each woman with her gynaecological cancer will be unique in terms of her personal experiences, social networks and support available (Lockwood, 2009; Moore-Schaefer, et al., 1999). The qualitative approach is useful in attaining a deep, rich, contextual insider understanding of personal experiences of members of a certain community and for understanding the intricate interplay of multiple interrelated variables (Dalton, et al., 2001). It is further not concerned with predefined variables as it is interested in the meanings attributed to events by the research participants themselves and not variables identified by researchers in advance (Willig, 2008). The nature and amount of gynaecological cancer experience variables complicates predefined variables and it will therefore be more suitable to select a research approach that does not rely on predefined variables but will rather allow the women to identify and discuss the variables as it is important to them.

Qualitative research is further a particularly appropriate choice in unique small study populations (Hansen, 2006a) as is the case with gynaecological cancer (Ferrell, et al., 2003). It considers the context of words and events which forms an integral part of the primary data, it is therefore mainly concerned with statements and questions couched in words and with detailed descriptions of settings and events (Mauch & Birch, 1998). Qualitative research grants the opportunity for the investigator not only to engage with the women but with the events and the ambience studied as an integral part of the research process (Patton, 2002a). Each gynaecological cancer experience is unique in terms of support networks and social structures which can influence women (Lockwood, 2009) and the focus that qualitative enquiry places on context can aid in a more comprehensive and in-depth understanding of each woman's unique experience.

Phenomenology shares these assumptions and characteristics due to the fact that it is one of many qualitative methodologies but a more detailed and focussed discussion on phenomenology in specific is needed.

Phenomenology

“Phenomenology is the study of essences” (Merleau-Ponty, 1974, p. vii).

In this discussion phenomenology will be presented as a theoretical framework for undertaking this research. It will be defined and a historical overview will be provided followed by the introduction of key phenomenological concepts. The interrelatedness of phenomenology to the lived experience of diagnosis, treatment and effects of various gynaecological cancers will further be discussed. The development of assumptions made by phenomenology which relate to: ontology, epistemology and theory (Patton, 2002b) were considered in selecting a methodology and the application of phenomenology as the ontology and epistemology for this research into gynaecological cancer survival will be amalgamated into the general discussion.

The term *phenomenology* is derived from two Greek words: *phainomenon* and *logos* and implies providing a logos or reason of various phenomena (Sokolowski, 2000). In the Online Oxford dictionary (Grathwohl, 2010) a phenomenon is defined as “a fact or situation that is observed to exist or happen, especially one whose cause or explanation is in question, the object of a person's perception or as remarkable person or thing”. The Oxford companion to philosophy further include things that are thought in the term *phenomenon* (Honderich, 1995). The term *phenomenology* therefore implies something that is revealed or shown that present itself in an experience (Blackburn, 1994). These definitions mention something that is presented to the individual's psyche through the senses, which is experienced and then interpreted in order to make sense of it.

The women in this study were presented with gynaecological cancer diagnosis and treatment in their past. They experienced and interpreted their illness and not only made sense of it but may be forced to continually do so due to the fact that they currently can be faced with long term treatment effects. Each woman looks upon gynaecological cancer as the object of their experience before any interpretation was made about it. The object of the experience is then perceived in the consciousness by means of the interaction of the senses and the interpretation then of the phenomenon becomes the lived experience.

As a philosophy, phenomenology has developed over many years and various perspectives evolved from it. These perspectives will be discussed next

and specific attention will be given to the historical and philosophical development of phenomenology.

Historical and philosophical background

Phenomenology is considered both a methodological approach and a philosophical perspective (Hansen, 2006b) and as many phenomenologies as phenomenologists exist (Audi, 1995). As a direct reaction to a world in which everything was understood through empiricism, German philosophers redirected their focus to an interpretive science that not only focussed on the investigation of individual lives and social worlds through the study of contexts, but the individual constructions and meanings formed within each context (Titchen & Hobson, 2005). Edmund Husserl is perceived as the founding father of phenomenology even though the term has been used by other philosophers before him (Giorgi & Giorgi, 2003).

Husserl founded phenomenology as a philosophy which initially focussed on the subject matter of the consciousness and experience but this was expanded later by Heidegger to include the human life (Kvale, 1996b). One of the basic philosophical assumptions made by Husserl was that only what can be experienced by attending to perceptions and meanings that awaken the conscious awareness, can be known (Patton, 2002c). Heidegger accepted this epistemological premise but did not see it as the starting point as Husserl did, instead Heidegger took a step back from the epistemological question of how we know what we know to an ontological question of what it means to be a person and how the world is understood by us (Titchen & Hobson, 2005). Crotty (1996b) acknowledges these two perspectives as the main areas of phenomenology in social research. The transcendental phenomenology of Husserl with an epistemological framework and the interpretive phenomenology of Heidegger with an ontological framework. Notwithstanding the above mentioned differences, the majority of researchers using phenomenology as methodology include that which contribute to their shared understanding of the whole phenomenon (Audi, 1995). Some of these shared mutual concepts applicable to this research will be introduced next.

Embodiment

Heidegger uses the term *dasein*, which translates to *here* or *there* and *being*, however does not perceive it as a specific location but rather as a whole area in which things can occur, it is therefore where the I is that belongs to the being (Greaves, 2010). This implies that individuals exist not simply as individuals but that they exist within a social context and that being here or there is embedded in the world as being in the world (Pascal, 2010). Humans are therefore physically in the world as a human body and in a dynamic relationship with the world where individuals react to the world and in turn where the world react to us (Crotty, 1996a).

This experience of the world will not only depend on the individual's context but on their mental orientation (wishes, desires, judgements and emotions), in its totality and this includes the physical characteristics as well as the thoughts and feelings that develop as individuals engage with the phenomenon and therefore include the experiential characteristics (Willig, 2008).

Using this theoretical perspective cancer can then be perceived as consisting of both physical characteristics and experiences or as pointed out above consisting of the individual's thoughts and feelings. Cancer is presented to the individual in terms of physical characteristics (diagnosis and symptoms) therefore acting upon the woman and in turn each woman will experience emotions with regards to her diagnosis and symptoms which in turn will influence her reaction to the illness. An understanding of the cancer phenomenon will thus not be attained by isolating only the physical characteristics of cancer presented to the woman but by investigating the whole dynamic relationship which includes the individual's emotions thus the reciprocal relationship that is continuously taking place in-the-world.

Heidegger elaborated even further on context by arguing that *dasein* is essentially temporal (Greaves, 2010). In other words that individuals exist within a unique personal and social historical environment (Pascal, 2010). This concept will be elaborated on next.

Temporality

Greaves (2010) indicate that Heidegger places great importance on temporality and perceives it as the key in unblocking a world of individual meaning. It includes the past, present as well as the future and incorporates how this influence human existence (Pascal, 2010). Temporality further consist of levels and Sokolowski (2000) identifies the first level of temporality as objective time which is public and measurable and therefore verifiable. As an example, for the women who survived gynaecological cancer diagnosis and treatment with its effects, this objective time level of temporality will include the clock and calendar time with relation to their experience. The date when the diagnosis was received which preceded the treatment with its own specific duration in terms of clock time and calendar days. Important to note here is that this time level does not consists only of a date and time but includes awareness of the order of happenings, thus that diagnosis precedes treatment. This time is located in the world in a common location which is shared. The second level of temporality mentioned by the author is subjective time and can be characterised by the duration and sequence of mental acts and experiences. For example by using memory the women can recall their prior gynaecological diagnosis and treatment experiences and re-enact the perceptions they then experienced. This time therefore is not public but private. The third and last level of temporality of time mentioned is awareness of the subjective time and is characterised as the area from which things as a phenomenon originate (Sokolowski, 2000). Temporality indicates that being-in-time is not only historical but can be developmental as well (Pascal, 2010).

However, as stated previously human beings exist within their own social historical contexts. Thus far the historical context from the phenomenological perspective have been outlined, in the next discussion attention will be focussed beyond dasein as an individual and shift to the being-in-the world where one has to relate to others. Or what phenomenology refers to as the they world. Crotty (1998) interprets the they world as the socio-cultural expectations all humans conform to. Here again the importance phenomenology places on the acting of the world on the individual and the individuals acting on the social context becomes evident. Greaves (2010) state that one striking aspect of the dasein's relations in

the world all of the time is, that no matter what is done in the world, there is always a feeling present about the self and the world it is in and these emotions are fundamental to its being. In other words phenomenology not only acknowledges, but accentuates the importance of emotions and moods of the women within their very personal and sensitive gynaecological cancer survival world.

Pascal (2010) mention that when individuals experience intense moods the essence of being is disputed. One such mood pointed out by the author is angst which will be assumed to be intensely disturbing in a life threatening illness, as it reveals the emptiness which is at the core of human existence, however, at the same time it is argued that this can potentially be an event characterised by personal development where the facing of it or the possibility of it can result in a higher level of appreciation of the current time and being. In other words by being faced with the ultimate reality of death the individual can be forced to re-evaluate the current being-in-time and appreciate it more.

Keeping the above outline of the theory in mind the discussion will now shift focus to pointing out the application of phenomenology as a theoretical framework for this particular research study which explored the lived experience of gynaecological cancer survival.

The main focus of phenomenological enquiry is the lived experiences that takes place in everyday life and by being presented to the individual, through the consciousness, it present the individual with the reality of the world and life (Pascal, 2010). Understanding of meanings and perceptions of another person's world can be attained by researchers through phenomenological enquiry by exploring the lived experiences (Van Manen, 1990). This forms the basis of interpretive phenomenology enquiry and is one of the reasons why phenomenology was applied as method and theoretical framework to explore the everyday lived experience of gynaecological cancer as it is presented through the consciousness to women.

One of the concerns of the current research study was being, therefore understanding what it means being a woman who had been diagnosed with and received treatment for gynaecological cancer. Phenomenological research is an

investigation into what it means being human and this includes understanding experiences and concomitant factors that pressure current meaning structures attributed to experiences by questioning boundaries of the nature and ground of ascribed meanings (Van Manen, 1990). The similarity in phenomenology's investigation of being and the research concern resulted in selecting phenomenology.

The study was further interested in the meanings these women with gynaecological cancer ascribe to their continuing unfolding. More specifically the study was interested in this continuing unfolding process and therefore how women experienced and gave meaning to their diagnosis and treatment, which belong to their past, as well as their treatment effects which belong to their present and future.

Temporality was a further consideration. Each gynaecological cancer experience will be personal and unique in terms of the type of cancer, treatment, effects and support as well as the temporal understanding of it and meanings ascribed to it.

Inter-subjectivity

A concept Heidegger challenged was, that by keeping a distance from one's own subjectivity the researcher could analyse what is being studied as it appears, a term he referred to as bracketing. However, Heidegger claimed that an individual as being-in-the-world could not be separated from the world and that only through reflection can awareness of one's own assumptions be attained (Pascal, 2010). In phenomenology the researcher is not detached from what is studied, but rather perceived as subjective (Schurink, 1998). So in terms of epistemology the researcher acknowledges their subjectivity and reflects on how their perceptions can potentially influence the process (Marecek, 2004). Advantage is taken of the researcher's personal feelings, insights and perceptions that can aid in the understanding of the social context involved, however, awareness of values and assumptions remains (Neuman, 1997).

In its core, this inter-subjectivity assumes a co-created and mutual research relationship which in turn decreases the object-subject divide and regards inter-

subjective experience of both the researched and the researcher as a significant source of knowledge (Pascal, 2010). It is apparent from the discussion on cancer diagnosis, treatment and treatment effects that this particular cancer can be extremely personal and emotional and the acknowledgement phenomenology gives to the researcher as a significant source of knowledge could perhaps aid in the understanding of the women's experiences of cancer. Previous exposure of the researcher to gynaecological cancer can provide some knowledge which can be utilised for a better understanding.

Summary

Phenomenology does not emphasise the idea of an objective independent external reality (Schurink, 1998). Rather it maintains the 'natural attitude' and everything accompanying it. In simpler terms, phenomenology penetrates the appearances to investigate the object itself, however, at the same time concentrates on that what is normally looked through (Sokolowski, 2000). According to Van Manen (1990) this quality is what makes phenomenological research different as it originates in the life world or what is referred to as the natural attitude of everyday life. It aims to understand reality by exploring meanings people attach to it in a specific setting (Hansen, 2006a). This interest of phenomenology to explore each individual's meaning attached to phenomena in a specific setting is an important characteristic to take note of especially with relation to gynaecological cancer diagnosis, treatment and effects. Gynaecological cancer survival is a fundamental existential issue in that it is pragmatic, presupposing existence, and metaphysical due to the fact that it enquires on the possibility of both being and non-being (Pascal, 2010). It is personal and unique and will be experienced differently by each woman and different meanings can be attached to it. From a theoretical perspective phenomenology does not enable theory with which the world can be explained or controlled but rather enables insights which enhance direct contact with the world (Van Manen, 1990). Phenomenology provided a perspective for understanding the gynaecological cancer experience and a lens for seeing the data.

In this discussion phenomenology as a methodology was defined and its historical and philosophical perspectives were presented. Key concepts

underpinning the phenomenology were introduced and justification was provided for selecting the methodology. In the next section the specific methods used are introduced and elaborated upon.

Method

The purpose of this section is to provide an overview of the methods used to address the research questions. To answer the research questions women who were diagnosed with gynaecological cancer and had undergone various treatment regimes were interviewed to gain an in-depth understanding of their lived experience. These women all have survived the prognosis and treatment for gynaecological cancer. Interviews were used to collect their experiences of survival and were transcribed verbatim. Interpretive phenomenological analysis was used to analyse the data related to the research questions. Each of these methods, however, will be discussed in more detail in the next section.

Setting

Most interviews were conducted in the homes of the participants to ensure convenience. Only one participant preferred a different setting for the interview and a private Massey location were arranged. This Massey location was a sound proof private room with its only contents a Massey University connected computer, a desk and chairs.

Recruitment

Ethics approval for this study was obtained from the Massey University Human Ethics Committee. Due to the intricate nature and sensitivity of gynaecological cancer, participation in this study was completely voluntary. Participants were recruited by placing an advertisement (see Appendix A) in local community news papers during June and December 2010. These newspapers are spread every week across various Auckland regions and are distributed to each home without any cost. The rationale for this method of recruitment was to ensure that more individuals will be exposed to the advertisement and to avoid limitation to only certain individuals who purchase specific news papers. This further increased equal opportunity to participation. Eight women interested in taking part responded to the advertisement by contacting a Massey University phone number. A message system was set up where participants provided contact details, to which the researcher responded individually. On first contact the researcher attained mailing information and an information sheet (see Appendix B) was sent

out. After sufficient time of two weeks was allowed for receiving and reading the information sheet another point of contact was made to enquire on willingness to participate and to arrange a time and setting for the interview to take place.

Sample

A purposive sampling frame was used as it was pivotal to identify and include information-rich cases that could provide a full sophisticated understanding of gynaecological cancer as a phenomenon. Careful consideration was therefore given to the aims of the research to make decisions about the desired range and characteristics of participants. Women were therefore not only included on the basis of their willingness to participate but participants were included that were considered representative due to the fact that they met certain pre-established criteria. These criteria included the ability to contribute to the understanding of the experiences of gynaecological cancer and treatment as well as accompanying effects. More specifically gynaecological cancer diagnosis that were included in the criteria were: endometrial/uterine corpus, ovarian, cervical, vulvar, vaginal as well as gestational trophoblastic neoplasia. Treatment regimes included in the criteria were: bilateral salpingo oophorectomy, omentectomy, abdominal hysterectomy, all three forms of vulvectomy (skinning, simple and radical), radiation therapy and chemotherapy. Other important inclusion participant characteristics were that they were over the age of eighteen years and had the ability to converse in English. Exclusion criteria included: recurrence, metastasis, insufficient English language comprehension, other cancer diagnosis, and mental and/or intellectual disabilities.

One of the eight women who responded to the advertisement declined participation on first contact and incorrect contact number provision resulted in the inability to contact two more respondents. Another responded to the advertisement after final analysis commenced and had to be excluded on the basis of time constraints. Information sheets (see Appendix B) were mailed to four respondents in total. On the second point of contact all four respondents agreed to participation after reading the information sheet. Of the four, two women had cervical cancer, one uterine and another ovarian cancer. Treatment consisted of

three regimes and included radical hysterectomy, radiation therapy as well as chemotherapy or a combination of the different regimes.

Despite clearly stated exclusion criteria two women were included of which one had a recurrence of cervical cancer, however, due to the fact that the recurrence presented eighteen years before the interview and that at the time of the interview the participant was cancer free, she was included in the sample. Another participant that was included in the study presented minor memory difficulties as well as liver, spleen and omentum cancer over and above her ovarian cancer. The memory difficulties were considered a minor effect of the chemotherapy treatment and to resolve over time. Memory impairment mostly included difficulty keeping to conversation flow, often forgetting what was discussed, but when reminded could proceed without any difficulty. The advanced progression of the ovarian cancer, the nature of ovarian cancer to be accompanied by other cancers on adjacent organs and the small response rate complicated exclusion criteria. None of the participants had any metastasis.

The female participants in this study all resided in Auckland and due to the nature of the cancer all participants were female. All four women were over the age of 50 years, were of European descent and had English as a first language. None had a physical disability prior to the cancer diagnosis. Only one woman could not walk at the time of the interviews and had to make use of aid. This limitation may have been a result of the cancer treatment but could not be confirmed. Three of the participants were from the North Shore region of Auckland and were representative of this regions higher socio-economic status (Statistics New Zealand, 2006). Only two women were employed at the time of the interviews. Three participants had some background experience of being employed in the health industry. Three women were married and one was divorced. Three women had children and two had grandchildren. Post treatment time ranged from less than a year to twenty six years.

Overview of participants

Pseudonyms were given to the participants to protect their identity.

Rose was diagnosed with cervical cancer twenty six years ago. She received a radical hysterectomy as treatment followed by radiation therapy. She since retired but her employment background in a medical setting contributed to her experience of her cancer. She lives with her husband and enjoys an active social life despite mobility issues. She was previously a smoker and enjoyed it but decided to give this up a few years ago due to health issues. She is thankful to all the medical staff that attended and cared for her during her cancer.

Iris had uterine cancer three years ago and had a total hysterectomy. She is a proud grandmother and enjoys an active life where she visits her children and grandchildren often. She is currently employed and enjoys her work tremendously. She supported her husband during his cancer illness and they are both actively helping other individuals with this illness, because of this she has a very sober view of cancer and its effects on those close to you. She is thankful for the care received but acknowledges that medical professionals are human.

Lily was diagnosed with ovarian cancer in the year of the interview. Her treatment consisted of a total hysterectomy and chemotherapy. Previous experience as a gynaecological nurse and a family member's previous experiences of this illness aided her in recognising and acting on the symptoms. She had a very poor prognosis but her positive attitude helped her through. She is grateful for her care and support. She is married with children and grandchildren. She has a passion for life and state that she wants to study further for pleasure.

Jasmine was diagnosed and treated for stage IV cervical cancer 25 years ago. Her treatment consisted of a radical hysterectomy. She is divorced and has three children. Although her experience was very emotional and traumatic she acknowledges the fact that the experience was valuable in the sense that it shaped her current perspective of life. She has a passion for life and lives life to its fullest. She shares the view that medical professionals are human and advocate own personal responsibility with regards to health.

Data Collection

Semi-structured interviews with four female cancer survivors in the Auckland region were conducted and transcribed. The rationale for selecting semi-

structured interviews was that on the one hand a sequence of themes and order of questions can be identified which need to be covered during the interview but on the other hand it has an openness to changes in order of questions and form to enable pursuit of answers provided and experiences shared (Kvale, 1996a). Only one interview was conducted with each participant and the aim was to enable women to raise areas of concern to them and to capture the widest expression to each gynaecological cancer experience. The interviewer had a list of questions (see appendix C) to raise in the event that women did not make mention to it out of their own, these included the diagnosis itself, the treatment and the effects on both the women and their social networks.

The data collection process took place over a three month time period. Interviews were conducted at both private university locations and in the houses of the women for their convenience. The interviews were conducted at a convenient time selected by the women and it therefore did not disrupt the participant's normal daily activities. It was further conducted with the women individually using the interview schedule (see appendix C). Written consent (see Appendix D for an example form) was obtained prior to all interviews and only after this was received did the interview commence. Each interview was audio recorded for accuracy and lasted between 50 and 110 minutes. Audio recorded interviews were then transcribed verbatim. Each participant was given the opportunity to revise their own transcript and a transcript release form (see Appendix E for an example form) was signed by each participant.

Data Analysis

Interpretive phenomenological analysis (IPA) was used as method of analysis. IPA aims to investigate how people make sense of objects and significant events in their personal and social worlds and the main currency for this type of method is the meanings attributed by participants to these objects and events (Smith & Osborn, 2008). This approach can therefore be seen as phenomenological as it is interested in the individual's personal perception or experience of an event rather than an objective account of it (Smith, Jarman, & Osborn, 1999). Although the focus of IPA is on the exploration of the participant's experiences from their own unique perspective, it acknowledges the fact that such an exploration will

include not only the nature of the interaction between the researched and the researcher but the individual researcher's own world view as well (Willig, 2008). So the access to the participants experience relies not only on the researcher's own conceptions but is complicated by it and it is imperative to explore this added personal world through a process referred to by IPA as interpretive activity (Smith & Eatough, 2007). The researcher thus aims not only to understand as far as possible the experience from the participant's perspective but to, simultaneously distance away from it to enable curious and critical questioning.

IPA as method of analysis was selected due to the phenomenological nature of this method, IPA implements in-depth qualitative analysis and is compatible with the aims of this research. It is not only concerned with questions of considerable importance to the participant at a particular critical time but focus on an ongoing basis as well (Smith & Eatough, 2007). Cancer pose such important questions that can be perceived as important to the participant at both a critical point in time as well as ongoing in their everyday lives.

Another reason for selecting this method was that IPA research is normally conducted in relatively small sample sizes as the focus is on doing justice to each case (Smith & Eatough, 2007). The focus for this research was on attaining a detailed and nuanced account to women's gynaecological cancer experiences, thus doing justice to each woman's unique and individual case.

Analysis of the data followed the IPA method as proposed by Jonathan Smith (Smith & Eatough, 2007; Smith & Osborn, 2008). During transcription, a record was kept of initial thoughts, comments and points of potential significance. Each transcript was then read numerous times and notes were made on anything of interest and of significance. Next the initial notes and ideas were transformed into more specific themes or phrases. Here psychological concepts and abstractions were introduced to capture the psychological quality inherent in the initial notes. Following this the data was reduced even more by establishing connections between the preliminary themes by clustering them. Finally a table was produced stipulating each super-ordinate theme and the themes which comprise it. The clusters were then given a descriptive label which conveyed the conceptual nature of the themes therein. In typical phenomenological form the

researcher moved back and forth between the various analytic stages ensuring that the integrity of what has been shared by women were preserved as far as possible. This was in line with the reflective nature of the mode of method.

Summary

In this section the method of data collection was addressed. It indicated that participant homes were the main setting in which interviews were conducted and other settings used were identified and described. The process employed to recruit participants received attention and rationale for following this particular recruitment procedure were provided. A detailed description of the sample was presented and stipulated various inclusion and exclusion criteria. This was followed by an overview of each participant and provided valuable background information that could aid the understanding of results. The interview process was outlined next as the method of data collection and motivation for selecting this particular method was provided. Finally IPA as data analysis method was motivated and explained and emphasis was placed on IPA as proposed by Jonathan Smith. These different methods employed contributed to specific results and will be discussed in depth in the next discussion.

Results and Discussion

The main purpose of this section is the presentation and discussion of results. An overview of findings will be provided after which the presentation and discussion of the results will revolve around the four common themes that were identified in the data including: female identity, identity threats, identity protection and the reconstruction of identity.

Overview of findings

Various commonly shared experiences and concerns arose from the interviews conducted. The analysis showed that identity was central to the women's concerns and issues relating to the female identity were mentioned in regard to gender roles, femininity, with sexuality and sexual responsibilities, body alteration or appearance, commonly shared misconceptions about female reproductive organs as well as caring responsibility. Threats to women's secure identities were described. Experiences relating to diagnosis, treatment, treatment effects, power in caring relationships, as well as social structure and role change were mentioned as threats and the effect this can have on the identity were elaborated upon. Women further described methods implemented by them to protect their concept of identity and acceptance and adaptation were mentioned and described. Finally the process of identity reconstruction was discussed by women in terms of their renewed power and position in caring relationships, personal responsibility, changes in perception, new focus on qualities that enhance self esteem as well as the adoption of a positive and hopeful attitude in life.

According to the encyclopaedic dictionary of psychology (Davey, 2005) identity is a concept which is used to refer to self-understanding and the self-concept. It further includes how the individual is recognised by others and three types of identity can be differentiated, namely: personal (qualities and attributes different from other individuals), collective (created categories like cancer survivors or employment) and relational identities (individuals part of the extended self concept like children or partner) (Matsumoto, 2009). In other words personal identity refers not only to how an individual understand themselves but to how they are distinguished from others as well as how they are related to or

behaved towards. One principle property of the self, accentuated by Layder (2004), is the fact that the self is flexible and changes, evolves and develops over time. The women who shared their gynaecological cancer experience in this study indicated that change has taken place following their cancer experience. This included changes in how they perceived their own female characteristics and roles. Threats to their self understanding were discussed and protection mechanisms were outlined in the form of coping and survival. Diagnosis and treatment effects introduced changes in self characteristics and necessitated identity re-evaluation and reconstruction. As mentioned earlier the next discussion will focus attention on each of these identified issues.

Female identity

The concept of female identity and related characteristics and responsibilities was common to all participants. Female identity is tied to the fundamental interdependence or connection with the self as well as others and women often judge themselves by standards of responsibility and care for others (Farganis, 1996). This connection with and responsibilities to the self and others, manifested in this study through gender roles, support with female role responsibilities, female role of mother, grandmother and partner, sexuality and sexual responsibilities, body alteration and appearance, female reproductive organs as well as the caring responsibility and will be discussed next.

Gender roles

The traditional female gender role is primarily concerned with responsibilities within the home and includes domestic chores and raising of children (Sigal & Nally, 2004). This domestic female role responsibility was supported by women in this study and the inability to perform this responsibility due to gynaecological cancer and treatments as well as effects were reported.

"...I couldn't do anything, I simply couldn't do anything, and I couldn't cook, I couldn't vacuum, couldn't do anything..." (Lily)

This gender role responsibility was not set within a patriarchal structure as characterised by some communities, but rather within a setting that supports

more egalitarian sharing of responsibilities between women and their partners. These settings are characterised by an increase in men being more involved with more traditional feminine roles like domestic chores and child rearing (Gerson, 2010). Although women in this study were grateful for the possibility of sharing domestic responsibilities, they still perceived it as their own or at least a female obligation and highlighted the influence this added responsibility had on their partners. This perception becomes evident when Rose mentions the added burden on the partner following her treatment.

"...after you had a hysterectomy you're not very good at doing many things mainly my husband did it."

It was not only partners who shared the female role responsibilities but other female relatives and the support received from these women will be elaborated upon next.

Support with female responsibilities.

Female relatives from a variety of relations, including mother-in-laws and step daughters, offered support and relief with female responsibilities.

"...I couldn't [perform normal house work] after I came home, actually his [refers to husband] mother was, really good...and his daughter came around and his mother, they were really, really good you know helping me." (Rose)

Female siblings were also reported to assist with female role responsibilities which influenced female identity as reported by Lily.

"...he [husband] just, did everything really, and it was good when my sisters came because they took over from him and I've got three daughters...and they were great too...they'd come and vacuum and things. I mean, things go on, even if you're not doing anything, things have to be done."

The female relative support in gender role responsibilities mentioned, is consistent with other findings such as Akyuz et al. (2008) where partners indicated that domestic gender specific tasks were taken over by mothers, older sisters as well as adult daughters during the postoperative phase. The authors

further speculated that the motivation behind the assistance was to preserve the family dynamics of traditional patriarch structures, where it was uncommon for males to take over traditional female roles even in extraordinary situations such as gynaecological cancer. Assistance provided to women in this study was set within an egalitarian setting and the support of female relatives was not only to assist women with their gender responsibilities, but to ameliorate partner burden as explained by Lily.

"...he [husband] just, did everything really...they [two sisters] came up at different times and they did that deliberately so they could spend more time with me. That was good because there, my husband had quite a heavy burden. He was working, and in the end he gave up work he just said, look I can't do it. So he gave up work, just you know to look after me really because I couldn't do anything."

This indicates that the inability to perform and conform to prescribed domestic gender roles added to partner burden and indirectly influenced the care women provided to the partner. Assistance by female relatives therefore aided with the caring role of women to their family as well. The self was not understood and evaluated only in terms of traditional domestic roles, but in terms of other female roles such as the role in the partner relationship, the role in the mother as well as child relationship and extended to the role as a grandmother. In the next section these identified roles will receive more attention.

Role of mother, grandmother and partner.

For participants children, grandchildren and having a partner were pivotal to being a woman or being female and this was another role that influenced female identity as highlighted by Iris.

"...that's individual to everyone, as to how they feel about themselves...I'm still female, I'm still a woman, I'm still a mother, I'm still a wife, together with all the other things..."

Due to this perception, cancer diagnosis and its concomitant treatment and effects, as a result of the removal of the sexual organs, did not seem to be an

important issue for their femininity. Most women were past child bearing years and did in fact have children of their own. Removal of the organs was therefore not perceived as a loss and did not form part of the female identity. Rather their children and grandchildren contributed to the makeup of their female identity. This seems to be consistent with findings of Sekse, Raaheim, Blaaka, and Gjengedal (2010) who found that most participants past child bearing years did not perceive their female sexual organs as important. Rose accentuates this by reporting on her inability to understand how other women could grieve the loss of the female reproductive organs.

"...other women like feel...really like oh you know, that that's the whole of their essence of womanhood or I mean I saw somebody on TV, I think it was on the doctor Oz thing the other day, I was looking at that and they were talking about fibroids and there was a lady there and she said 'oh I'm still grieving at the loss of my organ' after a hysterectomy, I mean I don't, I don't understand that."

Although the women's feeling of femininity seemed little influenced by their gynaecological cancer treatment and its effects on procreation itself, femininity was reflected on in relation to sexuality and body image or appearance and will receive attention accordingly.

Sexuality and sexual responsibilities

Another factor identified that influenced the female identity is challenges relating to the removal of female reproductive and sexual organs and its devastating impact on sexuality were reported by some women in the study. This were consistent with other studies conducted by Penson et al. (2006) which found that loss of sexual feeling and perceived loss of femininity contributed to negative emotional effects experienced. Sexuality or the role within the intimate partner relationship formed a major part of women's female identity and the loss of ability to perform the feminine role of being a lover was experienced with sadness, uncertainty, fear and anger.

"Just a sudden...the feelings aren't there, the sensations aren't there... you don't have the same need almost for sex but at the same time in your head you think

well I should still want it, I'm not old...this rush of hormones, of feelings, that's gone...just gone all together. You might say the words but you actually don't feel it and in the past you would feel it...it would be a physical sensation...but that's gone...what it takes a way is your womanliness...I wouldn't put myself in the category of being a lover.” (Iris)

Iris explains how women experience physical sensations when an attractive man is seen. As a result of menopause as a treatment effect, she no longer shares this common female sensation and feels the need to pretend that it is there, by saying the words. This is done because the lack of normal female sensation is damaging to her female identity. This finding is supported by previous research (Andersen, et al., 1997; Molassiotis, et al., 2002) which reported a relationship between loss of sexuality and its influence on the feminine identity and self schema or concept. The importance of this relationship is further accentuated by Stead et al. (2003) when they report that sexual activity during treatment can not only assist coping with treatment and its side effects, but contribute to feelings of self-esteem, femininity and confidence. In contrast women like Jasmine experienced no change in libido and therefore in sexuality and the role as lover could be fulfilled without any threat to the female identity.

“I was fine. I mean, the relationship with my friend developed into an affair ...a lover, but it was fine, I had no complications. We had a...very satisfactory relationship for 16 odd years so it [cancer and effects] didn't bother me...”

This is consistent with findings of Chan et al. (2001) who found no significant deterioration in partner relationship and sexual activity following gynaecological cancer. Jasmine implies here that the reason for her being fine was that her sexuality was not affected by her treatment. It can be speculated that this unchanged sexuality might be the result of the effect of hormone replacement therapy on libido.

“I took hormone replacement therapy...and look I was fine.” (Jasmine)

One study supporting this was conducted by Buster et al. (2005) and emphasised the beneficial effects of testosterone patches for low sexual desire in surgically menopausal women. Unfortunately however, treatment of decreased libido through hormone replacement therapy later proved not to be beneficial to

all women to alleviate symptoms associated with surgically induced menopause (Sun, Ramirez, & Bodurka, 2007). Some women in the study reported that the benefits of hormone replacement therapy were weighed and the decision was made by them not to proceed with the treatment, as the risk outweighed the benefits and no assurance existed that the treatment will work for them.

"...and hormone replacement therapy might work for some, but there's no guarantee it will work for you." (Iris)

After careful consideration, Iris made the conscious choice not to take the risk of proceeding with this particular type of therapy. By not taking hormone replacement therapy, symptoms were induced which affected how she perceived her own attractiveness. This influenced how she perceived herself, as well as her perception of how others perceive her. She considered her libido and the role she had to play as a lover as important factors to how she understood herself as a woman. The choice and concomitant effects therefore influenced her female identity and resulted in her not feeling confident to perform the role of sexual partner anymore as highlighted in her conversation.

"...you don't feel sexy anymore..."

Iris' feeling of being sexy or being attractive was closely related to body alteration and appearance which were reported as another influence on female identity and will be discussed next.

Body alteration and appearance

Appearance has become increasingly important in defining identity and this include the sexual identity (Negrin, 2008). As implied by Iris participants regarded body appearance to be closely related to sexuality and the feminine role of being attractive. Physical body changes were reported that were highly personal and which is associated with the core of being a mature female.

"...and of course you lose all your pubic hair and you don't realise how much you need it in the summer." (Rose)

Another alteration in body appearance reported which is closely related to hair loss and the core of being female was the loss of head hair.

"...you can't see the real me now, too with no hair..." (Lily)

This alteration in appearance was more visually visible to the general social public and it was interesting to see that some women did not perceive this change in appearance as the 'real me'. The changed person or altered appearance was therefore not perceived as attractive and part of the person or the female identity. It can be speculated that this detachment from the altered appearance could be due of feelings of not fitting with, or as it is referred to by Mathieson and Stam (1995) as disrupted feelings of fit with the general prescribed feminine role of appearance. As indicated by Brownmiller (1984) and Synnott (1993), women grow up with the perception that longer hair is feminine and hair is therefore a powerful symbol of the self as well as part of the cultural definition of femininity. The inability to fulfil these expectations could lead to questions about individual femininity and ultimately lead to the person being devalued (Sigal & Nally, 2004; Watzlawik, 2009). For women with gynaecological cancer their female identity incorporated the cultural prescribed female hair with its accompanying role of women to be attractive. Due to the fact that their altered body did not abide to these prescriptions it was not perceived as the 'real me'. This is supported by previous research conducted on women with breast cancer by Rogers and Kristjanson (2002) which found that alopecia (hair loss) can have adverse effects on women's sense of attractiveness. Becvar (1996) elaborates on this even more by accentuating the need she felt as a woman with breast cancer to be told she looked good and that bald and fat could be attractive, even if this reassurance was not truthful.

Weight alteration as an effect of induced menopause was another change in body appearance which influenced femininity, the female role of being attractive and the female identity. It had an impact on how women perceived themselves and constructed their identity.

".....you put on weight...and it makes you feel like a bloated whale. It makes you feel...disgusting. You look in the mirror and you don't like what you see."

(Iris)

For Iris the female role of being attractive was further an important part of her identity and she reported the helplessness of her attempts to control it.

“...you put on weight...and it doesn't matter what you do, you can't get rid of it... you have not a great control over it...I mean you doing the exercise all you like it won't make a difference.”

This emphasis on conformity to ascribed body appearances is not limited to this particular woman, but has been mentioned in the past by Adelman and Ruggi (2008) in their findings where they reported that Brazilian women not only give preference to the standardised beauty and sexiness, but placed it high in their sense of identity. The perception that individuals have control over weight alteration evolves from common consumer culture where women are convinced that ascribed bodily appearances can be attained with effort and simple work (Featherstone, 1991). When women like Iris then fail to manage desired body appearances it can lead to feelings of disgust and alter their perception of the self. Other surgically induced menopausal effects which influenced the women's sense of female identity were the loss of firmness of female genitalia.

“...the elasticity has gone. The fullness has gone in all your genital area... and if you've had major abdominal surgery, let's see I've had two, I've got train tracks right over down here [indicates to abdominal area] all the muscle, has been cut up. So you've no great control over muscle things...your breasts are already dropping post children but they've, totally lost any substance. They've lost any firmness.” (Iris)

Alterations in body appearance influenced how the woman perceived and understood themselves and their bodies. It further had an impact on how they experienced and understood relationships with significant others. Due to the close relation between female genitals and sexuality as well as femininity, the loss of firmness resulted in women questioning their attractiveness which raised concern in relation to femininity or female identity as indicated by Iris.

“No matter what you do and no matter how you dress up, no matter, what you do to yourself or what you wear...you don't feel sexy anymore, and that's damaging to you as a person because you think no one would be interested in you anymore whether it be your husband or whoever.”

If the alteration in body appearance resulted in changes in self image and the woman felt disgusted with herself, experiences of femininity and identity were affected. Similar findings have been reported in breast and ovarian cancer survivors. Landmark (2002) investigated how women live with newly diagnosed breast cancer and found that survivors experienced a diversity of emotions related to feminine identity instigated by the loss of a breast. Women living with ovarian cancer emphasised the devastation even further by reporting that the sight of a strange and new body altered by cancer, was blocked out in totality because they no longer perceived themselves as women attractive and wanted by men (Moore-Schaefer, et al., 1999). Therefore, any alterations to body appearance resulting from gynaecological cancer are associated with the need to reconfirm the identity as a sexual being, a partner, a woman and a mother (Butler, Banfield, Sveinson, & Allen, 1998).

An interesting finding from the study was how women understood and experienced as well as embraced common conceptions around women's reproductive and sexual organs. This was reported as another factor that influenced not only the female identity but behaviour in relation to reproductive as well as sexual organs and will be discussed accordingly.

Female reproductive organs

Some women regarded their sexual organs mainly as useful for reproduction and therefore regarded them useless after child bearing.

"Didn't want it [female organs], I reckon peoples uterus should, wombs should just self implode at about fifty...vanish you know...they should just disappear...it would be a nice thing." (Rose)

Previous research has found similar results where women reported that because they already lived through life change or in other words menopause, they no longer valued the female organs and could not understand what they would want them for any longer (Juraskova, et al., 2003). Being in the position of having had children or having gone through menopause appeared to have an influence on participant's female identity. This is supported by Butler et al. (1998) who found that both having had children and being post menopause affected women's self

concept and identity. Misconceptions relating to the pathological and unpredictable nature of female reproductive and sexual organs were reported in the study by most participants.

"...just intermittent spotting, but I put it down to just being post menopausal...you know, like a lot of women...and there aren't many days, that you don't have some discomfort or pain it's just a question of whether you call it pain or call it discomfort." (Iris)

"...women have things wrong with them..." (Lily)

"Women bleed a lot at different times and get use to bleeding and spot bleeding and stuff..." (Jasmine)

Women imply here that female reproductive organs are notorious for being in pain, for bleeding on a regular basis, as well as being associated with discomfort. This caused them to not pursue abnormal symptoms but rather to accept it as being normal and part of being female.

"I started having not light bleeding just intermittent spotting but put it down to just being post menopausal...and I thought it will pass..." (Iris)

Pain and blood was therefore expected and serious abnormal symptoms related to cancer were disguised by this unpredictable and convoluted nature of the organs. Research conducted by Lyons and Griffin (2003) which focussed on the ways in which menopause and women's bodies are represented in self-help texts, found that menopause as well as the female body were constructed as inherently complex and confusing, therefore putting it in a negative light. Women in this study supported this construction of the female body as complex and confusing and the perception is therefore not only limited to self-help texts as found by Lyons and Griffin (2003), but women with gynaecological cancer understood and constructed their own bodies in a similar way.

Lastly, the female identity included the caring responsibility and will be discussed briefly.

Caring responsibility

Participants reported the natural tendency of females to care for and protect children.

"I tried to protect my family...I did protect the family as much as I could. I mean they could see what they see but I did protect them. I didn't tell them how bad it was. I didn't tell them how bad the surgery was. They'd come and visit me and I'd be trying and be cheerful and everything but it was pretty horrific... I think you just do that...automatically really...you protect your children... and I'm sure other mothers do it." (Lily)

Their belief about the appropriate responsibility and obligation of women, namely being compassionate and caring, is accentuated here (Sigal & Nally, 2004). They felt that part of being a woman was to protect and care for their children. The influence cancer and its treatment had on this female responsibility will be discussed in more detail in the next section when more attention is given to threats to identity.

In summary, this section outlined and discussed participants' understanding of their own female identity. Gender roles, sexuality and sexual responsibilities, body alteration and appearance, female reproductive organs as well as the caring responsibility were all identified and described as important factors to the female identity. The understanding of female identity can however be influenced by certain threats brought on by gynaecological cancer and in this study women identified various threats to the identity which will be discussed in the next section.

Identity threats

O'Hair, Scannell and Thompson (2005) identify threats to the identity as one of the many challenges that faces individuals after cancer diagnosis. In an integrative literature review, which focussed on the existential concerns among patients with cancer, Hensch and Danielson (2009) identified themes related to threats to self identity and included suffering (uncertainty, vulnerability and fear of dying), loss of life values (hopelessness, loss of control, need for control and loss of self identity), loss of relationships (isolation and loss of roles) as well as bodily

expressions (changes in body). Due to the fact that changes in body were already discussed in the previous section on female identity, only reported matters relating to suffering, loss of values and loss of relationships as identity threats will be discussed next. To attain this, attention will be focussed on uncertainty, vulnerability, recurrence fear, treatment delay, loss of autonomy and control, isolation as well as loss of gender roles.

Uncertainty

Most experiences of gynaecological cancer diagnosis in this study were characterised by mixed emotions and included surprise, shock and disbelief as well as sadness.

"...it was a surprise because it wasn't something that had been there for a while that we've, was suspected it was any type of cancer... disbelief as I think most people would" (Iris)

"...how did I deal with the diagnosis...cried all night with my husband. Sobbed and cried all night. Thought the end of the world was coming." (Jasmine)

This initial experience of diagnosis is supported by previous literature which found that the initial diagnosis period is characterised by fear, uncertainty and distress brought on by a life threatening illness (Ferrell, et al., 2003). After the initial feelings of surprise, disbelief, sadness and distress women reported feelings of relief. This was ascribed to the elimination of uncertainty.

"...I was very happy to get the diagnosis because then I knew what was wrong with me." (Rose)

Uncertainty was the first identity threat reported. The confirmation of the cause of symptoms as implied by Rose above therefore eliminated to some degree, uncertainty with its accompanying difficulty of control and threat to autonomy. The fear women experience due to loss of control over what happens, which can be caused by uncertainty, is highlighted by studies such as conducted by B. E. Miller et al. (2003), which investigated gynaecological cancer patient's psychological needs. It can be speculated that the diagnosis eased suffering by providing the opportunity to control and to take action to a known cause, therefore aiding

autonomy. This is best demonstrated by the feelings and action taken by one woman in the study. Lily had a family history of ovarian cancer and she experienced the uncertainty of not knowing if she would develop cancer as a threat to herself and identity. The need to take personal responsibility and action to eliminate this threat was demonstrated when she investigated her susceptibility by performing the genetic test for the BRCA I gene. It was confirmed and she was therefore prepared for possible later development of ovarian cancer. She reported that the actual diagnosis by a medical professional was purely a confirmation to her own diagnosis.

"...I figured it out for myself, what it was, aided and imbedded by the knowledge that, we in our family and I do and my sister does, we carry the BRCA I gene and so, it was fairly obvious right from the start really, what it was, and so I thought it was fore warned..."

Current literature report uncertainty as a threat to self identity (Hench & Danielson, 2009). By attaining certainty about the presence of the BRCA I gene Lily to some extent eliminated a threat to her identity. Only by taking control and action did she become aware of her own susceptibility and the diagnosis as a result of this did not come as a surprise. At the same time Lily's vulnerability to ovarian cancer and this threat to her identity are accentuated here and will be discussed next.

Vulnerability

Lily carried the BRCA I gene and had no control over her developing the cancer and she reported disappointment with the diagnosis.

"...I mean it is disappointing...you couldn't say anything else really but it's very disappointing, to be given a diagnosis like that..."

The importance of diagnosis in the elimination of uncertainty, vulnerability and its relation to autonomy is further supported by Jasmine. She explains how failure to get test results and feedback, as well as limited autonomy of women in the medical health system in the past contributed to vulnerability the threat to the identity.

"...I didn't get any result and because I didn't get any result, I thought it was clear. I thought there wasn't anything to be worried about. Its 1985 when, patients didn't, there wasn't the same autonomy, you know you, so I kind of assumed everything was alright...I talked to a friend of mine who was a public health nurse, and I said, 'I haven't heard anything from my tests, you think it would be alright?'...I very nearly fell through a great big gap, and I very, any delay I've probably would have lost my life."

Jasmine emphasised that patients did not have the same authority in their own health related issues and she was therefore not forwarded any test results. One reason supplied for the lack in patient autonomy can be found in writings by Lyons and Chamberlain (2006) where they indicate that a power imbalance exist between patients and health care professionals in western worlds, where health care professionals have more status and power than patients. In Jasmine's case, test results were only released to health care professionals who had more status and power. Jasmine experienced unusual symptoms of concern and because she did not receive any test results her uncertainty and related vulnerability could not be eliminated. For her it was imperative to clear any uncertainty with relation to her symptoms before she could have any control and before any further action could be taken. This threat due to uncertainty was not only limited to the diagnosis itself but the treatment added its own threats to the identity. Uncertainty about treatment effectiveness was expressed by women.

"...naturally you worry of course, you're always a bit worried in the back of your mind, you just think oh I hope that's all..." (Rose)

"...99% of the time, removal of the offending place gets rid of the cancer...It's definitely not gone in your head, there's still that tiny, tiny bit that says, wonder if they got it all..." (Iris)

Iris accentuates her doubt by using percentages and indicates that there still remains a one percent uncertainty in her mind about the treatment effectiveness and this doubt or uncertainty can be detrimental to the self identity. Fear of recurrence accompanied treatment effectiveness doubt and will be elaborated upon next.

Recurrence fear

All women expressed anxiety and fear related to the recurrence of their cancer as another threat to the identity.

"...that's one of the other fears that you have too, of course is the, you know will it come back and you ask that question and they can't give you an answer, and you're silly to ask it really but we all do, and, then they just say oh well we can't give you an answer but we will follow you for five years and we do this, this, this and this...there is that, always that sort of thing, you get rid of one and you think ah, no don't say there's another one coming back. I don't know how I'd feel if they told me that it had come back. I think it would be pretty devastating..." (Lily)

Some women not only expressed their uncertainty but suggested their vulnerability when discussing their fear for recurrence and indicated the hopelessness of not knowing if the cancer will ever reoccur.

"I don't think anybody can ever give you that reassurance, that 100% you're free of it." (Iris)

This fear of recurrence has been shown to be significant in many cancer survivors and is experienced by women with gynaecological cancer as well (Allen, et al., 2009; Ferrell, et al., 2003). Once the physical threat of cancer is removed many individuals focus on the recurrence thereof (Lee-Jones, Humphris, Dixson, & Hatcher, 1997). Any symptom that is current at the time can be interpreted as recurrence of the cancer (Deimling, Bowman, Sterns, Wagner, & Kahana, 2006). The recurrence fear is therefore constantly present and is exacerbated by the lack of assurance that it will not return. This leaves women feeling vulnerable as they have no control over their own fate and this threatens the identity. Another factor considered a threat was the time following diagnosis but preceding treatment and will be discussed next.

Treatment delay

All women expressed the importance of immediate treatment action against cancer.

"...having being diagnosed with cancer, you don't want to sit on that knowledge, that's bad for your mental health... people diagnosed with cancer really want to be treated urgently, because they don't want to sit with this... if you have to sit and wait on the health system to fix it you could be sitting for months. Ah, I don't know about other people but I wouldn't be happy sitting for weeks and months, waiting for surgery to come up, knowing full well I have a cancerous tumour in me..." (Iris)

Iris's account emphasized the distress felt by women as they have knowledge of and have to live with a cancerous body in them but have no control over the management of their situation. All participants accentuated the importance of knowledge about the distress experienced as a result of treatment, unfortunately, however, as pointed out by Lim, Vinod, Bull, O'Brien and Kenny (2005) distress experiences are difficult to measure and are often ignored in the literature. Lily elaborates on women's vulnerability in treatment delay even more by indicating that control is not with women themselves but with medical professionals.

"...the worst part about it all was waiting for the appointments because when you've told you've got cancer you want someone to do something about it today...because they're so busy, the appointments were quite welcoming, well they seemed a while, one was a month and another one was 2 months before I actually started treatment, and it seemed a very long time... when we went to Greenlane to get the surgery appointment, they said no we can't do it, and that's probably the worst day off the lot really...because we'd gone there to get a date, and we were told, that no we can't do it. So that was very disappointing, because I, you sort of set your hopes on that really, cause you think oh surgery they will take all that nasty stuff away and then they'll do some mop op chemo and everything will be fine... with all this having to wait

for appointments and, wait for this and wait for that and everything else and that was anxiety provoking..."

Lily does not explicitly state that her identity was threatened but implied that her autonomy was threatened due to the lack of control she had over her treatment and this in turn had a detrimental effect on her identity. This loss of control as a threat to the identity will be discussed next.

Loss of autonomy and control

Lily deduced from her situation that she no longer shaped her own treatment but that it was controlled by her health professionals. The threat to her autonomy was therefore a threat to her self evaluation and identity. Other women reported treatment effects which had an impact on the control they had over their own lives. Rose made reference to mobility alterations due to neuropathy that threatened her autonomy.

"...it [neuropathy] certainly hampers you. I use to walk everywhere and everything, now I don't, I have to ride my scooter... he [husband] used to get the scooter up and down for me and he's got a bad heart... off course if he's in hospital which occasionally, he goes in, I'm kind of house bound... it does pisses you off occasionally because you can't go walking and there is a lot of things I can't do anymore..."

Other treatment effects reported that influenced autonomy were loss of employment and Lily's experience emphasised the anxiety and sadness experienced due to the loss of employment.

"...the worst part I think, you know taking aside the physical parts and ah, you know all the unpleasant things they do to you and everything, was the fact that I had to leave work and I found that very hard. I absolutely hated it...it was a huge disappointment and I didn't want to end my working life like that. I wanted, there was still things that I wanted to achieve, and ah, that, that I find very hard because, there wasn't anything I could do about it. You know it wasn't a conscious choice that I made, to stop work, because I came back from holiday straight to hospital that was it...it ah, it was just all over... it was just

chopped off. Bang! That's it, finish... And I was always one for keeping up, you know I always went for courses and did produce all these hours of post grad work which is fine because I enjoyed it... It was a very important part of my life... I find that quite frustrating as I've always studied something. I've always got something going..."

Cancer took Lily's choice away with regards to her employment. She had no opportunity to consciously make a premeditated choice in the termination of her employment. Her autonomy in the matter was taken away and because employment was an important part of her life and how she perceived and understood herself, this threatened her identity. She was no longer able to identify with being an individual who could function normally from day to day by engaging in activities like work and this was devastating to her.

Depression was another treatment effect reported by women that had an influence on self perception and identity. Rose accentuated that as a result of her radiotherapy, ovary function ceased and resulted in her menopause accompanied by depression.

"...I was sitting here... and I was thinking ah you know what's wrong with me...depressed and thinking like you know what's the point of living and usually if I'm bit depressed, I can always, you know, cheer myself out of it, like most of us probably and, I couldn't so I went down to see the chemist and I said, ah look I don't know what's wrong here, and I went to see the doctor first, I said, ah what's wrong, you know I can't snap out of this depression...I got like really, really depressed you know, clinically depressed, and I thought that's not like me...didn't feel like doing anything, just really depressed and thinking really bad thoughts like almost suicidal. Thinking oh what's the point of being here? You know, why am I here? All those sort of...dark thoughts that I couldn't shake off.

It is likely that individuals with gynaecological cancer will be at risk for psychiatric disorders such as depression (Thompson & Shear, 1998). Although previous studies such as Bodurka-Bevers et al. (2000) support this, by indicating that psychological symptoms like depression were more prevalent in women with

gynaecological cancer, it is more important for the purpose of this discussion to focus on the influence depression had on women's self identity. Rose implied that a part of her identity included her ability to overcome depression by cheering herself out of it, however, menopause induced depression eliminated her control over this depression and lead to questions regarding her self-control. The fact that she was unable to control the depression did not comply with her previous qualities of her identity and resulted in her questioning herself. Both depression and loss of employment is closely related to contact with the social world and Lily makes reference to the important role employment played in her contact with others in terms of her patients.

"It wasn't, only the job and all the people that I met on a day to day basis and you get very close to people when you're a practise nurse cause you're their life line and to practice it they ring you up a lot and pop in and see you and everything..."

She further reported that employment provided her with another valuable social contact namely colleagues, however, as soon as her employment were terminated she became more isolated.

"...the surgery I worked with, the girls were lovely and they came and saw me and rang up and that all the time but then that gradually wears off."

Therefore, another threat to identity reported was isolation and a comprehensive discussion will be presented.

Isolation

The effect of gynaecologic cancer and treatment on various relationships is usually profound and women often spend a prolonged period of time post treatment to try and comprehend its effects (Auchincloss, 1995). Research which investigated women with gynaecological cancer and their partners experiences, have indicated that social relations following their illness are experienced differently with some individuals who reports a decrease (Akyuz, et al., 2008). All participants in the current study could relate to how as a consequence of living with their cancer and effects, they had experienced some deterioration in social relationships and reported that many friendships were lost.

"I certainly had a few friends sort of dropped off..." (Rose)

Rejection by friends was met with surprise, confusion and anger by women as highlighted by Rose.

"One friend in particular said, 'Oh do you mind if I don't come and visit you I, I'd hate to see you in that state.' I said 'well what do you mean that state? I'm not in any state you know'...and another one said, 'Oh I don't, I don't think I can come and see you while you like that you know'...well ok don't bother...I mean that's extraordinary isn't it?"

Isolation due to the loss of relationships has been identified in the literature as a threat to identity (Hench & Danielson, 2009). Many women in the study attributed the cause of social detachment to the inability of others to cope with the cancer diagnosis of a friend, therefore accentuating the friend's uncertainty and insecurities rather than a change that took place in themselves.

"...there are some friends who can't cope with your illness...I never saw them...and these are the people I saw every week, normally...there were some people who just simply didn't front up." (Lily)

This finding is supported by previous research which found that following cancer and its treatment, women noticed that some individuals were comfortable with offering support where others were not and therefore detached themselves from them (Howell, et al., 2003). It can be speculated that by attributing the cause of isolation external to the self, women aim to protect their identity by not understanding and accepting the self as socially undesirable. Another threat which included social relations with other individuals was role changes and will be the next focus.

Role changes

The main concern here was how the self was perceived by other individuals due to their inability to perform normal roles and included partner, child and grandchildren as well as medical care relationships, and will be described in more detail.

Partner role change.

The first role change reported was alterations in partner relationships where male partners had to fulfil female domestic chores.

"...he [husband] just sort of took over. We call him the, you know the, newest house wife..." (Lily)

Non performance of role expectations can result in feelings of guilt and lead to questioning of identity (Watzlawik, 2009). By using humour, Lily manages to minimise feelings of guilt brought on by her inability to perform normal female domestic roles and responsibilities as a result of being too weak after her gynaecological cancer. This inability influenced the way in which she understood herself. She no longer could perceive herself as the woman performing these ascribed roles, but rather as a woman forced to surrender this responsibility to her already heavy burdened partner adding guilt to her experience. Gynaecological cancer therefore caused major changes in the family social structure, changes that influenced the whole family and will be described next when influences on children and grandchildren is discussed.

Child and grandchild role and relationship change.

The second role change reported was changes in family dynamics and included other routine behaviour as indicated by Lily.

"...everything changes for them...our two little, grandchildren who were four and six, and we weren't able to have them anymore, you know like we'd have them every second weekend. That's what we did and went to things with them and gave their parents a break and they would go out on Saturday night and things like that and it was great we all loved it cause they'd love coming here cause we've got a little boat for them and, you know they really love it and I wasn't well enough to have them, you know. Half an hour of them being here and I was completely exhausted and they didn't understand it. They couldn't jump on me the same as they use to and I couldn't do all the things with them that I use to be able to do...that's something that changed quite dramatically over those few months...so that was a huge change in the family dynamics."

Family dynamic alterations extended to role change that took place in the parent-child relationship. Often care provided by women include sensitive and emotional care to spouses, friends, elderly relatives as well as children (Eagly, 2009). Participants however emphasised that due to their illness and treatment the traditional protective and caring role of the mother could no longer be performed by them.

“You suddenly become the child. Whether you want to or not...no you sit down don't you do anything...have you done this and have you done that and have you taken your pills...it's that mother child relationship that just turns around. And you don't have the energy to do anything about it...so you just let it happen because it's easier that way...you're suddenly the child.” (Lily)

Lily clearly demonstrates how the self can be perceived by others as being too weak to perform own self caring actions due to gynaecological cancer. This can cause a change in traditional roles where the children perform the caring and protecting role instead of the mother. This can further lead to feelings of vulnerability as the situation can be experienced as hopeless due to weakness. Feelings of loss of control and autonomy contributed to the threat of the identity and although not all women in the study experienced such feelings in caring relationships, some reported strongly on power imbalances in patient –care relationships and the effect of this on autonomy and self identity. These power imbalances were the final role change reported by participants and discussion of this will commence in the medical care relationship section.

Medical care relationship.

Clear power imbalances between patients and care professionals were experienced and reported.

“...there was this sign up on the wall [in hospital room], that said if your nurse or doctor doesn't wash their hands, please tell them. I thought can you just imagine saying to some highfaluting specialist... 'have you washed your hands?' No...I can just see it...” (Lily)

She implies that her relationship with her medical specialists was imbalanced. She clearly expresses her reluctance and inability to confront any medical specialist on some issues related to her own health. The power balance differences were further accentuated by the control medical professionals has over information.

"...I find that amongst medical professionals, no matter what you dealing with and who you're dealing with...they won't tell you anymore than they feel you have to know... you can ask all the questions you like...but they're not going to be 100% honest..." (Iris)

Although sympathised with, this lack of information was perceived by women as a very real threat to the self identity. Not only does withholding of information hint to the fact that the self is perceived as vulnerable and not possessing the strength to cope with all information, but autonomy was taken away by not disclosing decision altering information. B. E. Miller et al. (2003) indicated that a majority of women with gynaecological cancer express the need to participate in decisions relating to their own life. Withholding of information was therefore perceived as a threat to autonomy and the understanding or perception of the self. This is supported by previous research which found that a sense of control related to informed decision making as well as self esteem are significant factors in adjustment (Juraskova, et al., 2003). Some women emphasised the vulnerability of this situation by discussing the position of women in the caring relationship.

"...I mean you're in their hands aren't you?" (Jasmine)

She further accentuates her vulnerability and her perceived patient-caring power imbalance by describing what she perceived as a direct threat to her autonomy, a situation where she was confronted for asking too many questions.

"...my doctors challenged me that I was asking too many questions and being too involved. 'Who do you think you are?' one doctor said to me...and my name at the time was [provided name] 'who do you think you are Dr. [patient name used]?"

Jasmine implies that she perceives herself as an individual that has autonomy and control and that she attains this by asking valuable questions, however, by asking these questions she feels that she was perceived as being petulant and therefore challenged. This misconception about the self and the attack on her attempt to maintain autonomy by asking questions resulted in her feeling a threat to her identity.

In summary, threats identified and discussed in this section included: uncertainty, vulnerability, recurrence fear, treatment delay, loss of autonomy and control, isolation as well as role change and the impact these threats can have on women was outlined. Due to the vast impact, women reacted by enforcing protecting behaviour. All women reported some variation of identity protection behaviour and will be discussed in the next section.

Identity protection

One of the ongoing challenges experienced by individuals with cancer is the establishment and maintenance of congruence between the identity and their own life within the context of social relationships (Yaskowich & Stam, 2003). As discussed in the previous section various factors can threaten the identity and contributing factors such as fears of own mortality and isolation, which is often associated with life threatening illnesses, can threaten the maintenance of self identity as a productive and healthy women (Coward & Kahn, 2004). Participants in this research study indicated that they use different aids to assist them with the task of establishing and maintaining congruence between the self and their own life. They identified and described these aids implemented by them. Although some unique protection strategies existed within the group, two major themes emerged from the interviews: acceptance as well as adaptation and this will be discussed in detail in this section.

Acceptance

This first concept of identity protection reported was perceived by some women as the most difficult to achieve.

"The acceptance is a hard part...getting to that part is the hardest." (Iris)

Iris elaborates on acceptance of cancer treatment effects by accentuating the fact that a need exists within the self to attain this acceptance in order to protect itself and to proceed with life.

"...it's only when you reach that part [acceptance] that you really feel peaceful within yourself about the situation."

She therefore implies that without acceptance the self would remain in constant turmoil and will remain threatened. Acceptance of cancer effects was compared to the acceptance of death of a loved one and emphasis was placed on the fact that it is a complicated and potentially lengthy process. In other words the process of rediscovering a complete and worthy sense of self is difficult and can take a long time to complete (Auchincloss, 1995). In contrast to acceptance of cancer effects, acceptance of cancer in the body was not perceived as a prolonged process and most women described it as follows:

"...it's [cancer] just something that you accept at the beginning that you have to go through, and so you just grit your teeth and get on with it..." (Lily)

It can be speculated that this immediate acceptance of diagnosis by women is the result of the perception that the diagnosis of cancer is temporary due to the possibility of treatment elimination. Treatment effects, however, is considered more long term with little or no possibility of relief. It is important to note here that in Lily's case she was a few weeks post cancer treatment and therefore could not yet comment on the longer term effects of cancer and its treatment. Other participants who were one year or more post treatment did experience the acceptance of cancer effects as more problematic. The term *have* used by Lily, was commonly used by various women in their conversation about acceptance. A sense of need is implied by this term and is closely associated with the second main theme namely moving on with life or adaptation. Women implied that acceptance precedes adaptation and one can only proceed with life completely once cancer and its effects were accepted. Therefore, women needed to reach acceptance in order to move on with their lives. These results are consistent with previous research which found that the acceptance of cancer, treatment and possible side effects is an important component of coping (Juraskova, et al., 2003). Women like

Lily emphasised that the process of acceptance and adaptation is a constant part of the woman with cancers' life.

"...I don't actually think I can go back and do what I used to do which is quite sad really because I really liked what I was doing, and you do adjust to new situations but I just can't imagine...part of it is that practices [medical practices] had moved on..."

Lily specifically refers to her acceptance and adaptation to employment termination. Adaptation was the second theme reported as a method of identity protection and will be elaborated upon next.

Adaptation

Lily acknowledges that individuals who experience cancer do adapt constantly but at the same time highlights the difficulty of this process for the individual. Studies such as conducted by Sekse et al. (2010) supports this finding by reporting that cancer survivors highlight the profound changes in their lives as a result of cancer and accentuates the need to adapt without having any choice in the matter. Although this process is acknowledged by participants to be difficult, all women reported the necessity of adaptation and moving on with life by providing the alternative as mentioned by Iris.

"...and move on...put it behind you, because if you were to sit and really think about it...it would infest you. It would just take over."

Rose demonstrates the need to proceed with life even further when she highlights her helplessness to the long term effects of her cancer treatment.

"...you have to adapt to it but look it's like anything. You got to adapt to anything in your life, if you don't you've, you're dead sort of thing you know, and, I think, well it's no use getting depressed about it because it is there and it's not going to go away. So you know just learn to live with it...and that's it. I mean, you know, just live with it."

Iris and Rose indicate here how acceptance and proceeding with normal life or adaptation, can be used by women to protect the self from being infested or

being overpowered by cancer and its concomitant uncertainties, fears and effects. For women with gynaecological cancer, it is not only a physical fight for survival, but a battle to retain a whole self and identity and this often involve alteration of the identity itself. Women who demonstrated active coping skills, by using positive reframing and acceptance techniques, reported an increase in functional, physical and emotional well being which in turn lead to a better quality of life (Lutgendorf, et al., 2002).

In summary, this section demonstrated two different aids used by women to protect the identity and the importance of acceptance and adaptation was accentuated. It was highlighted that without acceptance, adaptation would not be possible and that adaptation was considered crucial for woman to proceed with normal life. Women further reported that they had to reconstruct their identity to ensure adaptation to their changed circumstances, however, this identity reconstruction will be discussed in more detail in the next section.

Identity reconstruction

As a result of cancer diagnosis and treatment, previous self understandings and therefore the identity is no longer applicable to the changed situation (Yaskowich & Stam, 2003). This sets off the process of re-evaluation of the foundation of self understanding and forms an essential aspect of the lived experience of cancer individuals (Mathieson & Stam, 1995). In a study conducted by Whitehead (2006), which focused on identity reconstruction in individuals with chronic fatigue syndrome and myalgic encephalomyelitis, it was found that it is possible to reconstruct a new and positive self-identity following the onset of illness.

Results of the current study discussed so far, indicated that women experienced changes in their circumstances which was instigated by the diagnosis and treatment of cancer. This threatened their former self understanding and identity and necessitated the re-evaluation of the self and the reconstruction of the identity. In the next section this identity re-evaluation and construction will be discussed and reference will be made to the change in perspective that takes place following diagnosis. Personal responsibility taken as identity reconstruction will be discussed and identity reconstruction due to power imbalances will be

elaborated upon. Finally reconstruction by focussing on personal strengths and a new identity characterised by hope and being positive will be described.

Perception change

Many women with gynaecological cancer report that they discovered certain positive gains from their cancer experience (Akyuz, et al., 2008). All participants reported that although cancer and its treatment can be characterised by some unpleasantness it generally was experienced as positive and self enriching. Without exception they felt that cancer brought on a change in perception. Jasmine's account demonstrates this alteration in perception and the role cancer played in this change, by describing an experience she had during her treatment.

"...I had these flowers given to me and I remember having this experience where I went inside the flowers. Sort of some surreal experience. Like, I stopped being myself and went somewhere else and came back again. It was quite intense...don't know if it's the drugs...anyway I thought quite long and hard about it and made me realise that I am mortal, I'm going die anyway, you got to do with your life what you want to do with your life...I made a little note about it here [refers to a note pad] a telegram from Mother Nature, a wakeup call to live...so the cancer did wake me up, and I changed my life, and no, it was wonderful, but traumatic to...I probably wouldn't have done that without the cancer... It does change the way you think...and it benefits you...It's terrible, but it does change the way that you think about things and life and people."

Tower (2008) refers to this change of perception as transformative growth and explains it in terms of a person understanding the whole better after cancer, than before the onset of the illness. For participants this change in perception was accompanied by a renewed appreciation for life. This is supported by previous research where it was found that women felt that their lives had been significantly altered by cancer and how previous small and mundane events suddenly after cancer became vitally important (Ferrell, et al., 2003). Participants acknowledged that following cancer, greater value was placed by them on life as indicated by Iris.

"...as long as there's life, you should make the best of it. If not for yourself, then for your partner, your kids, or your grandkids or whoever. It should be for yourself first and foremost...so no matter what age you are and no matter what cancers you develop enjoy each day...you have to enjoy each day..."

This theme of living life for yourself, for your children, grandchildren or your partner was supported by all women. It is consistent with results from a study by Pascal (2010) focussing on the lived experience of cancer survival, which found that family relationships (partners, children and grandchildren) were considered important as sites for meaning making. Jasmine mentioned that this re-evaluation occurred after her cancer diagnosis and treatment and issues of importance to her were identified and changes were made to include this into her life.

"...that's why I am up here [Auckland]...so I can be near him [son]...It [cancer] does change the way you think."

Holland and Reznik (2005) reported on this in their study of pathways for psychosocial care of individuals with cancer and mentions that cancer survivors may develop greater intimacy with and acceptance of others. Women indicated in a study conducted by Molassiotis et al. (2002) that not only did they realise how precious life was but treasured family relationships more following their cancer diagnosis. Pascal (2010) further accentuates this by reporting that relationships are intimately entwined as crucial points of meaning making and self identity. Change in perception extended past immediate family to individuals in the greater community as indicated by Lily.

"...it's [cancer] changed my attitude towards other people. In the way that, I mean I've always tried to help people. It's a part of my nursing background and that but, you know, I've always taken people meals if they've been sick and all that sort of things and, but it does make us think back a little bit and there are times when I was sure that I could have done more, but it does change your attitude. You sort of think well, you know, I now know what it's like to need people, cause you do, and how much that you when you get well, will be able to help other people and that's something it's done for me. Not

that I didn't before hand, but it's brought it home in a very real sense. That it's the little things that people do for you that is just amazing."

All women reported that by living through a cancer experience an individual gains a better understanding of not only the needs of the self but the needs of partners, family, friends as well as other members of the community. This finding is consistent with previous research by Wyatt and Friedman (1996) which found that following cancer many women feel that they have something more to offer other individuals. Pascal (2010) explains this change in attitude of other cancer survivors by highlighting how participants described the cancer experience as a wake-up call which resulted in changes in the nature of relationships of care for both the self and others. Lily implies that women felt that before the cancer experience, no true understanding of their own mortality and therefore the value of their life or, what they truly regarded as important and the value this have for them was possessed. Jasmine accentuates this by indicating that before her cancer experience she took things for granted but that cancer changed how she perceived her life.

"...I would have taken things more for granted. I don't take things for granted now."

Cancer survivor Dudley O. Tower (2008) supports this when he mention that the cancer experience can lead to a transformation in meaning and consciousness when the existential realisation is made, that up until the cancer experience life was socially predefined. To him this understanding then results in an automatic shift in priorities, which in turn leads to an increasing appreciation of life, improved relationships as well as the ability to see new possibilities for own actions. Own action was closely related to personal responsibility for the women interviewed. It was accentuated that it is important to take personal responsibility through one's own actions. The importance of personal responsibility is therefore another identity reconstruction that took place as reported by women and will be discussed next.

Personal responsibility

Iris reports that before her treatment it was imperative for her to investigate her medical professionals' ability to perform the surgery and to provide the best possible care.

"...I had total trust in the gentleman [specialist surgeon] that I saw, and having checked him out as I do with most things...I'd gone through a bit of his background and I was fairly confident of his ability to do a good job."

This implies that Iris regards the gathering of information as pivotal to personal responsibility as well as important to make an informed decision about treatment. She stipulates that without proper information the decision on action to be taken on various treatments with its effects is complicated.

"...find out as much as you can about what the problem is, through all the various sources of information that are out there, find out the best treatment that suites your particular situation, and get it."

She highlighted the importance of asking proper correct questions in order to gain the needed information to make decisions and to take the best action, therefore living out autonomy.

"...you have to ask the questions...I think it is necessary..."

Iris implies here that by taking personal responsibility, through information gathering by asking questions, the self is its own advocate. Information opens the opportunity to participate in treatment decisions and enable women's sense of control not only over their cancer but over events and their lives (Walton, et al., 2010). Iris explicitly mentions this importance of information and personal responsibility when she refers to self advocacy.

"...I have found that you are your own advocate...I also believe the patient is their own advocate and that a patient has to tell the doctor..."

The phrase further accentuates the power attributed to women by Iris through her acknowledgement of the information which women have on the self or their own bodies. She emphasise the need to share this knowledge with medical

professionals as part of personal responsibility. Iris's account indicates how the identity was reconstructed to not only incorporate a strong sense of self advocacy and therefore self responsibility, but to include a power to women through the information about the self, which belongs to and can only be shared by them. Living through the cancer experience therefore aided the reconstruction process and resulted in women taking control over their own lives and in future be their own advocate by taking personal responsibility when it comes to their own health. This finding is supported by studies such as Moore-Schaefer et al. (1999) which found that as life with cancer progressed, women's persistence in attaining information as well as answers and their decisions to take responsibility for their health, enabled them to reclaim power. This taking of responsibility is demonstrated by Jasmine when she explains that after her experience with cancer she insists on her own copy of test results.

"...I still have regular smears...now I always insist, if I had any sort tests done that I'm sent a result...I insist, that I get results..."

Jasmine tells her story of how tests were performed based on questionable symptoms and how the results of her tests were forwarded to a physician that was not available at the time. Due to the fact that her results were not sent to her and because she relied on the fact that if the results was life threatening she will be informed she was unaware that she had stage III near stage IV cancer. Only by taking personal responsibility and asking for the results did she learn about the seriousness of her diagnosis and could she take action. In her opinion she avoided a terminal status by being her own advocate by taking personal responsibility. It resulted in her identity reconstruction to include these life saving constructs. This reconstruction of the identity to incorporate self advocacy and personal responsibility as indicated by Jasmine, as well as the power attributed to women by Iris, was influenced by previous relationships within the cancer experience. As a result, this had interesting repercussions for how power relationships between the women and their medical professionals were experienced and acted upon later. Some women indicated that the treatment decision was not made only by the specialist but that the patient's autonomy was respected as they were included in treatment decision.

"I was asked what did I wanted to do and I said well I guess that hysterectomy sounds like the best thing...it's [organs] got cancer...cut it out, take it away...he [specialist] said 'good choice'..." (Rose)

This has been found in previous research where women indicated that treatment options were all presented to them by medical professionals and that the final decision was left to the participant (Walton, et al., 2010). It was interesting however to notice that Rose's specialist commented on her decision by indicating that a choice was made which he approved off. The importance of this with regards to power relationships is not clear and can only be speculated upon. Power imbalances that were mentioned in conversations were the advantage health professionals have in regards to knowledge and will be discussed next when attention is focussed on power relationships as another catalyst for identity reconstruction.

Power relationships

Iris accentuates power imbalances when she mentions that some information is withheld from women by medical professionals.

"...the specialists...they won't admit, that this [treatment effects] is a, strong possibility after having his type of surgery." (Iris)

It is imperative in the clinician-patient relationship to offer women treatment options and allow them to make voluntary choices about potentially life altering health care regimes, as this discourage potential paternalism in health care and unwanted intervention (Entwistle, Carter, Cribb, & McCaffery, 2010). Some women reported that although they were granted the opportunity to make the treatment decision, questions were raised over if this were truly the woman's choice as well as whether it was an informed decision. Lily's account demonstrates the imbalance that can exist in the decision making process when she describe how medical professionals informed her when they could proceed with treatment.

"...they [specialists] said no we can't do it...I had to go and see the kidney specialist, the heart specialist, everybody. I had all these appointments for

them to all to check off that it was ok for me to have the surgery...we were extremely nervous when we went back...they said right May 17th ...”

Although it can be argued that her medical professionals acted in Lily’s best interest, by not proceeding with treatment when it could be detrimental to her health or even be fatal, she was not given any choice in delaying the treatment once approval was given. At this point Lily was not prepared to proceed with her treatment.

“...my first thought was no...it’s too soon, I’m not ready.”

From this perspective it can be argued that because Lily at that point felt that she was unprepared for her treatment she was forced into unwanted intervention. She had no influence over when her treatment would proceed and therefore had no autonomy over this aspect of her life. Many women with gynaecological cancer share this loss of power of influence or voice in the caring relationship with medical professionals (Moore-Schaefer, et al., 1999). In relation to the question whether women made an informed decision, participants indicated that they understood what influence the lack of full disclosure of information by medical professionals potentially can have on decision making.

“You know if you’re told you’ve got a particular disease and someone says well the treatment for it is, tadalada and you say oh that’s fine we’ll go ahead with it, and then they say to you, but, one of the possibilities, of the outcomes is that this might happen. Might happen not definite but might happen, you might then sit back and think, well I don’t know if I actually fancy that. Maybe I should review, and maybe I should look at all the other options.” (Iris)

Previous research outlined the potential impact a lack of full information disclosure can have by indicating that some women were devastated to find post operatively, that a lesser invasive treatment could have been implemented and that negative and life hampering treatment effects could have been avoided (Walton, et al., 2010). Participants further felt that due to power imbalance between medical professionals and patients, women are often not acknowledged for their knowledge of the self. In other words only you truly know your own body.

Iris's account demonstrates this when she explains a previous health experience with a specialist.

"...doctors are very narrow in their thinking. I have a gastroenterologist who I've had a run in with...he was convinced it [symptoms experienced] was the Crohn's disease, and I was telling him from the minute I walked in it was not, but he wouldn't listen, and the doctor and the hospital wouldn't listen. Kept telling them it wasn't the Crohn's disease, the pain was different. Everything was different. No it has to be that. Has to be flair up. It was a trapped nerve...I had a little hernia up near my navel area, and the nerve had come out through the hernia and got trapped. That's what was causing the pain. They didn't find it. I ended up going somewhere else and it was found by somebody else, but it's that, doctors not listening to patients so when I went to see him the next time I said to him, 'you didn't listen, to me'...you didn't listen one bit...I've got more outspoken..."

Moor-Schaefer et al. (1999) reported that this experience has been found to be shared by more women and is not only limited to individuals with gynaecological cancer. They mention that in some experiences with physicians where women describe symptoms, they had no voice and were not heard. By directly denying a woman's voice or by indirectly promoting a system that permits the development of a voice, the identity is threatened (Mathieson & Stam, 1995). The imbalances in patient-specialist relationships and the threat this can have for the identity mentioned thus far, resulted in women re-evaluating their own position and how they understood the relationship. Jasmine highlights the reconstruction that followed this re-evaluation by indicating that medical professionals are only human and prone to mistakes. It is therefore in her opinion necessary for women to assist carers by asking questions, sharing valuable symptom related information and by being critical over their own symptoms and illness. In other words, rather work with health professionals as equal partners to attain health.

"That's the way to work with people, collaboratively." (Jasmine)

In this newly constructed identity women perceived themselves as an equal contributor to their health and no longer placed their health in the hands of another individual.

“I insist that I get results [medical tests] otherwise you just get into the habit of thinking, they will take care of it and you resolve yourself of that responsibility, they’ll take care of it...no!” (Jasmine)

Women explained that they learned through their cancer experience that they cannot place the responsibility of their health solely in the hands of specialists as medical professionals are only human and prone to mistakes. It is therefore important to take personal responsibility by working collaboratively with carers by gathering information on the illness, asking questions and by helping to attain the best possible treatment outcome. Similar findings have been reported by Butler et al. (1998) where women accepted their cancer, adjusted to their situation, took control of their own health and put the cancer experience behind them. It was further reported, in the same study, that women took control by selecting their own specialist and by asking questions throughout the whole process. This newly formed identity therefore included autonomy, control and responsibility over their own health.

Autonomy, control and responsibility were common themes in the reconstruction of the identity and extended into other areas used by women to define themselves. As mentioned earlier women reconstructed their identity to include family, members of the community and employment. By doing this the self identity was regained. This is supported by research studies such as conducted by Coward and Kahn (2004), which indicated that women in their study regained their self identity as healthy individuals through socially scripted roles, family, as well as employment. Employment and other personal strengths were fundamental to women’s identity reconstruction and will be discussed next.

Employment and personal strengths

Employment formed a major part in how women made sense of and understood themselves after cancer diagnosis and treatment as indicated by Iris.

"...I work full time. I work hard and longer now than I've ever done."

Iris explains that her employment is a coping mechanism against her fear of recurrence as well as an escape route from the reality of her losses due to cancer and its treatment effects.

"...it's also, in some way's my little saviour, because [sigh], I can concentrate on work. It's my escape hole, if I'm, not wanting to do other things, if I'm not wanting to, deal with other things, and can just bury myself in my work, and that's for me quite therapeutic. Other people, they'll look at what I do and think you're mad. You put all that time and effort in and you get all that stress, but it's actually something I enjoy..."

She acknowledges the fact that focussing on her work it might not be perceived as dealing with her fears and losses. She argues however that her work does help her live with cancer on a daily basis.

"It's not really dealing with it but at the same time you'll live with it."

This reconstructed identity of Iris imply that woman are emotionally strong and capable of controlling fears and sense of loss on a daily basis and can proceed with normal life which includes employment. She perceives herself further as being successful and this can be beneficial to her self-esteem.

"I know I am relatively good at my job."

For her identity reconstruction it was important to focus on other aspects in life which she was good at and she outlined how she perceive and understand herself within this new identity.

"...and start maybe to feel a bit positive about the other sides of life... I know I am a relatively good mother and grandmother...I think if you're aware of the other things in life that can make you feel good about yourself you know, you have to hang on to that and not feel bad about what you've lost."

Holland and Reznik (2005) supports this by indicating that cancer survivors may identify with new and other areas of strength. This included various other

aspects of the woman's life and, employment, being a grandmother as well as being a mother were mentioned.

"...I'm still a woman. I gave birth to 3 kids I'm still a woman..." (Iris)

By saying this Iris highlights the fact that she now associate and identify with being a woman who had children and is a good mother. So rather than lingering on her losses she made the decision to focus on her being a mother which is more positive. This positive reconstructed identity was common amongst participants and attention will shift to a discussion of this positive identity in the next section.

Hope and positive identity

Following cancer diagnosis women reconstructed the identity to be more positive as well as to focus more on hope. Similar findings have been reported by Molassiotis et al. (2002) where women in Hong Kong who reported on adaptation issues faced after cancer diagnosis, mentioned that following their illness positive changes were made to mood and temper to include a positive outlook to life as well as planning for the future. The necessity of positive thinking in healing after cancer was accentuated by Lily. She implies that a positive view can aid the healing process.

"...you just have to believe that you're going to get well because if you don't and I have met people, that haven't believed that they will get well and they make life very hard for themselves...I think you just have to believe that you could get well... believe you can get well..."

In the past Lily shared the experience of individuals who did not have a positive view on their recovery possibilities and learned that this lack of positive view complicated matters. She emphasise that if an individual lack a positive mood, recovery can be complicated. This is supported in the literature where the link between depression and medical outcomes have been reported in the past (Thompson & Shear, 1998). Lily's learning experience of the past, together with her cancer diagnosis and experience of her positive view shaped a new identity

which included being positive. She implies further that this positive mood can protect her against the devastating effect that news of recurrence can have.

"I don't know how I'd feel if they told me that it had come back. I think it would be pretty devastating...you know to sort of gone through this whole year and then suddenly to be hit with...I've decided that that's not going to happen...not having any of that."

So by being a positive person Lily not only protects herself and her identity but ensures better healing. Being positive extended past treatment outcomes and included a general positive view of life. All participants reported that although the cancer experience did cause many changes and challenges in their lives, it did not eliminate life in totality.

"...it's [cancer's] the end of the life as you knew it, but there is still life." (Iris)

Cancer is acknowledged here by Iris as being devastating but the positive is still seen in the fact that there is still life and therefore hope.

"...and as long as there's life...you should make the best of it."

This emerges in Lily's account when she discusses future research and the possibility of treatment and cure. She highlights the fact that as long as there is life the possibility exist that treatment can improve.

"...if you are diagnosed with that [cancer] it isn't the end of the world and...most things these days something can be done about it...like I know there's things that my sister had or didn't have and mine has been quite different, same problem but quite different treatment...the, research is just going on all the time and you know one day someone is going to make the big breakthrough..."

Individuals diagnosed with cancer seek hope and this include hope for survival (Yaskowich & Stam, 2003). By reconstructing the identity, to include a positive view as well as maintaining hope, the women addressed their own fears and concerns and protected the self. To be more specific, an identity characterised

by hope and the belief that a cure will be found in the near future helped participants to lessen their own fears of recurrence.

In summary, this section focussed on identity reconstruction by reporting and explaining perception change, personal responsibility taken, repositioning of the self in power relationships, the focus on employment and other personal strengths as well as the new positive and hopeful identity. The life threatening situation induced by cancer presented women with certain realities which caused them to re-evaluate their identities within their changed situations and to establish what was important to them. This resulted in identity reconstruction and self growth. It was attained by creating a better understanding of the self, both in terms of how each woman understood themselves and their situation, as well as in terms of how the self relate to others, in other words their social context. So although cancer caused many challenges and changes to the life and identity as they knew it, it brought on self evaluation and growth that intensified their relationships. This is concurrent with studies conducted by Mathieson and Stam (1995) which reported and discussed participants re-evaluation and re-negotiation of identities following cancer.

Experiences reported in this section further demonstrate women's newly reconstructed identities characterised by autonomy, strength and a passion for life. They not only overcame a physical threat to their lives but a threat against their essence of being and courageously continue to preserve the self in their everyday life as gynaecological cancer survivors.

Summary

This results and discussion section provided an overview of findings before commencing with a discussion of female identity. Within this description of female identity emphasis was placed on gender roles, sexuality and sexual responsibilities, body alteration and experiences as well as discussion of female reproductive organs and the caring responsibility. It elaborated on identity threats and here specific reference was made to uncertainty, vulnerability and fear of recurrence experienced by women. Loss of autonomy, role changes and isolation was further explained as threats. Two identity protection methods used by women

were identified and explained after which identity reconstruction was highlighted. This final discussion on identity reconstruction focussed on the change in perception that occurs after cancer and personal responsibility taken in own health was accentuated. Power relationships, new focus on strengths as well as hope and a positive identity formed the remaining part of this discussion on identity reconstruction.

Conclusion

In this final section of the study an overview of results will be presented. This will be followed by an outline of limitations of the study within which results should be interpreted. Following this, suggestions will be made with reference to future research and to conclude the section as well as the study, contributions made by the study will be elaborated upon.

Overview

Results from this study indicate that women who were diagnosed with gynaecological cancer were faced with tremendous changes and challenges as a result of their illness. Challenges that were not only extremely personal but invasive and affected various levels of their personal, family, professional and social lives.

Getting confronted with one's own mortality, like in the case of gynaecological cancer, can be a lonesome and very personal process which left women vulnerable in their encounters with both themselves and others. Former meanings on which the healthy individual based the self and identity no longer existed due to cancer diagnosis, treatment and treatment effects and women talked about a certain loss of identity which referred to how they viewed themselves, as well as how other individuals perceived them as a woman who had gynaecological cancer. In particular, they explained how as a result of their illness, their female identity was altered. Changes to gender roles, sexuality and body appearance were reported to all influence how women perceived and understood their bodies and themselves. Although they still believed that they were female and a woman, due to the fact that they had children, the inability to conform to full socially scripted expectations in terms of traditional gender roles other than bearing children, alteration in sexuality and body appearance, made them question their own female identity.

Other threats to the identity were highlighted and discussed by participants. The threat to individual autonomy was particularly emphasised. Loss of autonomy were explained by women in terms of delay of treatment, mobility constraints, the control women had over their own lives and decisions that affect

their lives, as well as employment termination. This was however all discussed within the diagnosis, treatment and effects experience. Isolation in terms of the change in social structure was explained, as well as uncertainty and vulnerability experienced in caring relationships. Role change and reversal were further highlighted and the affect this had on their own and other individual's perception of them were accentuated. Due to the threats experienced, it was necessary to re-evaluate themselves and to create new meaning out of the changed circumstances and characteristics.

Women therefore had to cope with various changes on many levels and had to adapt to new ways of living. They identified coping mechanisms applied by them to protect the self and their being and discussed acceptance of their gynaecological cancer. They accentuated how acceptance aided their adaptation to their changed life and circumstances and advocated hope. This process of coping included not only the re-evaluation of the identity but the reconstruction thereof.

Within the identity reconstruction discussion women placed emphasis on how their gynaecological cancer experience caused a change in perception. That they now understood the value of life and the part they had to play in living their lives to its full potential better. A common feeling was that because cancer resulted in them feeling vulnerable, helpless and unable to care for others as socially prescribed, they better understood their changed situation and own needs and were in a better position to assist and care for themselves and others. The identity was therefore reconstructed to include caring as a major underlying construct. Caring included personal responsibility and the effect this had on the power women had in caring and other relationships were discussed. In the new identity women were constructed as strong and in control and were no longer submissive to external instruction. Reconstructed identities acknowledged and accepted their losses but did not dwell on it. Rather attention was shifted to personal strengths and women focussed on personal characteristics which enhanced their self esteem.

So the results from this study demonstrates that women who survived gynaecological cancer had to cope with various changes on many levels and had to adapt to new ways of living. It revealed that women not only had to face demanding challenges but had enriching experiences as well. Unfortunately as is

the case with all research, this study had its limitations and it is important to understand the results within the restrictions of its limitations.

Study limitations

The findings presented and discussed in this study needs to be viewed within the context of the limitations of the study. The sample was small and non representative and caution should be taken not to generalise to any other populations. It is important to note that the goal was not to obtain a representative sample, but rather to learn from a variety of experiences of women for the purpose of in-depth and a nuanced exploration of the process. This methodology proved to be very useful for hypothesis generation, however, it cannot test hypothesis and should not be generalised beyond the participants.

All participants were older women and many were past childbearing age and already had children of their own. The different perception, with relation to experience, of women who already had children of their own is well known (Sekse, et al., 2010). It is therefore important to consider and understand that this participant characteristic will influence findings and that samples who include younger women who no longer can have children due to gynaecological cancer will present differently. The results presented in this study are therefore not representative of the general population as younger women who no longer can have children due to gynaecological cancer were not represented in the sample.

Another limitation of the study is that the sample was limited in geographical terms. Most participants, with the exception of one woman from the Auckland central region, resided in the North Shore region of Auckland New Zealand and individuals from other regions were not represented in this sample. Participants were further of European decent as well as educated and represented a higher socioeconomic group. No other ethnic or socioeconomic groups were included or represented in this sample. Most women were married, only one woman was divorced. The possibility exist that women from other ethnic and socioeconomic groups, as well as individuals from other geographical areas and of different marital status, could experience their cancer diagnosis differently due to

different circumstances and that the identity could be re-evaluated and reconstructed differently than the individuals represented in this sample.

The interpretive nature of this study is worth acknowledging and important to mention. Van Manen (1990) stipulates that phenomenological description is only one interpretation and description of an event or experience and that only one interpretation of an experience cannot exhaust other perhaps deeper descriptions. Phenomenological focussed research is therefore open to interpretation. The results presented in this study is based on the interpretation and description of only one researcher and under different circumstances, time and investigations the data might have been interpreted and presented differently. Ongoing research possibilities therefore exist and suggestions for future research will be discussed next.

Future research

In contrast to what was believed in the past, the procreation ability of a woman alone no longer insure a feminine identity and the prescriptions of being a woman now extends past the female reproductive organs and functions which were central to defining the body (Malson & Swann, 2003). Following gynaecological cancer the female body can endure many changes and the need arises to reaffirm the identity (Butler, et al., 1998). This includes the identity as a woman, a sexual being, a partner, a mother, grandmother, a friend, a professional individual and a person who care for others. This process of developing new identities can not only influence relationships with care providers but impact general well being as well and a sad reality is that very little is currently known about these post-cancer identities (Park, Ziateva, & Blank, 2009). Further qualitative study is therefore needed to be replicated in different populations to establish how women re-evaluate and reconstruct their identity. Quantitative study can help determine the extent to which the themes that emerged in this sample are representative of women's experiences.

The current study only consisted of older women past their child bearing years and did not include younger women prior to menopause and child bearing. Sexual dysfunction is relatively prevalent in younger women with some gynaecological cancer (Wenzel, et al., 2002). Future research incorporating this

group can not only help to establish how identity re-evaluation and reconstruction is managed in younger women without children, but can indicate how this process differs amongst the two groups.

Women reported that they experienced psychological distress where cancer treatment was delayed. This was a result of the knowledge of a confirmed cancer diagnosis and uncertainty, which was damaging to the person. The psychological distress brought on by treatment delay which women, their loved ones and treatment centre staff experience, is difficult to measure and is often ignored in the literature (Lim, et al., 2005). Future research focussing on this can determine the extent of psychological distress which can in turn result in intervention development that can possibly alleviate the distress experienced.

Lastly, results clearly demonstrated that not only women with gynaecological cancer are affected by their diagnosis, treatment and effects, but that their partners, family and friends are influenced by their changed situation as well. It is however unclear how the process of identity re-evaluation and reconstruction are experienced by partners, family and friends and how this changed identity influence these relationships. Future research can aid to determine the extent of this influence and perhaps contribute to intervention programs which address any issues that might arise.

Future studies will hopefully assist women who experience gynaecological cancer to cope with the many challenges and changes of treatment and post treatment effects. So any study focussing on the improvement of well being would be welcome and can contribute to overall quality of life of women. Specific contributions made by the current study will be addressed in the final section.

Contributions

The methodology and method used in this study encouraged women to share experiences and concerns of importance to them rather than predefined issues identified by the researcher. This resulted in a rich in-depth description of a relatively unexplored area of experience namely the re-evaluation and reconstruction of identity in women with gynaecological cancer. The findings open various new possibilities for future research and intervention relating to identity following gynaecological cancer diagnosis, as well as the impact this can have on the women themselves and significant others.

Women reflected upon and shared their experience in this study freely and by doing so they created and recreated the meaning attributed to the whole gynaecological cancer experience. Many women reported that by sharing their experience and reflecting on it as it was shared, a better understanding was attained of many experiences following the interview.

The study further accentuated what women identified as threats to their identity. This knowledge in turn can aid specific people in various relationships with the women to, in future, evaluate how they affect and possibly reinforce threats. Perhaps in the long term such reinforcement can even be addressed by behaviour alteration and by changing the nature of relationships to the extent that threats to the identity are lessened.

In conclusion, by providing the opportunity for women to share their unique experiences of their cancer, diagnosis and treatment or letting their voices be heard, this phenomenological study contributed to a richer and more detailed understanding of the sensitivity of challenges faced, emotions experienced and meanings attributed to the gynaecological cancer experience. Perhaps in future this knowledge generated from the study, can contribute to improved care and support provided to individuals who are faced with similar circumstances.

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Appendix A

Advertisement

Advertisement for recruitment of participants placed in:

- North Shore Times
- East and Bays Courier
- Manukau Courier
- Papakura Courier
- Western Leader
- Whangarei Leader
- Northern News
- Rodney Times
- Waiheke Marketplace
- Cancer Association Centres
- Gynaecological Surgeries around Auckland

Experiences of gynaecological cancer and treatment of female survivors.

I am a Massey University Master's degree in Psychology student who would like to talk to 6-8 people about their experiences of gynaecological cancer diagnosis and treatment. This research is part of my Master's degree in Psychology. Participants will be interviewed about their experiences and will agree to have their experiences recorded for the purposes of this research project. Confidentiality and anonymity will be respected. The Massey University Human Ethics Committee has approved this research project. For more information please contact Adele Smit on phone number: 09 414 0817

Appendix B

Information sheet

Experiences of gynaecological cancer and treatment of female survivors.

Researcher Introduction

My name is Adele Smit and I am a student at Massey University Albany. I am currently completing a Masters degree in Health Psychology. My supervisor is Dr. Christine Stephens who is an Associate Professor in Psychology at Massey University. The research which I am about to commence has been approved by the Massey Human Ethics Committee. Over the past few years I have been in contact with many health related problems which have impacted various people close to me and as a result I became increasingly interested in one such a problem, namely cancer. As I have walked a path with these people close to me I have developed a personal interest in those who survive gynaecological cancer.

What is this project about?

Women diagnosed with gynaecological cancer face challenges on a daily basis and knowledge of their experiences can provide valuable information which can be used in future to ease some of these challenges. This project will aim to explore the experiences of survivors of gynaecologic cancer. It will aim to understand what it is like to be diagnosed with and treated for gynaecological cancer. It will therefore be ideal if women who were diagnosed with endometrial/uterine corpus, ovarian, cervical, vulvar and vaginal cancer as well as gestational trophoblastic neoplasia and had undergone various treatments can be interviewed to gain an in-depth understanding of their experiences. These women will all have survived the prognosis and treatment for gynaecological cancer and continue to live as survivors. Much can be learned from women who have experienced and survived this and for this reason I would like to invite women to please take part in this research project.

Who can take part?

Ideally six to eight women will be interviewed who have experienced gynaecological diagnosis, treatment and who continue to live as survivors. The reason for this would be to get a nuanced analysis of the experience. Inclusion criteria for the research study will include:

1. Diagnosis of any of the following conditions: endometrial/uterine corpus, ovarian, cervical, vulvar, vaginal cancer as well as gestational trophoblastic neoplasia.
2. Cancer treatment which may include: bilateral salpingo oophorectomy, omentectomy, abdominal hysterectomy, all three forms of vulvectomy (skinning, simple and radical), radiation therapy and chemotherapy.
3. Be cancer clear for at least the preceding year.
4. Being over the age of 18 years.
5. Be willing to be interviewed in English.

Each woman will decide what information will be shared in the interview. Any information too sensitive or too distressful does not have to be shared if they do not wish it to be included. However, as women share certain experiences in the interview, there is the possibility that talking about these experiences is distressing. If help is needed for any ongoing problems of this nature, I will be able to supply information about appropriated counselling services and you may wish to contact Helen McMaster at the Centre for Psychology Albany to ask about these services yourself (ph: 09 441 8175).

How will the interviews proceed?

After you have read this information sheet, I will contact you to enquire if you are interested in taking part in the research project. If you are interested, a time and date will be established for a meeting in which further discussion of the information sheet, formal consent and the interview will take place if you still wish. The interviews will take place wherever it suits you; either in your home, a university location or other place of convenience.

Interviews will take between one and two hours. The interview will be audio-recorded with your consent and will later be transcribed by the

researcher/interviewer. The format of the interview will be unstructured and only a few questions will be asked as I will invite women to share issues of importance to them with regards to their cancer diagnosis, treatment effects and experiences.

A copy of your completed transcript will be sent to you for comment and any changes that you wish to make. A final summary of the findings will be sent to all participants at the conclusion of the write up.

What will happen to the information?

The only people who will have access to the audio recording, data, consent forms and contact details will be my supervisor, Dr. Christine Stephens and myself. Recordings and transcripts will be securely stored and will be separate from any identifying information like names, contact telephone numbers and addresses to ensure confidentiality. Identifiable information will only be used to contact or mail to participants. Following the research contact details will be promptly destroyed, and consent forms, audio recordings and transcripts will be retained for five years then destroyed. You may also choose to keep your audio recording or transcript yourself.

Results will be published in a thesis as part of academic requirements. The researcher will further aim to present the findings at professional conferences and publish the results in peer reviewed journals. This will contribute to identification of rehabilitation needs, education for health care providers and to gather information for future research as well as programs by other individuals.

Participant's Rights

- You are under no obligation to accept this invitation as participation in this research project is completely voluntary.
- If, you decide to participate, you have the right to decline to answer any particular question. At any time during the interview you can request that the audio recording be turned off.
- You can withdraw from the study at anytime during participation up until the final analysis commences.

- You have the right to ask any questions about the study at any time during participation.
- You may provide information on the understanding that your name will not be used in any discussion or publication of the results.
- You have the right to be given access to a summary of the project findings when it is concluded.

Project Contacts

Please contact either Dr. Stephens or myself using the details provided below if you have any additional questions.

Researcher: Adele Smit

Phone no.: (09 414 0817)

Supervisor: Dr. Christine Stephens

Phone no.: 06 356 9099 ext 2081

E-mail: C.V.Stephens@massey.ac.nz

Centre for Psychology Albany

Contact: Helen McMaster

Phone no.: 09 441 8175

This project has been reviewed and approved by the Massey University Human Ethics Committee: Southern A, Application 10/28. If you have any concerns about the conduct of this research, please contact Professor Julie Boddy, Chair, Massey University Human Ethics Committee: Southern A, telephone 06 350 5799 x 2541, email humanethicsoutha@massey.ac.nz.

Appendix C

Interview schedule

Experiences of gynaecological cancer and treatment of female survivors.

1. Introduction

- 1.1. Provide background information on the researcher/interviewer related to qualifications.
- 1.2. Provide information relating to the research project re-emphasising information provided in the information sheet.
- 1.3. Restating the rights of the participant in the research project.
- 1.4. Enquire if there are any uncertainties regarding the research project or any questions.
- 1.5. If questions arise time will be taken to clarify them to ensure that a fully informed participant consent.
- 1.6. Consent forms presented and signed.
- 1.7. If participant consent the interview will commence if no consent is received no interview will proceed.

2. Diagnosis experience

- 2.1. How did you experience news of your diagnosis?
- 2.2. What did your diagnosis mean to you?
- 2.3. How did your diagnosis influence your family and social life?

3. Treatment experience

- 3.1. How did you experience your treatment?
- 3.2. How did the treatment impact you emotionally?
- 3.3. How did your treatment influence your family and social life?
- 3.4. How does the treatment impact your everyday life?
- 3.5. What is the effect of the treatment on your long term quality of life?

4. Overall experience

- 4.1. If you as a gynaecological cancer survivor have to share one important experience with other women with gynaecological cancer, what would this be?
- 4.2. What experience would you single out to share with women and men who do not have gynaecological cancer?

5. Closing

- 5.1. Is there anything more you would like to share and include in this research project?
- 5.2. Provide an overview of the interview and the goals of the research project.
- 5.3. Do you think we have captured your lived experience of your gynaecological cancer diagnosis, treatment and treatment effects?
- 5.4. Ask how the participant feel about the interview to assess if any needs or distress exists brought on by the interview so that she can be referred for appropriate counselling.
- 5.5. Re-emphasise the procedure which will follow from here on with specific focus on the summary report and the opportunity to address any problematic data.
- 5.6. Thank the participant for taking part in the interview.
- 5.7. Greet and disperse.

Appendix D

Consent form

Experiences of gynaecological cancer and treatment of female survivors.

Participant consent form – individual.

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/do not agree to the interview being sound recorded.

I wish/do not wish to have my recordings returned to me.

I agree to participate in this study under the conditions set out in the Information Sheet.

Signature:

Date:

.....

Full Name -

printed

.....

Appendix E

Transcript release form

Experiences of gynaecological cancer and treatment of female survivors.

Authority for the release of audio transcripts.

I confirm that I have had the opportunity to read and amend the transcript of the interview(s) conducted with me.

I agree that the edited transcript and extracts from this may be used in reports and publications arising from the research.

Signature:

Date:

.....

**Full Name -
printed**

.....