WOMEN'S EXPERIENCE
of
SEXUALITY and BODY IMAGE
following treatment for
EARLY STAGE VULVAR CANCER

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Abstract

This study reports on the experiences of sexuality and body image of ten women following surgery for early stage vulvar cancer. Vulvar cancer is a rare cancer, with only about 250 women diagnosed in Australia each year. Treatment for vulvar cancer has evolved to become highly individualised, with the emphasis now on performing the most conservative surgery consistent with cure of the cancer. There is limited information describing the psychosexual outcomes for these women. Much of the previous research conducted to determine the psychosexual outcomes of treatment for vulvar cancer, have been on women having had a more radical surgical approach than is currently performed.

A qualitative approach based on interpretive phenomenology was used to interview a purposive sample of 10 Australian women who had previously had surgery for an early stage vulvar cancer. Women were interviewed for this study from April to August 2009. Data was generated from verbatim transcription of the semi-structured interviews. Thematic analysis of this data revealed four essential themes and within these themes, several sub-themes that were considered essential to the experience of sexuality and body image.

Findings from this study indicated that access to information and support had a significant effect on how the women coped with the diagnosis and treatment of their vulvar cancer. Some women experienced disruption to some of the more functional aspects of sexual intercourse. It was also evident that intimacy and relationship status were more important to women's sexual

satisfaction than physical arousal. Factors contributing to women experiencing negative emotions were more radical vulvar excision, multiple vulvar procedures and/or the development of lymphoedema. A small number of women never resumed sexual intercourse after treatment and this appears to be related to the absence of a committed sexual partner, and a more radical surgical excision.

This study was only the second Australian study to investigate women’s experience of sexuality and body image, and one of only a few studies to look exclusively at psychosexual issues for women with early stage vulvar cancer. The findings from this study may serve as a relevant platform for the development of future research into the psychosexual outcomes for women diagnosed and treated for vulvar cancer. The findings also relate to the practice of health care professionals working in this area, as they highlight areas that need improvement such as, access to timely and relevant information.

I specify that the substance of this thesis has not already been submitted for any degree and is not currently being submitted for any other degree or qualification.

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Glossary

Radical Vulvectomy: excision of the complete vulvar skin and the subcutaneous tissue

Radical Hemivulvectomy: excision of the vulvar skin and the subcutaneous tissue on one side only

En-bloc Radical Vulvectomy: removing the complete vulvar tissue and groin node dissection in one piece

Radical Local Excision: excision of the tumour with a margin of 1cm both horizontally and vertically

Inguinofemoral Lymphadenectomy: removal of all lymph node bearing fatty tissue between the inguinal ligament, the sartorius muscle and the adductor longus muscle, and dissection of the femoral lymph nodes located in the fossa ovalis medial to the femoral vein

Inguinal Lymphadenectomy: removal of all lymph node bearing fatty tissue between the inguinal ligament, the sartorius muscle, and the adductor longus muscle above the level of the fascia lata.

Vulva Intraepithelial Neoplasia: is a cellular abnormality of the vulva which is confined to the epithelium.

Squamous epithelium: is an epithelium characterised by its most superficial layer consisting of flat, scale-like cells called squamous cell.

Squamous cell hyperplasia: is a common, benign abnormal growth of the skin of the vulva

Lichen sclerosis: is a non neoplastic condition of the vulvar skin of unknown etiology, which causes severe pruritis.

Paget's disease of the vulva: is an uncommon non squamous intraepithelial lesion of the vulva.

Stroma: the supportive framework of an organ or gland, usually composed of connective tissue.

Leukoplakic: a clinical term used to describe patches of keratosis (surface keratin)

Lymphocyst: collection of lymphatic fluid in the area around the groin node dissection

Lymphoedema: accumulation of protein rich fluids in the interstitial spaces of subcutaneous tissue

Sentinel node: is the first node in the lymphatic chain that receives primary lymphatic flow from the suspected lesion

Female genital mutilation: partial or total removal of the external female genitalia, or injury to the female genital organs for cultural or other nontherapeutic purposes

Cystocele: when the bladder bulges or protrudes into the vagina

Rectocele: when the rectum bulges or protrudes into the vagina

Labioplasty: plastic surgery of the labia

Pruritis: itching

Ipsilateral: one sided

List of Abbreviations

WHO	World Health Organization
AIHW	Australian Institute of Health and Welfare
VIN	Vulvar intraepithelial neoplasia
HPV	Human papilloma virus
SEER	Surveillance Epidemiology and End Results
FIGO	International Federation of Gynecology and Obstetrics
LLL	Lower limb lymphoedema
IWHS	The Iowa Women's Health Study
LAW	Longitudinal Assessment of Ageing in Women
SESIAHS	South Eastern Sydney Illawarra Area Health Service

CHAPTER 1

1NTRODUCTION

It is predicted that cancer will be the leading cause of death worldwide in the year 2010, surpassing heart disease. The most frequently occurring cancers among women are breast, lung, stomach, colorectal and cervical cancer. In Australia, breast cancer is the most commonly occurring cancer in women (World Health Organization 2009). In contrast, vulvar cancer is a rare cancer representing 4% of malignancies of the female genital tract, and only 1% of all malignancies in women. In Australia, the current incidence of vulvar cancer is 1.2 per 100,000 females, equating to approximately 250 women diagnosed each year with the disease (Australian Institute of Health and Welfare, 2006). About 90% of these vulvar cancers are squamous cell carcinomas, and much less commonly, melanomas, adenocarcinomas, basal cell carcinomas, and sarcomas (Hacker 2010). Squamous cell carcinoma of the vulva is predominately a disease of post menopausal women, with a mean age at diagnosis of approximately 65 years (Hacker 2010). The number of younger women with the disease appears to be increasing, and this has been associated with an increase in the prevalence of the human papilloma virus infection (Ghurani & Penalver, 2001).

Background

Radical surgery for early stage vulvar cancer has been the preferred treatment for the last 50 years, and has resulted in excellent survival figures, with overall disease free survival rates of approximately 80% (Green et al. 2000; Tjin Asjoe et al. 2008). However, this type of surgery has been associated with high morbidity rates, with wound healing problems and lymphoedema occurring in a significant proportion of patients (Hacker 2005; Ansink, et al. 2006). Subsequently, many women have experienced major disruption to sexual functioning and body image (Andersen & Hacker 1983) and also to limitations in social activities (Ryan et al. 2003).

Over the last two decades a significant advance in the management of vulvar cancer has been the individualisation of treatment for all women. The primary treatment remains surgical, but modifications have led to less mutilating surgery, decreasing morbidity without compromising survival (Ghurani & Penalver 2001; Ansink, et al. 2006). Increasing awareness of the psychosexual consequences of radical vulvectomy, and the increasing incidence of the disease occurring in younger women who presented with smaller tumours, have been contributing factors leading to these modifications (Hacker 2005).

Rationale and Implications for Clinical Care

Many women have expressed dissatisfaction with the provision of information both before, and after treatment for vulvar cancer, particularly in relation to the sexual outcomes of treatment (Andersen & Hacker 1983; Andreasson et al. 1986; Andersen et al. 1988; Green et al. 2000). Stead (2004) contended that as sexual dysfunction was the primary source of symptom induced distress following treatment for gynaecological cancer, then every effort should be made to communicate with these women and their partners about sexual function before problems develop. She also highlighted the need to understand the individual woman's own thoughts and feelings towards sexual activity.

Nurses and doctors are reluctant to discuss sexual issues with women, and this has been attributed to not only a lack of knowledge about sexuality, but also the lack of understanding of the sexual activities of older women, and the subsequent fear of causing offence (Burke 1996). In the past, health care professionals have generally focused solely on the medical aspects of cancer, often not addressing the psychosexual aspects of treatment (Lagana et al. 2005). All women treated for vulvar cancer need to be informed of the potential sexual implications of their disease and treatment (Hughes & Handscomb 2001). The promotion of sexual health for women treated for gynaecological cancer is essential for preserving quality of life, and should be an integral part of holistic nursing cancer care (Bruner & Boyd 1999). The specialist gynaecological oncology nurse is uniquely placed to provide this information and offer guidance and counselling for these women (Allen 2003). In order for nurses to provide this care, research that is meaningful to women, as well as the profession, is needed to further develop educational interventions to promote sexual health and coping (Bruner & Boyd 1999). Despite the potential for significant adverse psychosexual consequences, there is very little documented data on sexual function following treatment for vulvar cancer (Wilmoth & Spinelli 2000).

Following treatment for vulvar cancer, women find the experience of sexuality and body image is highly individual, and personal. Lawler (1998) argued that nurses have a limited capacity to help patients if they are not aware of the meanings patients attach to events that disrupt their lives. Because women's perception of themselves and feelings of sexuality are at the centre of the present study, qualitative investigation of this topic will provide an exploration of the unique human experience, not possible with a quantitative approach (Osborne 1994).The literature identifies the distinct lack of qualitative investigation into this topic, resulting in limited insight into the subjective experience of sexuality, and body image following treatment for vulvar cancer. This study seeks to contribute to the limited body of knowledge available describing the psychosexual outcomes for women, following treatment for early stage vulvar cancer. The common experiences, and also atypical responses that are generated by a qualitative study will allow for a greater understanding of phenomena, not previously articulated, thereby adding to nursing knowledge.

Evolution of the Research Topic

As a Clinical Nurse Specialist in a gynaecological cancer centre, my role is to coordinate the care of women requiring surgery for a gynaecological cancer. Over time this position has evolved to encompass a broad range of responsibilities, including screening and assessment of patient needs, advocating for patients and their carers, and coordinating care to link care providers and patients. A significant component of this role is to provide both information and support to these women, beginning at diagnosis and continuing through their cancer journey.

Treatment for vulvar cancer has evolved to become highly individualised. The emphasis now is on the most conservative surgery consistent with cure of the cancer (Hacker 2010). For this reason I have at times been impressed by the very conservative nature of the vulvar excision. For some women, their wounds heal to reveal only minimal tissue deficit. Certainly, some women have described to me that their excision, once healed has little impact on their lives. However, other women experience continued psychological distress associated with their treatment for early stage vulvar cancer. One of the challenges in providing support to these women is the time that is needed to adequately address these issues. A busy outpatient setting is not always conducive to eliciting these patient's concerns, most particularly regarding their psychosexual issues. Often when these women are questioned about sexuality they can appear to be dismissive, disinterested, or unwilling to discuss the topic. It is difficult to determine if they are uncomfortable with the topic of sexuality being raised, or simply have no issues around this topic. Likewise, I am also unsure if the information, counselling and support we have provided these women is relevant to their needs.

Therefore, the decision to explore the experience of sexuality and body image, developed initially from a desire to write an information brochure for these women, covering such topics as: post operative discomfort, wound healing, and potential sexual implications of treatment for vulvar cancer. While investigating the literature it became apparent that there was a paucity of information describing the psychosexual outcomes for these women. Most particularly there was a distinct lack of qualitative investigation of this topic, limiting deeper understanding of these women's individual subjective experience. This literature provides a limited description of these women's feelings of the experience, and the challenges they face. Additionally, much of the previous research conducted to elicit the psychosexual outcomes of treatment for vulvar cancer, have been on women having had a more radical surgical approach than many of the women treated in our centre.

The aim in conducting this study was to provide a deeper understanding of the experience as it was for each of these women treated for early stage vulvar cancer. The research question focused on the experiences of women with an early stage vulvar cancer. Specifically, what is the experience of sexuality and body image for women following treatment for early stage vulvar cancer, and what meaning and importance do women attach to these experiences?

Organisation of the Thesis

This thesis has been organised into five chapters. In the first chapter, the topic of sexuality, body image and early stage vulvar cancer is introduced. The background to this research topic, the evolution of the study and the objectives of the study have also been described.

Chapter 2 will present the review of the literature relevant to the topic of sexuality and body image following surgery for vulvar cancer. This includes a review of the clinical literature, related to biomedical information and the current management of vulvar cancer. Also described in this chapter is a broad description of the literature related to female sexuality and body image through the adult life span. This is then followed by a discussion of previous research that has focused on the psychosexual implications of treatment for vulvar cancer. An overview of the literature related to the provision of information and support following the diagnosis of vulvar cancer is also provided in this chapter. In the final section of the literature review, the role of the specialist cancer nurse is discussed.

Chapter 3 describes the methodology used in the research project. The rationale for using phenomenology as the philosophical context for this qualitative research project is explained. A brief comparison of qualitative and quantitative research techniques is provided. The process of sample selection and participant recruitment is then outlined. A description of the participants is also included in this chapter. Following this, the data collection, and the techniques used to analyse the data, are described. Strategies related to ethical considerations and participant's protection have been identified. Finally, the techniques utilised to ensure the rigour of this research project are outlined.

Chapter 4 presents the findings of the study. The analysis of the data elicited four essential themes that described the structure of the experience of the women, and within these essential themes, several sub-themes were identified. Together these themes illuminate the experience of sexuality and body image following treatment for early stage vulvar cancer. Each of the key themes and the related sub-themes are described in this chapter. Also in this chapter the participants own words are used to add meaning and depth to the discussion.

Chapter 5, the final chapter of this thesis, presents a discussion of the study findings in relation to the literature relevant to the four essential themes identified. Comparisons are made between the results from this study and those described in the literature. Implications for future nursing practice are then identified. Finally, the limitations of the study are acknowledged and recommendations for future research made.

CHAPTER 2

LITERATURE REVIEW

Introduction

In this chapter the literature considered relevant to the topic of sexuality and body image following surgery for vulvar cancer is reviewed. The literature review has been categorised into four main areas: biomedical information related to vulvar cancer and a description of the current management of vulvar cancer; a broad description of the literature related to sexuality and body image through the adult female life span; a more detailed focus of the literature on the psychosexual implications of treatment for vulvar cancer; and an overview of the literature related to the provision of information and support following the diagnosis of vulvar cancer.

The literature search revealed only twelve studies specifically investigating sexuality and body image following treatment for vulvar cancer. The majority of the research on the psychosexual outcomes following treatment of vulvar cancer originated from the United States, the United Kingdom and Scandinavia. Only one of these 12 studies examined the experiences of Australian women. Additionally, several of these studies were conducted on women who had been treated many years prior to the introduction of the more modified surgical approach to treatment, or in countries where surgeons still perform radical surgery to remove small vulvar cancers.

Literature Search Strategy

The strategies to identify literature included searches throughout the following computerised databases: Clinical Information Access System

(CIAP), this provided access to Cochrane Library (providing access to Cochrane reviews), MEDLINE, PubMed, EMBASE, PsycINFO and CINAHL. ProQuest provided access to multiple other databases. Online journals were accessed through The University of New South Wales, The University of New England and the South Eastern Sydney Illawarra Area Health Service (SESIAHS) electronic journal collection. Masters thesis and doctoral dissertations were accessed, online through Pro Quest, and through personal communication with authors. Electronic sources, particularly for epidemiological statistics, were searched through the Internet, to links with the World Health Organization (WHO) and the Australian Institute of Health and Welfare (AIHW).

Reference lists of relevant articles and reference books were searched manually to source other relevant literature. All literature searches were restricted to English language articles. The original search period was confined to articles published from 1980 to March 2009. Following data analysis another literature search was conducted up until November 2009. Finally, another electronic literature search was conducted to cover the time period up to February 2010 to determine if any new information had been published. The literature search was built around four main categories:

- Sexuality and body image in the general female population, and in the older woman.
- Identification of studies pertaining to sexuality and body image for women treated for a gynaecological cancer, most specifically those concerned with the effects of the treatment of vulvar cancer on all aspects of sexuality and body image.
- Information and support care needs following treatment for cancer, including the role of support groups.
- Information pertaining to the research methodology and data analysis.

A broad definition of terms was used when searching for literature on sexuality, body image and vulvar cancer. Some of the key terms used for the search included; ‘body image and cancer’, ‘sexuality and cancer’, ‘sexuality and vulvar cancer’, ‘sexuality and gynaecological cancer’, ‘sexuality and vulvar neoplasms’, ‘body image and cancer’, ‘intimacy and cancer’, ‘sexual response and cancer’. A number of other search terms were used to broaden the literature search and to adequately cover the topic being investigated, these were: ‘sexuality and the older adult’, ‘women and ageing’, ‘cancer and older adult’, ‘body image and older women’, ‘intimacy and cancer’, ‘self image and women’, ‘body image and labial reduction surgery’.

Following data analysis another literature search was conducted to review the literature specific to issues identified as relevant to the lived experience, which had not been covered in the earlier literature review. These issues related to the unmet information and supportive care needs of women following treatment for vulvar cancer. In this instance the key terms used were: ‘information and cancer’, ‘gynaecological cancer and information’, ‘sexual counselling’, ‘support groups and cancer’, ‘unmet needs and vulvar cancer’, ‘supportive care and gynaecological cancer’.

Some of the key words and terms used for the search on research methodology included: ‘qualitative research’, ‘qualitative methods’ ‘phenomenology’, ‘interpretive phenomenology’ ‘qualitative research and nursing’ ‘interviews and qualitative research’, ‘rigour’, ‘trustworthiness’. These search terms and words were used either alone, or in combination with one another.

Section 2.1: Biomedical Information Related to Vulvar Cancer and the Current Management of Vulvar Cancer

In order to understand the topic being discussed it was necessary to first identify the anatomy of the vulva, describe the biomedical aspects of early stage vulvar cancer, and establish an understanding of the current management of this disease. An overview of the long-term physical implications of the treatment for early stage vulvar cancer is also provided in the following section.

Anatomy of the External Female Genitalia

In females the external genitalia are referred to collectively as the vulva. The vulva includes the vulvar vestibule, the clitoris, the labia majora (or labium majus), labia minora (or labium minus) and the mons pubis (or mons veneris). The labia majora are the most prominent features of the the vulva, and contain sebaceous glands and subcutaneous fat. The labia minora lie medially, and contain sebaceous glands and nerves. The labia minora can vary in size from scarcely visible structures to 'leaf-like' flaps, up to 3cm in length (Gambone 2010:23). The labia majora and labia minora provide a split covering for the entrances to the vagina and urethra. The vestibule is the inner area of the labia minora around the opening to the vagina. The clitoris is located beneath the point where the labia minora meet. These vulvar structures are covered by squamous epithelium (Hughes & Handscomb 2001:249).

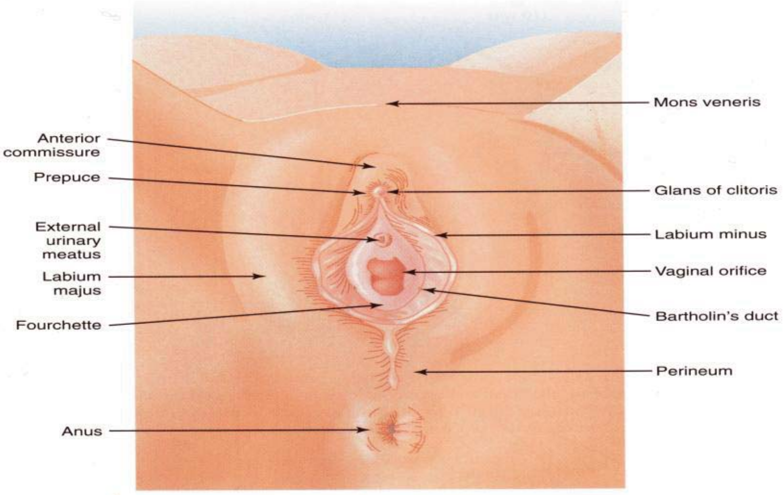

Figure 2.1 Diagram depicting the structures of the vulva
(Reproduced from Gambone GC. Female reproductive anatomy and embryology. In: Hacker NF, Gambone GC. Essentials of obstetrics and gynecology, 5th ed. Elsevier Saunders, 2010, with permission of N.F Hacker).

The Aetiology of Vulvar Cancer

It has been suggested that there are at least two different subtypes of squamous vulvar cancer. The more common, seen in elderly women, arises in a background of lichen sclerosis[1] and/or squamous cell hyperplasia. This subtype is usually unrelated to a history of tobacco smoking and human papilloma virus infection (HPV). The less common type, presenting mainly in younger patients, is related to HPV and smoking and is often associated with basaloid or warty VIN (Vulvar intraepithelial neoplasia) (Jones, Baranyai & Stables 1997:448; Stehman & Look 2006:720).

In recent decades there has been an increased incidence of VIN and VIN related vulvar cancer in young women. This has been attributed to a number of behavioural risk factors such as smoking, early age of sexual intercourse, multiple sexual partners, and the increase in the incidence of HPV infection (Hacker 2010:536). It has also been determined that venereal warts, a history of abnormal cervical cytology, chronic immunosuppression, hypertension, diabetes and obesity were also associated with an increased risk of vulvar cancer (Brinton et al. 1990:859; Ghurani & Penalver 2001:250). Syphilis and nonleutic granulomatous venereal disease are also occasionally associated with vulvar cancer, but are uncommon in Western countries (Hacker 2010:538).

Although the role of HPV in the development of vulvar cancer is not fully understood, HPV DNA has been reported in 20%-60% of patients with invasive vulvar cancer (Hacker 2010:537). HPV types 6, 16 and 18 have been detected in vulval intraepithelial neoplasia (VIN), a premalignant condition of the vulva, and in invasive cancer (Hildesheim et al. 1997; Hughes & Handscomb 2001). A recent review of 13,176 in situ and invasive vulvar carcinomas from the Surveillance Epidemiology and End Results (SEER)

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[1] Lichen Sclerosis is a non neoplastic condition of the vulvar skin of unknown aetiology, which causes severe pruritis.

database of the period 1973–2000, identified a 411% increase in the incidence of insitu carcinoma, while the incidence of invasive vulvar carcinoma increased 20% during this time (Judson et al. 2006). It is anticipated that the recent implementation of prophylactic HPV vaccination for young females will result in a significant decrease in the incidence of HPV related in situ and invasive vulvar cancer in younger women in the future (Hacker 2010:536).

Vulvar Intraepithelial Neoplasia (VIN) is a cellular abnormality of the vulva which is confined to the epithelium. VIN has generally been considered to have a low malignant potential. However, in 2005 Jones, Rowan and Stewart reported a series of 405 cases of VIN 2-3 seen over a 40 year period in Auckland, New Zealand. The authors found that 10 of 16 (62.5%) women with persistent untreated VIN had progressed to vulvar cancer. The treatment of this preinvasive condition is aimed at control of symptoms and prevention of progression to invasive cancer. As in vulvar cancer, the therapeutic approach is individualised to each woman (Campion 2010).

Vulvar cancer is generally a slow growing condition which presents as a localised lesion that maintains well defined margins (Hughes & Handscomb 2001). Most women will present with a vulvar lump or lesion, often reporting a long history of pruritis (itching). The vulvar lesion is usually raised and may be ‘fleshy, ulcerated, leukoplakic, or warty in appearance’ (Hacker 2005:546). Other less common presenting symptoms are pain, bleeding, ulceration, dysuria, and vaginal discharge (Ghurani & Penalver 2001:294; Hacker 2005:546). Squamous cell carcinoma of the vulva occurs most often on the labia majora, but the labia minora, clitoris, and perineum are other common primary sites. However, a recent German study identified that the most common vulvar tumour presentation had changed from the labia, to the area between the clitoris and the urethra (Hampl et al. 2008). In about 10% of vulvar cancers the lesion is too extensive to determine a site of origin (Hacker 2010:541).

An important aspect of vulvar cancer is the delay of the patient to seek medical treatment, and this can often be due to women dismissing their vulvar symptoms, embarrassment, fear or the lack of access to medical care (Hall 2002:117). In general, vulvar symptoms prompt the younger patient to present early, unlike elderly women, where there is often a delay in presentation (Barton 2003:684). Likewise, it is not uncommon for physicians to delay diagnosing vulvar cancer, due to prolonged treatment of lesions presumed to be benign. This is most common when the lesion has a warty type appearance (Hacker 2010:541). In the obese or debilitated patient it may be difficult to perform a thorough examination and vulvar lesions may go undetected (Barton 2003:684). Diagnosis for vulvar cancer can only be made on histological examination of biopsied tissue, and this can generally be done under local anaesthetic in an outpatient setting (Hacker 2010:541).

Current Management of Early Stage Vulvar Cancer

Modern management of vulvar cancer necessitates an experienced, multidisciplinary team approach, which is available only in tertiary referral centres. Surgery continues to be the main form of treatment for cancer of the vulva, but has been increasingly tailored to the individual. There is no 'standard' operation, applicable to women with carcinoma confined to the vulva, and emphasis is on the most conservative surgery consistent with cure of the cancer (Hacker 2010:546). Generally, two factors are taken into account when planning management: the patient's age, and the condition of the remainder of the vulva. Radical local excision has now replaced radical vulvectomy for women with unilateral (one sided) vulvar tumours, and an otherwise normal vulva. For those women whose vulvar cancer arises in a background of VIN or another epithelial abnormality, treatment is influenced by their age. For an elderly woman who has been troubled by many years of chronic itching, a radical vulvectomy is not as disturbing a prospect as it is for a younger woman. In these instances, for younger women it is desirable to conserve as much of the vulva as possible. Therefore, radical local excision is suggested for the invasive disease, and the associated disease treated in a more conservative manner, such as; topical steroids for lichen sclerosis or squamous hyperplasia. VIN should be treated by superficial local excision (Hacker 2010:546). Radical local excision involves a wide and deep excision of the primary tumour maintaining a 1cm clear surgical margin. Radical vulvectomy involves the dissection of the tumour, contiguous skin, subcutaneous fat, and the vulva.

The experience of women treated for early stage vulvar cancer at the Royal Hospital for Women in Sydney, has recently been reported. There were 339 patients with invasive vulvar cancer treated in the department from 1987 to 2005, 121 of these for early stage vulvar cancer. 116 (96.5%) of these women were treated with a radical local excision, only 5 women underwent a radical vulvectomy, in all cases for multifocal disease (Tantipalakorn et al. 2009).

The status of the lymph nodes is the most important prognostic factor for survival in vulvar cancer (Gori et al. 2002:152), and appropriate management of the lymph nodes is paramount in reducing mortality (Hacker 2005:556). Women with negative nodes (as in early vulvar cancer) have a 5 year survival of about 90%, however for those patients with positive nodes, 5 year survival decreases significantly (Hyde et al. 2007). All women whose tumour invades the stroma to a depth greater than 1mm require inguinofemoral lymphadenectomy (excision of the inguinal and femoral lymph nodes). However, it is not now considered necessary to perform bilateral groin node dissection if the lesion is confined to one side, except in the case of tumours involving the anterior labia minora (Hacker 2005:556).

Elimination of routine pelvic lymphadenectomy for those patients, whose tumour invades the stroma to a depth no greater than 1mm, is now considered a safe option with no compromise to survival (Hacker 2005:552).

The omission of the groin dissection for women with stage 1 tumours, and only minimal invasion, and the elimination of routine pelvic lymph node excision for selected patients have contributed significantly to decreased post operative morbidity (Lin et al. 1991:80). The use of separate groin incisions over the inguinal ligaments, instead of the en bloc method of vulvectomy, and unilateral (one sided) groin dissection in suitable patients, in an attempt to decrease both acute and chronic morbidity are now widely practiced (Ghurani et al. 2001:295; Hacker 2005:556; Stehman et al. 2006:722).

Long Term Implications of Removal of the Lymph Nodes

The excellent survival figures for women following treatment for early stage vulvar cancer yield a population of survivors who will continue to live with the long term consequences of the disease and its treatment. Although the innovations to the surgical techniques for vulvar cancer have resulted in decreased morbidity, the surgical removal of the lymph nodes still account for the most significant postoperative and long term complications. Lower limb lymphoedema (LLL) is a chronic condition that occurs following lymph node removal, as the lymphatic system is unable to maintain tissue fluid homeostasis, resulting in an accumulation of protein rich fluids in the interstitial spaces of subcutaneous tissue (Hacker 2005:562). This accumulation of fluid leads to leg oedema, which distorts the size and shape of the affected limb and can impair function (Ryan et al. 2003; Hacker 2005). Initial presentation of LLL is the patient reporting a limb heaviness or fullness, generally associated with discomfort (Lockwood-Rayermann 2007). Additionally, patients can present complaining of tightness in the affected limb and mobility and gait disturbances (Langbecker & Newman 2008). If left untreated the affected limb can become heavy and large, with resultant loss of skin elasticity (Lockwood-Rayermann 2007).

The reported incidence of LLL for women following groin dissection varies from, 30% to 59% (Ryan et al. 2003; Rouzier et al. 2005). In 2004, a cross-sectional survey of 802 Australian gynaecological cancer survivors was conducted to determine the incidence of LLL. The authors identified that LLL was more prevalent (36%), amongst vulvar cancer survivors (Beesley et al. 2007). Results from this study also confirmed those previously reported by Ryan et al. (2003), with both studies determining that most lymphoedema developed within the first year after cancer treatment. Other studies have shown LLL to occur anytime from days to years after nodal dissection (Abang et al. 1999; Lockwood-Rayermann 2007).

Figure 2.2 Example of bilateral lower limb lymphoedema
(Photo courtesy of Prof NF Hacker)

Ryan and colleagues (2003:418) described the current treatment for LLL involved massage, bandaging and the wearing of correctly fitted compression garments. They found in their study to determine the prevalence and incidence of LLL following treatment for gynaecological cancer that 27% of women experienced a significant financial burden associated with the cost of treating lymphoedema. In this study, 51% of women had altered their everyday activities because of swollen legs, and 79%, identified having to make major changes to their wardrobe to disguise the appearance of swollen legs. From these results the authors determined that LLL was not only associated with high cost but can lead to major changes to body image and self esteem for those women affected.

In 2004, Janda et al. while attempting to develop a vulvar cancer specific quality of life sub scale, found in their cohort of women treated for vulvar cancer that LLL was the most frequently reported symptom, negatively influencing several aspects of quality of life. Likewise, Farrell (2009) in her recent study of 60 women treated for vulvar cancer found the effect of complete lymphadenectomy on quality of life was a negative one in 37% of the women (R. Farrell 2009 pers. comm., 2nd February). Similar findings have been reported following studies of breast cancer survivors who develop lymphoedema of the upper extremity. These women have also been shown to experience anxiety and adjustment problems related to their lymphoedema (Lockwood-Rayermann 2007). The Iowa Women's Health Study (IWHS) collected data on 1,287 women with breast cancer. One of the key findings from this study was that for breast cancer survivors with arm lymphoedema, health related quality of life was lower than for breast cancer survivors who had not developed lymphoedema (Ahmed et al. 2008).

It is important to note that there are attempts being made to spare these women the complications of the full groin node dissection, through sentinel node detection. The sentinel node is the first node in the lymphatic chain that receives primary lymphatic flow from the suspected lesion (Ghurani & Penalver 2001). The technique to identify the sentinel node involves the injection of a blue dye and /or a radioactive colloid into the primary tumour, with the subsequent identification of a "blue" node, this node is then surgically removed to determine if metastases are present. If the sentinel or "blue" node is positive for metastases then a complete dissection is undertaken. If the sentinel node is negative then all the other lymph nodes are left intact (Stehman & Look 2006:724). The rationale for this being, if the sentinel node was negative, all other nodes will be negative (Hacker 2005:556).

However, this sentinel node procedure is associated with a certain false negative rate, which could ultimately lead to a worse prognosis in a small subset of women (Hacker 2010:554). In this regard, de Hulla et al. (2001) conducted a study of women who had previously undergone a radical vulvectomy and bilateral groin node excision, and the gynaecologists treating these women. The participants were questioned regarding their preference for sentinel node biopsy, or complete lymphadenectomy, if there was a 5% false negative rate. The authors found that 60% of the 106 women who were questioned preferred the 'safer' option of a complete lymphadenectomy, although 49% of these women had reported experiencing severe pain and/or lymphoedema in the legs. Interestingly, 60% of gynaecologists were willing to accept a 5-20% false-negative rate for the sentinel node procedure. The authors concluded that although gynaecologists may consider this a promising approach the majority of women with vulvar cancer would not take any risks which might compromise their survival.

Long Term Implications of the Surgical Excision of Vulvar Tissue

Women treated for vulvar cancer have to contend with not only a diagnosis of cancer, but surgery which can involve the removal of substantial sections of the external genitalia including, the labia majora and labia minora, removal of the clitoris and the excision of, or trauma to surrounding tissues, adversely affecting sexual function and body image (Green et al. 2000; Robertson 2005:294). Many women experience embarrassment and despair when diagnosed and treated for cancer in such an intimate area (Robertson, 2005:295). For some women alterations to her urinary stream may cause distress or embarrassment. Additionally, the loss of vulvar tissue, and or groin swelling, may require some women to wear loose fitting underwear or clothing, negatively affecting their body image (Mellon 2009:10). The physical consequences of partial or radical vulvectomy can lead to stenosis (narrowing) of the vaginal introitus (entrance) and long term genital numbness, resulting in decreased perception of sexual arousal, and reduced tissue cushioning over the pubis and/or the perineum (Jensen 2007; Weijmar Schultz et al. 1991). Fertility is not usually an issue for this group of women as the surgery leaves the vagina, uterus and ovaries intact, and more commonly it is a disease of post menopausal women (Hughes & Handscomb 2001:256).

Decreased pelvic and genital sensitivity, pain, embarrassment, or even shame can certainly compromise any or all phases of the sexual response cycle for women following treatment for vulvar cancer (Wilmoth & Spinelli, 2000; Sheppard & Whiteley 2006). In order to provide a clear understanding of the psychosexual changes that can take place, it is essential to understand sexuality and female sexual response. A discussion of sexuality and body image is provided in the following section.

Section 2.2: Sexuality and Body Image in Women across the Adult Life Span

The following section provides a review of the literature relevant to sexuality and body image for women in the general population. Considering that the predominance of vulvar cancers occur in post menopausal women, the literature on sexuality and the older adult woman is also reviewed.

Sexuality

The World Health Organization (WHO) identifies sexuality as an integral component of the human experience (WHO 2010:1). Sexuality encompasses all that we are as male or female and is expressed through our thoughts, dress, roles, relationships, and values (Wilmoth 2006:905). Sexuality incorporates all aspects of sexual activity including fantasy, kissing, touching, hugging, masturbation, oral genital stimulation and intercourse. However, sexuality is more than the ability to have sexual intercourse. To many women sexuality includes feelings about their body appearance and femininity, their ability to bear children and to function sexually. A woman's age, past experiences and cultural influences will all impact on sexuality (Tierney

2008:72). Likewise, sexuality changes over time, and for women with cancer it is as complex and varied as it is for those without cancer (Pelusi 2006:32).

> "Sexuality is influenced by the interaction of biological, psychological, social, economic, political, cultural, ethical, legal, historical and religious and spiritual factors" (WHO 2010:1).

In conjunction with the psychological, emotional and social factors that determine a woman's sexuality there are also distinct physiologic changes that occur in sexual response. These physiologic changes are mediated by the central nervous and limbic system. During sexual arousal, which includes the subjective experience of excitement, vasocongestion of the genitalia occurs in response to increased blood flow. As a consequence of several processes, vaginal lubrication occurs and relaxation of smooth muscle causes the vagina to lengthen and dilate (Tierney 2008:72; Woodard & Diamond 2009:19). This increased blood flow to the genitalia causes the clitoris to protrude, and the labia minora to evert and become engorged. Orgasm is an intense period of rhythmic muscular contractions occurring in the vagina, uterus and anus (Woodard & Diamond 2009:19).

It is evident from the literature that most of the research conducted into sexuality focuses on genital or functional sexuality. To understand the effects of cancer treatment on sexuality, it must be considered in its broader context, not only as sexual activity (Tierney 2008:71). Women differ in regard to men by what they find pleasurable about sex. For some women, the desire for sexual pleasure and orgasm is important other women are motivated by the desire for intimacy, or a sense of connectedness (Bancroft 2007:821). Likewise, some women report minimal sexual libido, or desire, and others experience desire, only when they are sexually aroused. There are also women who never experience orgasm, with or without intercourse, but still enjoy sexual activity (Howard et al. 2006:356). A study to assess the prevalence of distress about sexuality among heterosexual women reported the more important determinants of sexual distress for women were; lack of emotional well being, and experiencing negative emotions during sexual interactions, rather than any impairment to the physiological aspects of the female sexual response cycle (Bancroft, Loftus & Long 2003).

Body Image

Body image is an important component of sexuality and includes a person's perception of, and satisfaction with, physical appearance and bodily function, including how we think others see us (Reboussin et al. 2000:239; Krebs 2006:313). Body image may be altered not only by visible physical changes but also by changes not visible to others (Krebs 2006:313). Body image is developed in childhood and although intensely personal, is tied to our relationship with others. It is reinforced by societal attitudes, values and the media (Sundquist 2007). It is generally believed that women are 'objectified' more than men; their bodies are more frequently assessed, evaluated, and 'sexualized' (Wiederman & Hurst 1998:272). More worth is placed on the way women look than any other aspect. In Western culture the collective understanding of female beauty, (that which is most often portrayed by the media) is closely defined as: white, glossy skinned, fit and strong, and most importantly, young and thin (Davis 2000:36). This objectification of women's bodies has caused some women to have a heightened awareness of how their body appears to others, most particularly to men. Women's sexual desirability is often compared to physical attractiveness and thinness. Indeed women's own body dissatisfaction is generally measured according to their perception of being too fat or having body parts too big or too small (Wiederman 2000:60). This concern about body image can impact on sexual function and satisfaction (Sanchez & Kiefer 2007:808).

Perceptions of Body Image and its Relevance to Sexuality

In recent years body dissatisfaction for some women has evolved to include the physical appearance of their genitalia. Women and their sexual partners are progressively more exposed to an 'idealised' image of the female genitalia leading to an increased demand by women for cosmetic surgery to their genitalia, most particularly, labial reduction surgery (Lloyd et al. 2005:643). Historically, this type of surgery was restricted to women with ambiguous genitalia, vulvar cancer, vulvar intraepithelial neoplasia and Paget's disease of the vulva (Likes et al. 2008:210). In Australia, over the last 15 years there has been a 5 fold increase in women, across all ages undergoing labioplasties. It is unclear whether this is driven by medical need or aesthetics, however it has been suggested that it is likely to be the latter (Grover 2009:615).

The amount of genital tissue that is removed in aesthetic labial surgery is similar to the amount of tissue removed in the treatment of vulvar cancer, or preinvasive conditions of the vulva, and in types 1 and 2 female genital mutilation, (Liao, Michala & Creighton 2010:23). Female genital mutilation is the 'partial or total removal of the external female genitalia, and injury to the female genital organs for cultural or other nontherapeutic purposes' (Ibeanu & Giuntoli 2009:1). However, cosmetic surgery on the female genitalia has not been viewed as negatively, and this has been attributed to it being voluntary, and performed by licensed practitioners (Liao, Michala & Creighton 2010:20). Liao et al. (2010:23) proposed that the idea of patient autonomy that makes cosmetic labial surgery acceptable, should consider the perspective from which these women are making their decisions.

There is no such thing as 'normal' genitalia but embedded in the desire to alter the genitalia is a belief for some women that their labia are abnormally large or asymmetrical (Likes et al. 2008:213). In a Spanish study of 15 women who sought reduction of their labia minora for psychological reasons, one of the most commonly cited reasons for doing so derived from a woman hearing jokes made at her expense, usually by her partner, during oral sex. Understandably this resulted in a lack of self confidence, lower self esteem and lower sexual libido for these women (Giraldo, Gonzalez & de Haro 2004).

Bramwell, Morland and Garden (2007), in an attempt to understand women's reasons for undergoing labial reduction surgery, conducted a qualitative study of six British women who had undergone this procedure. They found the women believed their genital appearance before surgery was 'odd' or made them look like 'freaks' (p. 1495). None of the women studied could describe normal female genitalia but were confident theirs were abnormal, and they strived for 'normality' (p. 1495). For those women in this study who were sexually active, a common theme was the impact their dislike of their genitalia had on their sex lives. The expectation that this surgery would enhance their sex lives was not achieved for all participants; however, some of the women described improvements in self confidence, which positively impacted on their sexual experiences.

In a study designed to test whether body shame was related to sexual problems and pleasure among heterosexual men and women, Sanchez and Kiefer (2007) found body shame was directly related to greater sexual self consciousness, this in turn predicted lower sexual pleasure and arousability. Likewise, in an American study to determine young women's body image self consciousness during physical intimacy with a partner, 35% of 198 college women, experienced body image self consciousness during physical intimacy. Also of note in this study was the relationship of higher sexual esteem to the participant's subjective view of their own attractiveness (Wiederman 2000). However, Reboussin et al. (2000) found no such association in their study to correlate satisfaction with body appearance in middle aged and older adults. They reported body function and cardiorespiratory fitness were the factors directly related to women's satisfaction with their body appearance. In this study, older age was more positively related to measures of body satisfaction, the authors concluding from this, and previous reported data, that somewhere in the mid 50's, the attitude to one's body begin to improve, and that older adults may value body function, more than appearance. Similarly, Kingsberg (2000:33) in her paper discussing the psychological impact of ageing, on sexuality and relationships, hypothesised that ageing allows for experience that leads to learning, and maturity, which in turn changed attitudes, identity and values. This author argued that women who perceived the physical signs of ageing as unattractive will ultimately develop a poor body image. Alternatively, women who perceived ageing as reflective of maturity and self confidence may experience increased feelings of desirability and sexual desire (p. 36).

Nobre and Gouveia (2006), while investigating the sexual beliefs of men and women with sexual dysfunction, found a distinctive characteristic of sexually dysfunctional women was the importance they attributed to body appearance as a central factor to sexual success and satisfaction. An example of this was the comment made by some women, "Women who are not physically attractive can't be sexually satisfied". Women in this study also endorsed the belief that ageing, particularly after menopause, implied decreased desire and sexual pleasure (p. 74).

In a similar theme, Ackard, Kearney-Cooke and Peterson (2000) conducted a survey to investigate the relationship between self image, body image, and frequency and type of sexual activity in 3,627 Canadian women. Women ranging in age from 14-74 years responded to the survey titled 'Does your body image affect your love life', 60% of these women reported dissatisfaction with their appearance. The authors predicted, and found that the 40% of women who were satisfied with their body image, reported initiating sexual intercourse more often, having more frequent sex, faking orgasm less often, were more comfortable to undress in front of their partner, and to have sex with the lights on, compared to those women dissatisfied with their body image. No reference was made by the authors to any age differences in the above responses across the survey group (p. 425).

Sexuality, Body Image and the Older Woman

Despite the ageing of the population there is limited information on sexuality in older adults, most particularly in older adult cancer survivors. Equally, for older adults, sexuality and body image concerns are often overlooked. To assume that older adults are unconcerned about sexual attractiveness and appearance is almost always incorrect (Kagan, Holland & Chalian 2008). Society views the young and beautiful as sexual and older adults are often seen as incongruent to this stereotype (Bauer 1999:37). However, sexual response has been said to decrease in older women due to diminished sexual hormone production. This can lead to a lessening of libido, delay in arousal response rates, and a decrease in intensity of sensation and orgasm (Masters & Johnston 1980). For post menopausal women the continued decrease in oestrogen results in atrophy of oestrogen dependent tissues such as the uterus, ovaries and the vagina. The vagina can become less elastic and drier. During sexual arousal, older women experience a slower onset of vaginal lubrication than younger women. In addition, the vaginal and vulval mucosa thins, contributing to the reduction in lubricating secretions (Laufer & Gambone 2004). However, the assessment of these post menopausal physiological changes as the primary influence determining women's desire for sexual activity, neglects the importance of emotional and intimacy issues for women (Juraskova 2003).

Lindau et al. (2007) have provided the most recent report on the sexual behaviour of older adults. The authors surveyed a random sample of 3,005 older American adults, aged from 57-85 years, on their levels of sexual activity. They found that sexual activity declined with advancing age and illness. Women were less sexually active than men; however, some women maintained sexual and intimate relationships throughout their lives. The most common sexual problems reported by this group of women were decreased desire and vaginal dryness. Women were also more likely to lose their sexual partner as they aged and these women were unlikely to be sexually active. Surprisingly, only 22% of the female participants in this study reported having discussed sex or sexual issues with a doctor since age 50.

Similar results were reported by the authors of the Longitudinal Assessment of Ageing in Women (LAW) study. This study investigated the sexual behaviour of 474 older urban Australian women and found that older women participated in a wide range of sexual activities. The loss of a woman's partner or the loss of the partners' ability to have sexual intercourse had an inevitable impact on sexual function for women. In this study, 83% of women in the 40-49 year age group had a sexual partner, this percentage dropped to 46% of women in the 70-79 year age group, with only 27% of these older women identifying having a partner able to have sexual intercourse. Interestingly, for all women in this study there were no significant differences in sexual distress scores between women whose partners were unable to have sexual intercourse, and women who had able partners. Despite older women reporting decreased sexual activity, and decreased sexual interest compared to younger women, they experienced less distress about sex than younger women. From these results the authors concluded that decreased sexual activity for ageing women may be viewed either, as a sexual dysfunction or attributed to the biological changes of the ageing process. Alternatively, they suggested it may simply be the result of women responding to their changed circumstances (Howard, O'Neill & Travers 2006). Another Australian study, The Melbourne Women's Midlife Health Project, is a longitudinal population based study of 336 women, examining the effects of hormonal and relationship factors on sexual function during natural menopausal transition. The results of this study indicated that previous sexual function and the status of the relationship were the most important predictors of levels of sexual response in these women (Dennerstein, Lehert & Burger 2005).

In an earlier population based study of a cohort of 2,109 American women, with a mean age of 56 years, Addis et al. (2006) identified demographic characteristics, as strongly predictive of sexual activity, sexual frequency, sexual satisfaction and dysfunction. The analysis examined middle aged and older women for correlates to sexual function, and found that younger age, higher education/income, being in a significant relationship, and consuming a moderate alcohol intake, all correlated positively with more frequent sexual activity. However, women with increased education status were also more likely to report a sexual dysfunction. Sexual satisfaction for women in this study was more frequently associated with being African American, having a higher mental health score and a lower body mass index.

Prior to these studies a much larger, more comprehensive study was carried out to assess the importance of sex and the prevalence of sexual dysfunction among middle aged and older adults. During 2001 and 2002, The Global Study of Sexual Attitudes and Behaviours collected data from 27,500 men and women, aged between 40 to 80 years, in 29 countries around the world. Approximately 65% of the women reported participating in sexual activity in the previous twelve months. Among the women, this proportion was 88% in the 40 to 49 year age group, and 21% in the 70 to 80 years age group. Overall, 39% of these women reported at least one sexual dysfunction, and were twice as likely as men to experience difficulty with sexual desire, sexual pleasure and orgasm. The most common problem for women was lack of sexual desire, with greater rates of this found in women from South East Asia and the Middle East. A further 16% of women reported that inability to reach orgasm, and lack of lubrication was problematic, again both these issues were more prevalent in Asian women. Interestingly, unlike men, for sexually active women the only sexual problem that was consistent with age was lack of lubrication. From this data the authors concluded that, sexual desire and activity for middle aged and elderly women was widespread and persisted into old age (Nicolosi et al. 2004). Increasingly, for women as they age, relationship factors and mental health status are proving to be better predictors of sexual well being, than sexual arousal, and sexual response (Bancroft 2007).

SECTION 2.3: The Psychosexual Implications of Treatment for Vulvar Cancer

Disruption to Sexuality and Body Image Following Treatment for Gynaecological Cancer

For female cancer survivors, disruption to sexuality and body image are generally a consequence of cancer treatment, rather than a function of the cancer itself (Schover 2007:259). The physiologic component of sexuality, sexual functioning (the physiologic and anatomical ability to participate in sexual activity) has been identified as the most adversely affected by treatments for gynaecological cancer (Wilmoth & Spinelli 2000:414), with sexual functioning reported as the most compromised quality of life issue women face following treatment for gynaecological cancer (Bodurka & Sun 2006:621). Andersen and Van Der Does (1994) found sexuality for women treated for gynaecological cancer was the most vulnerable to quality of life morbidity, and disruption to sexual activity generated negative feelings for women in relation to sexual self esteem, and their view of themselves as women. Many women treated for a gynaecological cancer report that maintaining a positive self image, and feelings of sexuality, contributed significantly to their perception of good quality of life during and after treatment (Ekwall, Ternestedt, & Sorbe 2003). Disruptions to the female sexual response cycle after treatment for gynaecological cancer have been attributed to physical, psychological, and relationship factors (Sheppard & Whiteley 2006:24; Schover 2007:259).

In order to understand the impact of treatment for early stage vulvar cancer on sexuality it is important to understand that sexual dysfunction is not unique to the cancer population. It is estimated that between, 38% to 45% of healthy women experience sexual dissatisfaction or a sexual dysfunction

(Rosen et al. 1993; Addis et al. 2006). The manifestation of sexual dysfunction in women is generally attributed to, disruption to any or all of the five phases of the female sexual response cycle (Andersen 1986 cited in Weijmar Schultz et al. 1991:177). These disruptions can include inhibited sexual desire, inhibited sexual arousal, orgasmic dysfunction, dyspareunia (painful intercourse), and/or inhibited arousal resolution (Weijmar Schultz et al. 1991:178). However, none of the aforementioned disruptions are sexual dysfunction if a woman experiences no personal distress associated with these sexual issues, and reports satisfaction with her sexual life (Gierhart 2006).

Disruption to Sexuality and Body Image Following Treatment for Vulvar Cancer

An extensive search of the literature, dating back to 1980 revealed only a small number of papers reporting on the psychosexual outcomes for women treated for vulvar cancer. In 1983, Andersen and Hacker attributed the lack of available data on vulvar cancer's impact on sexuality as reflective of the opinion that, as it more commonly occurred in post menopausal women then sexuality was considered unimportant at this stage of life. One year earlier, Springer (1982:20) argued against the myth that older women were not interested in sex, although acknowledging there may be some reduction in sexual interest. She suggested the most common reason for a reduction in sexual interest in this group of women was the lack of availability of a sexual partner.

Andersen and Hacker (1983) were the first to undertake formal psychometric testing of the psychosexual outcomes for women following treatment for vulvar cancer. In a group of 15 American women who had a radical vulvectomy, on average five years earlier, they found that sexual functioning and body image underwent major disruption. Women reported sexual arousal at the 8th percentile, reflecting only slight arousal, and body image in the 4th percentile, suggesting extreme disruption. Many women in this study described persistent genital numbness, with some women reporting that during sexual intercourse they were unsure when penile penetration had occurred. Interestingly, preservation of the clitoris did not appear to have a positive effect on these women's ability to achieve or maintain orgasm, as women with, and without excision of the clitoris reported orgasmic difficulties.

In a study to determine the psychological effects of vulvectomy, compared to hysterectomy for endometrial cancer, Stellman and colleagues, also from the US, reported that women who had a vulvectomy were more likely to experience depression, and harbour feelings of sexual guilt than women who had a hysterectomy. Several women from the vulvectomy cohort felt the need to protect their partners from the sight of the vulvar wound, suggesting that women feared arousing feelings of 'distaste' or 'rejection' from their partners (Stellman et al. 1984:782). Interestingly, in the vulvectomy group, the authors found no differences in sexual function or satisfaction between women who had undergone simple or radical vulvectomy, suggesting that loss of sexual function was related more closely to psychological issues than to anatomical deficits.

Danish investigators reporting on sexual activity in 25 women following vulvectomy found that 40% of women did not resume coital activity, 63% reported reduced sexual arousal and 57% reported orgasmic dysfunction. Significant differences were found between satisfaction with the sexual relationship prior to, and following treatment, with 93% of women reportedly satisfied with their sexual relationship before treatment, compared to only 32% after treatment. In addition, more than half of the women reported a lack of respect for their own bodies, and a feeling of not being a 'proper woman' since the surgery. An interesting aspect of this study was the inclusion of the women's partners, who like their spouses, reported experiencing depression.

(Andreasson et al. 1986:7).

Satisfaction with the sexual relationship was described more positively by Dutch women, who had undergone a radical vulvectomy for cancer of the vulva. Weijmar Schultz and colleagues (1986) interviewed ten women and their partners, approximately two years after surgery. The authors found that 4 of the 10 couples had achieved complete sexual rehabilitation. Two other couples achieved only partial sexual rehabilitation, and for 2 couples there was no sexual rehabilitation. Of the 9 women who could achieve orgasm preoperatively, only 5 reported being able to do so postoperatively. Despite these changes, 9 of the 10 women reported satisfaction with their sexual relationship postoperatively (Weijmar Schultz et al. 1986).

In contrast to the earlier study by Stellman et al. (1884), Andersen et al. (1988) compared women treated for in situ vulvar cancer with a matched sample of gynaecologically healthy women, all from the mid west region of the United States. They reported that women with more genital disruption experienced more sexual difficulties, particularly with the desire and resolution phases of the sexual response cycle, yet they maintained their interest in sexual activity. Likewise, in another study of Scandinavian women, Theussen, Andreasson and Bock reported less sexual disruption in women who had local vulvar excision compared to women who had a vulvectomy (1992).

Of interest in the aforementioned American study was the reported reluctance of women to initiate relationships with new partners, which was attributed to the women's discomfort with their perceived genital changes. Andersen et al. (1988) also identified that these women experienced significant psychological distress in comparison to healthy women, supporting the earlier findings of Stellman et al. (1984). It is difficult to compare these results with other studies, as the authors have provided no information regarding the extent of the surgical excision, particularly pertaining to the removal of the clitoris. A limitation of these earlier studies was the retrospective design, which did not provide pretreatment observation of sexual function. Small participant numbers in these studies also limit generalisation of findings.

In order to avoid the limitations of the retrospective study design, Willibrord et al. (1990), conducted a study of women with vulvar cancer, and their partners. This study was a 2 year longitudinal study of 10 couples, starting when the women commenced treatment. Similar to their earlier findings, only 50% of the sample reported being able to achieve orgasm up to 2 years following treatment. However, despite a reported poor perception of genital arousal, all women reported satisfaction with their sexual relationship. The authors interpreted these results to indicate that intimate aspects of the sexual relationship, rather than physiologic arousal, were more important predictors of sexual rehabilitation after surgery for vulvar cancer.

A cross sectional study of 105 British women following surgery for carcinoma of the cervix or vulva, reported that approximately two thirds of the 62 women who had resumed sexual intercourse experienced sexual problems post operatively. These sexual problems correlated significantly with higher reported levels of anxiety. The authors suggested that women without a partner were particularly vulnerable (Corney et al. 1992). Interestingly, the majority of women over 65 who did not resume sexual intercourse following treatment reported little to no distress associated with this abstinence.

Almost 10 years later, another American study retrospectively studied 41 women following vulvectomy for vulvar cancer, and reported significant alteration to body image, decreased sexual frequency and arousal. They found women who were depressed following vulvar excision were more likely to have body image disturbances and sexual dysfunction. However, the extent of surgical excision of the vulva did not correlate with sexual dysfunction. From this the authors concluded that all women are at risk for sexual dysfunction following vulvar surgery (Green et al. 2000). In contradiction to these findings Likes et al. (2007), reported their findings from a study to correlate the extent of vulvar excision with sexual dysfunction, in a sample of 43 predominately Caucasian American women with vulvar intraepithelial neoplasia (VIN). They found that quality of life scores decreased as vulvar excision size increased, and that sexual function decreased as excision size increased. However, despite the authors hypothesising that excision position (removal of the clitoris, or unilateral excisions) would impact to a greater extent on sexual function, no such correlation was found.

Similar contradictions exist regarding the extent of surgical excision and the impact on sexuality and body image for patients undergoing treatment for breast cancer. There is no agreement in the literature about whether the type of surgery women with breast cancer receive, ie; mastectomy, mastectomy with breast reconstruction, or breast conserving surgery, is related to sexuality and body image disturbances (Fobair et al. 2006:581). Ganz, Kwan and Stanton (2004) reported sexual dysfunction was worse in women having had chemotherapy, regardless of the type of surgery they had received. In contrast, an earlier study by Ganz et al. (1998) reported fewer body image disturbances in women having had breast conserving surgery, than women having had a mastectomy.

Several authors identify age as a risk factor for sexual dysfunction following treatment for vulvar cancer. Green et al. (2000) in their earlier retrospective study identified older age, body image disturbances, depression and pretreatment sexual dysfunction as significant risk factors for sexual dysfunction following treatment. This is similar to observations made almost 20 years earlier by Springer (1982), who described age as strongly influencing a woman’s response to radical vulvectomy. Likewise, several years later Likes et al. (2007), from their study to correlate sexual function with the size of the excision, reported older women were more at risk for poor sexual function and quality of life following vulvar excision.

In contrast to these findings, an Australian study conducted to develop a vulvar cancer specific quality of life sub-scale, reported that reductions in sexual functioning were a major concern for five of 15 patients interviewed, all of these women younger than 65 years. Of the ten patients over 65 years, four women did not wish to talk about sexuality, and the remaining six were either not, or very rarely sexually active since surgery. These women described sexuality as not important. Interestingly, the authors did not acknowledge a limitation of the study posed by three women from the older cohort being interviewed within only 4 months of surgery, two of these within two weeks, raising doubts as to the validity of these participants' responses to the questions on sexuality following treatment (Janda et al. 2004).

Although the psychosexual consequences of treatment for cancer are now considered a fundamental aspect of a patient's care, addressing and managing these issues still remains a challenge to both medical and nursing practice (White 2006). The following section discusses the issues faced by health professionals in providing information and support to patients.

SECTION 2.4: Information and Support Following a Diagnosis of Cancer

Information on Sexuality

While disruptions to sexuality and body image seem to be common consequences of treatment for vulvar cancer, sexual information and sexual assessment are not routinely provided in the oncology outpatient setting (Krychman 2005:381). A recent Australian study conducted to determine issues of sexuality and intimacy, from the perspective of patients and health professionals in cancer and palliative care, found that many patients were disappointed by the lack of information, support and strategies provided by health professionals to help them deal with the intimate and sexual changes they experienced following their cancer treatment (Hordern & Street 2007).

There can be a broad gap between what clinicians believe they should do in addressing sexual function, and what they routinely do in practice (Sheppard & Whiteley 2006:26). There is often a reluctance of health care professionals to discuss sexual issues with women and this has been attributed to not only a lack of knowledge about sexual function, but also to; time constraints, embarrassment, lack of privacy, and a lack of understanding of the sexual activities of older women (Burke 1996:239). From a survey conducted in the United Kingdom to study the views of multidisciplinary health professionals on discussing sexual issues with patients, Haboubi and Lincoln (2003) found that despite 90% of the 813 respondents agreeing that addressing sexuality was an important aspect of holistic care, 94% admitted they were unlikely to discuss sexual issues with their patients. The participants in this study felt they lacked training and were ill prepared to address sexual issues with their patients.

Another UK based study was conducted to investigate the attitudes and behaviours of 27 physicians and 16 nurses, who provided care to women with ovarian cancer. From statistical analysis of semi-structured interviews it was found that only 25% of doctors and 20% of nurses, actually discussed sexuality concerns with their patients. The reasons these health professionals described for not addressing sexuality, in addition to those previously articulated, included; a perception that it was not their responsibility, and the lack of available resources to provide support to their patients (Stead et al. 2003). There can also be an assumption of health care providers that following a diagnosis of cancer, sex is the ‘last thing on a patient’s mind’ (Sheppard & Whiteley 2006:26), and that patients are focused only on their survival (Wilmoth & Spinelli 2000). Discussing sexual issues at this time can be low on a list of priorities that appropriately place survival at the forefront of both the patient and the health professionals mind (White 2008:488). However, several years ago, Gamel and colleagues conducted a review of the literature pertaining to women's informational needs about the effects of gynaecological cancer on sexuality. They determined that women needed sexuality information at three time points, and these time periods coincided with specific events in the disease trajectory. These three time periods were; 'diagnosis and treatment period; recovery and first intercourse; the period of rebuilding sexual life' (Gamel, Hengeveld & Davis 2000:678).

Patients may also experience barriers to discussing their sexuality issues with health care professionals. Brandenburg and Bitzer (2009:725) suggested that patients have many reasons for not approaching this topic, these may include; feelings of shame, or fear of being viewed negatively by the clinician. Patients may also consider sexuality not relevant to their medical condition, or too time consuming for the clinician. Other patients may believe there is nothing that can be done about their sexual issues and subsequently never bring the topic up. Similar observations have been described following studies of patients with a chronic illness. A study of 33 Swedish women with diabetes conducted to determine women's preferences for medical intervention for their sexual issues, reported that many women considered their general practitioners personal characteristics, before consulting with them about sexual issues. Some of these women felt their GP was 'too shy' or 'not the type' to discuss sexuality with. Many expressed a preference to see a female gynaecologist, who was also of a similar age to them. Additionally, time constraints and a lack of privacy, were cited by these women as preventing them from broaching sexual issues with their general practitioner (Sarkadi & Rosenqvist 2009:163).

In contrast to this, in an earlier qualitative study of British women with ovarian cancer, it was found that most of the participants wanted to discuss sexual issues with their care team, despite some of the women expressing embarrassment at the thought of doing so. These women felt the personal benefits gained, would overshadow any discomfort they might experience discussing such intimate topics (Stead et al. 2001). Furthermore, from their later quantitative study, Stead et al. (2003) reported that none of the 15 patients interviewed had received written information on sexuality and only two had received verbal information. Seventy-three percent of the women interviewed in this study felt they should have been provided with written information. In addition to this, 60% of women felt sexual issues should have been discussed with them. Most of these women showed no preference for who provided this information (Stead et al. 2003). Likewise, Lindau et al. (2007) reported the findings from their cross sectional survey, comparing long term survivors of vaginal and cervical cancer, with national norms. They identified that these participants from the United States, rated 'very high' their overall satisfaction with the quality of cancer care, but satisfaction with information and support services for sexual issues, rated significantly lower. Seventy percent of the participants in this study reported they would be 'comfortable' discussing sexual issues with a doctor however, 62% had never had the topic raised by a doctor (Lindau et al. 2007:416).

Addressing Sexual Health Issues with Patients

In order to provide this information and address women's concerns about sexuality effectively, health care professionals need to learn how to approach sexuality as they would any other topic, and be proactive in providing opportunities for women to present their concerns (Crowther et al. 1994). The most important approach to improving the discussion of sexual issues for women is 'normalisation' of sexuality by including it as part of the admission history, which could be done by either the doctor or nurse conducting the assessment (Quinn 2007:494). Likewise, Wilmoth and Spinelli (2001:419) contended that sexual assessment should be a part of the routine nursing admission. Including sexual function into the routine history gives the patient permission to discuss sexual issues and reassures them that the health care professional is comfortable and familiar with the topic (Quinn 2007; Wilmoth 2006; Wilmoth & Spinelli 2000).

The literature suggests that cancer nurses have a crucial role to play in the provision of information of such sensitive topics as sexuality. Overall, these nurses play a dominant role in the provision of acute cancer treatment and the management of treatment related side effects, and can take specific action to focus on sexuality in the cancer population (Pelusi 2006:33; White 2007:304). Specialist gynaecological oncology nurses are uniquely placed to provide this information and care to women following treatment for a gynaecological cancer, as they are in frequent contact with patients, and are routinely involved in offering guidance and counselling (Burke 1996:239; Robertson 2005:294). However, the specialist nurses' contribution to women's sexual rehabilitation is dependent on a number of factors, including their own individual qualities and professional status (White 2007:304). Additionally, they require knowledge of the information, practical strategies, support and resources that these patients need to assist them to adjust after treatment for cancer (Hordern & Street 2007:17). Capability to perform sexual assessments, recognise alterations to sexual function, and address sexual issues, require the specialist nurse to not only have the necessary knowledge and communication skills, but a willingness to initiate discussion about sexuality with these women (Hughes 2008:99). In addition to this, these nurses must be aware of their own underlying values, opinions and beliefs in regard to sexuality, to successfully meet their professional responsibilities (Mick 2007:671).

There are several supportive models that nurses can use to assist them to develop a culture of permission to discuss sexuality, and to conduct sexual assessments. These conceptual frameworks, such as the PLISSIT, ALARM, and BETTER Models are useful in guiding assessment and education about sexuality (see figure 2.5). They can also assist health professionals to differentiate between problems that require simple interventions, and those that require more specialized expertise (Wilmoth & Spinelli 2000:420; Robertson 2005:295; White 2007:305; Krebs 2007:314; Mick 2007:671). These models can be particularly helpful to specialist nurses as they assist them to determine at which point they can provide treatment, within their own level of expertise (Bodurka & Sun 2006:622).

Figure 2.3: PLISSIT, **ALARM** and **BETTER** Sexuality Assessment Models

PLISSIT (Annon 1976) a four level approach to addressing general sexual concerns

Permission to discuss: give the patient permission to discuss sexuality issues
Limited **I**nformation: provide limited sexual information
Specific **S**uggestions: provide specific suggestions re. sexual function
Intensive **T**herapy: provide intensive sexual therapy (refer on)

ALARM (Andersen 1990) focuses on the functional level of sexuality
Activity: frequency of sexual activity
Libido (desire)
Arousal
Resolution (orgasm)
Medical Information: health and cancer status

BETTER (Mick et al. 2004) developed specifically for cancer nurses to assess and discuss sexuality issues with patients
Bring up the topic
Explain that sexuality is part of life and patients can talk about sexuality issues
Tell patients you will find the appropriate resources to address their concerns
Timing, acknowledge that patients can ask for information at any time
Educate patients about the sexual side effects of their cancer
Record the patient assessment and interventions into the medical record
(Annon 1976; Andersen 1990; Mick, Hughes & Cohen 2004; White 2007; Krebs

2007; Mick 2007; Hordern 2008)

Other Informational Needs of the Oncology Patient

Despite its relevance and importance, the provision of information on sexuality is only one facet of the oncology patient's informational needs following a diagnosis of cancer. For those anticipating a positive diagnosis of cancer, fear and anxiety are a significant issue (Lyons 2004:11). Likewise, a considerable component of the emotional distress experienced following a diagnosis of cancer is directly related to the anticipation of treatment (Andersen, 1996:65; Pelusi 1997:1342). Medical ethics emphasises the right of cancer patients to be fully informed about their diagnosis and treatment options, and to take part in decisions about their treatment (Brown, Dunn & Butow 1997:877). Patients cannot realistically provide informed consent unless they have been provided with appropriate information (Thomas et al. 2000:1536). Receiving accurate information about their cancer positively influences the patient's contribution to decision making about their treatment. They are also more likely to comply with treatment, experience less fear and anxiety, and better manage treatment related side effects (Iconomou et al. 2006:515; Sharpley & Christie 2009:221).

In a study conducted by Corney and colleagues, to determine the information, emotional support and counselling needs of women undergoing treatment for cervical, or vulvar cancer, it was found that the period of most distress for these women usually correlated with the period of most uncertainty. In this study, 39% of participants experienced more distress and anxiety between the development of their symptoms and the diagnosis of their cancer. Equally, another 37% of women indicated that the most distressing time was between diagnosis of the cancer and their surgery (Corney et al. 1992). Likewise, a recent UK based qualitative study that explored the lived experience of 13 women who had been treated for vulvar cancer, ascertained that the time from diagnosis to first consultation with a gynaecological oncologist involved a period of “searching” for information. However, a lack of available information, compounded by the lack of understanding of vulvar cancer among the general population led to these participants experiencing a sense of “being alone” and “isolated”, exacerbating their already heightened levels of anxiety (Jefferies & Clifford 2009:35).

The literature also identifies a lack of understanding and poor recall of the information given in medical consultations among patients with cancer (Knox et al. 2002). More than 10 years ago, Gattelari et al (1999) conducted a survey of 244 adult Australian cancer outpatients, to determine not only their level of understanding of information provided to them, but whether the psychological mechanism of denial contributed to these patients screening out information they perceived as threatening. The authors concluded that in some patients denial led to misunderstanding of information, however, the clinician’s ability to effectively communicate with the patient was also implicated. Similar results were reported from a later qualitative study from the United States. This study was performed to examine the reasons why patients do not want or seek information about their cancer. The results indicated that while all patients wanted basic information on their diagnosis and treatment, not all wanted further information. The need for further information was generally dependent on the patient’s coping strategy, or their attitude to managing their cancer (Leydon et al. 2000). Likewise, fear can also play a part in preventing patients from seeking and understanding information (Fleissig 2000).

One of the challenges in providing information to patients is to provide in a format which is most acceptable to the majority. Numerous methods have been developed to provide information to cancer patients. These methods include but are not limited to: verbal communication, written material such as handouts and information booklets, audiotapes and videotapes, cancer help lines and support services, and the Internet (Iconomou et al. 2006; Sharpley &

Christie 2009). Sharpley and Christie (2009) conducted a study to determine whether time since diagnosis affected patient's recall of the information they had been provided at the time of their diagnosis for prostate cancer. These authors found in a group of 237 patients, the most frequent format for information provided to them was verbal information provided by their oncologist. Participants rated this as their most valuable and preferred source of information. Second to verbal information was the information booklet, with very few patients having received any other form of information. Similar results were found in another study of men with prostate cancer. This study from the United Kingdom demonstrated that the participants ranked the value of the verbal information they were given based on the status of the information provider. Verbal information provided by their treating physician ranked highest, while information in booklets or leaflets ranked above television programs and the media. In addition, these participants evaluated information provided to them more positively if they perceived it to have been given with warmth and empathy. The authors concluded from this that 'context, as well as content of information' was significant in determining patient satisfaction (Nanton & Dale 2009:1603).

Similar results to these were reported by Jefferies (2001) following her mixed method study to determine if the emotional and informational needs of British women with ovarian cancer were being met. In this study, 96% of the 24 respondents described having received verbal information, while 66% had received additional written information. However, 31% of these women felt the written information they had been given was lacking in detail. Qualitative analysis of the data also showed that; the timing, the amount, and the delivery of information were important. These participants described having gained more benefit from receiving information from a specialist gynaecological oncology nurse, in addition to the consultant, rather than from the consultant alone. Several of the respondents in this study also highlighted the benefits of the multidisciplinary team approach to their care.

In addition to written and verbal information, information in the form of video has also been shown to be acceptable and beneficial to patients (Thomas et al. 2000). A randomised controlled study was conducted by the above authors to assess the benefits of a take home information video for patients undergoing chemotherapy or radiotherapy. This UK based study of 220 patients, also aimed to test the hypothesis that increasing preparatory information might assist in improving anxiety and depression levels for cancer patients. Results from this study showed 81% of the 113 patients who watched the video felt it was helpful. Patients in the video group were also considerably more satisfied with the information they had received, than the group who did not receive video information. Data from this study also demonstrated that patients who were better prepared for their treatment, through video information, reported lower levels of anxiety during treatment, than at their pretreatment assessment, whereas little difference was shown in anxiety levels in the non video cohort (p. 1540).

Similar to this, another randomised study was undertaken to determine Italian cancer patients rating of information they had been provided, prior to commencing chemotherapy. Results indicated that while the majority of patients found the booklet useful, the videotape was regarded as 'quite' or 'much' more complete than the booklet. In addition to this, the researchers found that during treatment, the booklet plus video group described improved quality of life, in comparison to the booklet only group (De Lorenzo et al. 2004:721).

It may be concluded that inadequate information following a diagnosis of cancer can be associated with patient dissatisfaction and unfavourable psychological consequences. Providing information in the form of empathic verbal and written information, possibly accompanied by well designed video information, should be an important component of the overall management of the cancer patient (Thomas et al. 2000:1536).

Cancer Support Groups

Cancer support groups have also become an accepted strategy to improve quality of life for those diagnosed and treated for cancer. In the past breast cancer support groups have been identified as benefiting women physically, socially and psychologically following treatment for breast cancer (Michalec 2005:160). Likewise, evidence from the study by Jefferies (2001) suggested that women diagnosed with ovarian cancer who participated in a cancer support group reported more emotional support than those women who did not. Peer support programs for women with breast cancer have also been shown to be effective in alleviating many of the physical and emotional effects of breast cancer (Power & Hegarty 2010:9). In 1997, Lugton conducted a qualitative study of 35 women with breast cancer, to determine their perceptions of the social support available to them. Many of the respondents in this study described a decrease in their sense of isolation, due to their involvement with other women in the same situation. These women felt that peer support had reduced the stress of their cancer diagnosis by making it seem less overwhelming. Additionally, many participants when comparing themselves to their peers, who seemed to be coping well, were reassured that they also would be able to cope with their breast cancer. For the women in this study the social support provided by their peers was significant to their maintaining their identity. Flanagan and Holmes (2000:743) explained this by using the social theory of deviancy, "whereby support from peers is one way by which individuals who have become unsure of, or who have lost their status, are re-integrated back into society or into the norms of the deviant group, those others sharing the stigma".

Despite the perceived benefits of support groups, evidence suggests that many patients do not participate in cancer support programs. In the study by Jefferies (2001), the women who did not participate in a support group cited ‘the need to return to normality’, and the desire to get on with their lives as their reasons for not attending (p. 46). Additionally, many patients might not feel the need for psychosocial intervention and therefore are not interested in joining a support group (Moyer et al. 2009:345). Estimates of patient involvement in cancer support groups vary. Hewitt and Rowland (2002) reported from their study across various cancer types that only 14% of adult cancer patients participated in a cancer support group following diagnosis. Whereas, Owen and colleagues (2007) found the prevalence of support group use higher among cancer survivors, 24%, compared to 14% of those with chronic medical conditions. Likewise, a survey of 958 American women listed on a breast cancer registry showed that 82% of women with cancer were not currently, or had never participated, in a cancer support program. However, women that did participate, or were participating in a support group at the time of the study, reported significantly higher levels of social and overall quality of life than those who were not, or had never participated in a support group (Michalec 2005). Conversely, in this study, support group participants were found to be significantly younger, wealthier, were more often employed, reported higher levels of education, and more often married, than the non participants of support groups. From this the author hypothesised that demographic characteristics of the participant may have created an erroneous relationship between participation in a support group and quality of life (p. 174).

While it appears that participation in cancer support groups may be beneficial to some patients, in the context of vulvar cancer there is almost no evidence in the literature to determine these women’s attitude, or preferences for this type of psychosocial support. Weijmar Schultz et al. (1986) found in their study of ten women, who had undergone vulvectomy, and their partners, that once women were discharged from hospital their most important source of support was their husband, the family doctor or the outpatient doctor. However, seven of these ten women thought it would be beneficial to be put in contact with another vulvectomy patient, but only five participants thought involvement in a support group would be beneficial to them. Similar results were reported from a later study by Pistrang and Winchurst (1997) examining gynaecological cancer patient's attitudes towards psychological services. These authors found slightly less than half of the 35 respondents said they would currently use either one of three types of psychological services, which were: individual counselling, a support group and couple counselling. However, despite these women describing a positive attitude to psychological support services, they showed no overall preference for one type of service over another. It is clear that health professionals involved in the care of these women should provide them assistance to identify and access cancer support groups. However, more effort is required to identify vulvar cancer patient's preferences for information and support, and to match the provision of information and support to the needs of the individual patient.

Conclusion

From the literature it can be concluded that sexuality is adversely affected by surgery for vulvar cancer, and that there is an increased prevalence of sexual dysfunction for this cohort, compared to healthy women. It is also evident that for most women intimacy and relationship status are more closely linked to sexual satisfaction than physical arousal. However, there are obvious inconsistencies in the literature as to the impact age, and the extent of surgical excision for vulvar cancer, has on sexual function following treatment. Despite the potential for significant adverse consequences on sexuality and body image following treatment for vulvar cancer, the paucity of literature specific to this disease site indicates a need for greater attention to the sexual concerns of these women, irrespective of age. In addition to this, a better understanding of the information and supportive care needs of vulvar cancer survivors is important to informing health care initiatives and services, to assist both the physical, psychological and sexual recovery of these women.

Because of the inherent gaps in the literature the design of this study was strongly influenced by a desire to understand the experience of sexuality and body image following surgery for early stage vulvar cancer from the perspective of Australian women, who had been treated with the most conservative surgery that was consistent with cure of their cancer. In the following chapter, the design and methodology of the present study are described, along with a detailed description of the women who participated and how the study was conducted.

CHAPTER 3

METHODS

Introduction

In this chapter the qualitative research design and the theoretical perspective underpinning this research project are explained. The process of sample selection, data collection and data analysis are described. Additionally, specific aspects relating to ethical considerations and participant protection are identified, and finally, the techniques utilised to ensure the rigour of this research project are discussed.

Justification for the Research Design and Methodology

In recent years it has gradually become apparent that the more traditional quantitative research approaches are restricted in their ability to portray the meanings people attach to their health experience (Collingridge & Gantt 2008:389). Quantitative research concentrates on causal relationships, whereas qualitative inquiry focuses on the exploration of human behaviour and the quest for understanding (Ryan-Nicholls & Will 2009). The instrument routinely used to collect data in quantitative research, the questionnaire, forces participants into categorical responses often ignoring the individual nature of an experience (Serber & Rosen 2010). In comparison, qualitative research uses predominately text based data to understand participant's experiences. It begins with an objective to explore a particular area and collects data directly from participants, usually in the form of open ended interviews that look to understand from the individual's perspective (Serber & Rosen 2010).

The evolution of qualitative research has been in response to the inability of quantitative inquiry to portray the significance and meaning people ascribe to their health, and their health care experience (Collingridge & Gantt 2008). The limitations of quantitative research became apparent when researchers needed to ask questions outside of the 'observe and analyse' domain (Taylor et al. 2006:323). There is a need now to conduct research, that is more patient centred and which values participants own interpretations of experiences (Edwards & Titchen 2003).

Qualitative research is particularly well suited to study the human experience of health (Beanland, Schneider, LoBiondo-Wood & Haber 1999), as it allows rich insights through in depth examination of phenomenon (Simons Lathlean & Squire 2008). In qualitative research the researcher is an involved participant in the generation of naturally occurring knowledge, but rather than achieving definite answers, gains understanding and formulates new questions about their research topic (Malterud 2001). Therefore, qualitative research is an important medium to learning about the complexities of patients (Serber & Rosen 2010). However, qualitative methods are not appropriate to answering numerical questions, such as extent, or distribution, and are more appropriate to gaining insight into, rather than an explanation of phenomena (Malterud 2001).

Following a detailed review of the literature specific to sexuality and vulvar cancer a key finding was that most studies had used quantitative methods. The assumptions of some authors being, that the measurement of functional sexual intercourse was the benchmark to determining the sexual outcomes for women following treatment for vulvar cancer. Although the data generated by these earlier quantitative studies identified defined outcomes of treatment, which when compared to findings from other studies, can be generalised to wider populations, they do not provide the researcher with a deeper understanding of each individual's experience. In the context of this research project it was determined that due to the limitations of the quantitative research design to portray the individual subjective experience, a qualitative research design would be the most appropriate approach to conducting this study (Pope & Mays 1995). Utilising a qualitative research technique, such as the in-depth interview could 'provide a description and an understanding' of the experience of sexuality and body image following treatment for early stage vulvar cancer (Pope & Mays 1995:44).

Phenomenology as a Theoretical Perspective

Qualitative research is grounded in an array of theoretical frameworks, and uses a number of different methodological approaches to direct data collection and analysis (Cohen & Crabtree 2008). Phenomenology is one such theoretical perspective and has been described in the literature as a philosophy embedded in the phenomenological movement of the late 19th and early 20th centuries, beginning in Germany, with the work of the philosophers, Husserl and Heidegger (Rose, Beeby & Parker 1995). The purpose of phenomenology is to comprehend phenomena from the perspective of those who experience it, 'to know an experience the way that the participants know it, to understand the meanings they attach to their experiences, and to capture the essence of a phenomenon as they experience it' (Collingridge & Gantt 2008:393). Max van Manen (1990) suggested that anything that offers itself to consciousness is possibly of interest to phenomenology, and whatever falls outside of consciousness is external to the lived experience. Phenomenology asks "what is this or that kind of experience like?" (van Manen 1990:9). However, the experience is always retrospective as it is a contemplation of an experience that is already lived.

There are several variations to phenomenological approaches and these are based on the philosophical tenets of the two aforementioned German philosophers. The two main phenomenological approaches described include descriptive (eidetic) phenomenology, and interpretive (hermeneutic) phenomenology. These two approaches have distinct differences in how the findings are generated and utilised (Lopez & Willis 2004).

Descriptive and Interpretive Phenomenology

The descriptive phenomenological approach to qualitative inquiry is based on Husserl's earlier philosophical ideas. It was his belief that experience, as comprehended by human consciousness was valuable to scientific study (Lopez & Willis 2004). The result of a descriptive phenomenological inquiry is the construction of the phenomenon of interest with bracketing as a distinguishing feature (Kleiman 2004). It was Husserl's belief that bracketing, or the suspension of preconceptions, ideas, previous knowledge, or biases by the philosopher allowed them to look at things as they truly were, "the philosopher could return to pure consciousness of the phenomenon" (Beech 1999:36). In order to achieve this some researchers suggest that descriptive researchers not conduct a detailed literature review, or develop specific research questions, prior to initiating a research study (Lopez & Willis 2004).

One philosopher, who modified the work of Husserl, was Heidegger, who contested some of Husserl's notions about how phenomenology could direct meaningful inquiry. Heidegger's ideas comprise the interpretive or hermeneutic research philosophy (Lopez & Willis 2004). This philosophical perspective is not limited only to the concepts of Heidegger, but also to philosophers such as, Gadamer and Ricouer (de Witt & Ploeg 2006). Unlike descriptive phenomenology, based on the work of Husserl, who believed the researcher must suspend all prior knowledge, this interpretive approach values the expert knowledge of the researcher. It was Heidegger's belief that it was impossible to clear the mind of the background of understanding, which initially led to the realisation that research, was needed (Lopez & Willis 2004). This position maintains that we 'are in our culture as it is in us' (Koch 1995:22). This type of inquiry looks further than a description of an experience, but to the meanings embedded in the description of an experience. These meanings are not frequently obvious to the participant but are constructed from their narratives (Lopez & Willis 2004). Rather than providing theory for generalisation, this type of research approach 'increases sensitivity to human ways of being in the world' (Dreyfus 1991 cited in Crist & Tanner 2003:202). The goal of interpretive phenomenology is to create a text that is solid and insightful, that is an accurate representation of the phenomenon being investigated (Kleiman 2004). Hermeneutic interpretive phenomenology is frequently recognised in the literature as a basis for nursing inquiry (Koch 1998; Draucker 1999; Whiting 2001; Crist & Tanner 2003). Furthermore, this type of inquiry can emphasise all results, even those that deviate from the norm, enhancing the health professional's insight, into the range and depth of their patient's experience (Douglas, Hamilton & Grubs 2009).

Max Van Manen (1990), a more contemporary phenomenologist described a combination of the earlier concepts put forward by both Husserl and Heidegger. Although he believed that prior knowledge or assumptions could conceal or influence the researcher to interpret the phenomenon prematurely, he argued that if we try to suspend what we 'know', we may find it keeps coming back into our consciousness. Van Manen suggested it is better to come to terms with our knowledge, not to forget, but to put it aside (p 27).

Hermeneutic Interpretive Phenomenology as the Theoretical Perspective

With regard to the specific research questions being asked, a qualitative approach based on interpretive phenomenology, informed by the works of Heidegger and van Manen, was used for this study. The decision to be informed by phenomenology as the philosophical context for this qualitative research project was taken to specifically describe these women's lived experience of sexuality following treatment for vulvar cancer. This approach, offered the possibility of credible insights into the lived experience, as it focuses on what a person experiences rather than what they consciously know (Van Manen 1990). The aim being that it would accurately portray the experience being studied, as it exists for the individual, allowing emphasis of each woman's unique perspective (Morse & Field 1995).

Van Manen (1990:31) highlighted six recommendations, or themes that he considered essential to conducting interpretive phenomenological research. These are: 'turning to the nature of the lived experience', 'investigating experience as we live it, rather than as we conceptualize it', 'reflecting on the essential themes which characterize the phenomenon', 'describing the phenomenon through the art of writing and rewriting', 'maintaining a strong and oriented pedagological relation to the phenomenon', and 'balancing the research context by considering the parts and the whole'. Utilising the principles of Van Manen's approach assisted in providing clarity and direction to guide the investigation and interpretation of the lived experience of these women. However, phenomenological research is conducted more from a philosophical viewpoint than a rigid method, and van Manen's 'six steps' were only used to guide the research process, not as a prescription to conducting this research project.

Additionally, an interpretive approach allowed the researcher to bring to the research project the knowledge gained from the literature on vulvar cancer and from the experience of engaging with women throughout their experiences of illness and survivorship. Although, van Manen suggested that a problem with phenomenological inquiry is that we can at times know too much about that which we are investigating, he also proposed that no understanding can be achieved without pre understanding. He did suggest however, that the researcher 'come to terms with their assumptions' exposing the concealing nature of their prior knowledge (van Manen 1990:47). The researcher must acknowledge presuppositions and examine them, which can be done through the exposure to the different opinions of other researchers, colleagues or through reading the literature. Fleming, Gaidys and Robb (2002:117) suggested a conversation with a colleague was one approach to triggering one's preunderstandings. Likewise, these preconceptions can then be incorporated into the discussion, indicating that the researcher has learned from the research encounter (Fossey et al. 2002).

Data generation in phenomenological research is primarily through conversational interviewing and observation (Van Manen 1990). The aim of the interview in qualitative research is not to predict or produce theory, but to understand the lived experience, complete with all its richness and meaning (Sorrell & Redmond 1995). It is especially suited to exploring the more intimate aspects of an experience (Johnson 2002 cited in Taylor, Kermode & Roberts 2006:414). Unstructured and semi-structured interviews are the most frequently used in qualitative research. In the unstructured interview the participant takes the lead, directing the interview. However, in the semi-structured interview the participant is encouraged to talk, but at the same time the focus of the interview is maintained, therefore making possible a more purposeful investigation of a specific topic (Fossey et al. 2002; Taylor, Kermode & Roberts 2006).

Study Setting

The population of interest in this study was those women who had undergone surgery for early stage vulvar cancer, in a hospital in the eastern suburbs of Sydney, Australia. The Gynaecological Cancer Centre at the Royal Hospital for Women is a specialist tertiary referral centre for women diagnosed with a gynaecological, or breast cancer. Women come to this centre for surgery, chemotherapy, radiotherapy, symptom control and palliative care. In 2009, 539 surgical procedures were performed in this centre, on women with a proven or suspected gynaecological malignancy. Chemotherapy is administered to approximately 670 women a year and approximately 1,630 women are seen in the outpatient's department annually.

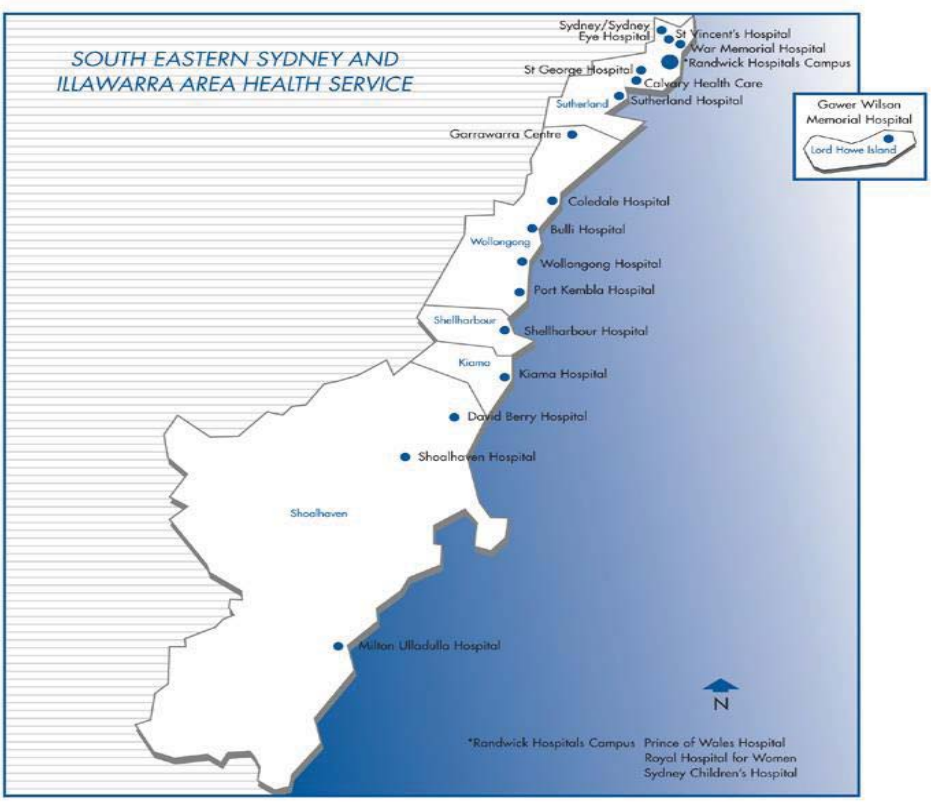
The age range of women is from 16 to 92 years, with an average age of 62 years.

Approximately 50% of women referred to the centre are from rural or regional NSW, the remaining from metropolitan Sydney. Some of these regions include, but are not limited to Wollongong, Canberra, Wagga, Orange, Dubbo, Lismore, Gosford and Tamworth. A very small number of women come to this centre from the remote islands off the coast of Australia, and from the South Pacific regions. Following surgery many women from both metropolitan Sydney and rural NSW, are referred back to their area health service for radiotherapy and chemotherapy.

National and international guidelines indicate that the vast majority of women with actual or a suspected gynaecological cancer should be referred to a gynaecological oncologist. There are four designated specialist tertiary gynaecological cancer services in New South Wales, three in Metropolitan Sydney, and one in Newcastle. The Gynaecological Cancer Centre at the Royal Hospital for Women is within the South Eastern Sydney Illawarra Area Health Service (SESIAHS), and patients within this area health service are generally referred to this centre. Additionally, there are frequent instances where referral pathways for regional women are based on existing relationships between clinicians (Cancer Australia 2010).

The SESIAHS area covers approximately 6,331 square kilometres, stretching from Sydney Harbour in the north, to Durras in the south. The Area includes highly urbanised areas of eastern Sydney, southern Sydney, Wollongong and Port Kembla, in contrast with the predominantly rural areas of the South Coast. In 2004, the estimated population of this area health service was approximately 1.2 million, representing about 17% of the total population of NSW (South Eastern Sydney Illawarra Area Health Service Home Page 2010) **(**see Figure 3.1**).**

Figure 3.1: Map of the South Eastern Sydney Illawarra Area Health Service (SESIAHS) catchment area



(Downloaded from SESIAHS web site 7th March 2010).

This setting was chosen as the researcher had been involved with this department as a Clinical Nurse Specialist and research nurse, for more than ten years. Having had the opportunity to work with women from the time they are diagnosed with vulvar cancer, through their surgery, and beyond it was evident that there was a distinct lack of information available pertaining to these women's sexual issues. Likewise, it was obvious to the researcher that a busy outpatient setting was not always conducive to broaching this topic with women, making it difficult to generate information from them on their thoughts and feelings towards sexual activity following treatment for vulvar cancer. Eliciting this type of information from women in the outpatients clinic can be hindered by staff time constraints and the presence of medical students or junior medical staff during consultations. The literature identifies both these factors are frequently cited by health professionals as barriers to broaching sexuality with patients (Hordern 2008). However, it is also important to use sensitivity and timing when discussing sexuality issues with patients and the presence of a third party can be inappropriate at this time (Krebs 2006).

Sampling Procedure

Sampling for qualitative research involves identification of participants who can most appropriately and adequately inform the study. Qualitative researchers seek cases that are rich in specific information (Fossey et al. 2002). Sampling in qualitative research is, therefore, an application in "exploring diversity, difference, variation and heterogeneity" (Morse 1991 cited in Nicholls 2009:638). Qualitative sampling is described as purposive when it selects participants as appropriate information sources to provide a richness of data about a phenomenon (Fossey et al. 2002). This type of selection strategy is used to choose participants who are typical of the population to be studied, who are considered to 'best represent' the phenomenon (Taylor, Kermode & Roberts 2006:206). It can also assist in identifying diversity within groups by increasing sample coverage, as it allows the researcher to include participants who can offer a range of descriptions of the phenomenon being studied (Collingridge & Gantt 2008). Likewise, sampling is described as theoretical when it is used to select participants who are capable of providing insight into emerging ideas and to assist in building theory, as analysis progresses (Fossey et al. 2002; Lopez & Willis 2008).

Qualitative sampling may involve only small numbers of participants. Phenomenological studies commonly use as few as five to eight participants, relying on small numbers to study in depth and detail (Tuckett 2004). There is no fixed number of participants necessary to conduct qualitative research, however there needs to be elicited a depth of information to adequately describe the phenomenon being studied (Fossey et al. 2002).

Since the purpose of this study was to describe the experience of sexuality and body image following treatment for early stage vulvar cancer, purposive sampling was used to select women who had previously been diagnosed with vulvar cancer, and treated with primary surgery, with or without a groin node dissection. In order to describe long term, if any, psychosexual implications the women were considered for inclusion if it had been one year or more since their treatment. For these women, a year allowed for recovery from the physical effects of treatment and the resumption of sexual activity. Additionally, any psychosexual changes from the disease or its treatment would have occurred within this time (Weijmar Schultz et al. 1990:40). Although it was important to choose a time to allow for recovery from surgery, and possible resumption of sexual intercourse there were no additional limitations placed on time since surgery for women to be included in this study.

Because of the conflicts inherent in the literature concerning the importance older women attributed to sexuality after cancer, and in order to better understand the experience of sexuality and body image for all women after treatment for vulvar cancer, women from across all age groups were selected as potential participants. However, following discussions with the treating specialist and the psychologist in the unit it was decided to not approach women over 80 years of age. Initially, consideration was given to include only women who had a sexual partner. However, sexuality is more than the ability to have sexual intercourse, and to understand vulvar cancer's treatment effects on sexuality it must be considered in its' broad context. Therefore, a decision was made to include all eligible women, regardless of whether or not they were currently involved in a sexual relationship. Women from across NSW including, metropolitan, rural and regional centres, were purposively sampled to make the sample population more diverse.

Participant Identification

In order to identify potential participants for this research project the departmental data manager at the Gynaecological Cancer Centre was asked to generate a list of women being treated for an early stage vulvar cancer. There were 121 women who were identified as having undergone treatment for early stage vulvar cancer. The outpatient file of each of the 121 women was reviewed to determine her eligibility to be approached to participate in this research project. Unfortunately, a number of these women had more advanced disease at diagnosis, so therefore were not eligible for inclusion. Several more women had developed another cancer, or had a recurrence of their vulvar cancer. Two women had previously undergone a renal transplant; several more had another medical condition that might adversely affect their participation in the study. Also a significant number of these women were over 80 years of age and excluded. Similarly, women who had not had been in contact with the department for more than 5 years were considered lost to follow up and excluded.

Inclusion /Exclusion criteria:

The inclusion criteria for this study were that:

- the woman was not younger than 18 years of age;
- she had been treated for an early stage vulvar cancer, with primary surgery, with or without groin node dissection, one year or more previously;
- she had sufficient English to participate in an in depth interview; and
- she gave informed written consent to participate in the study.

The exclusion criteria consisted of:

- women who had recurrence of vulvar cancer;
- women diagnosed with another cancer, or a medical condition which might adversely affect their ability to participate in the study;

- women aged over 80 years.

The determination of women having sufficient English to participate in an in depth interview was based on whether an interpreter was used when consent for surgery was obtained. This information is documented in their outpatient file.

Data Collection Procedure

From a list of a possible 41 eligible women, a letter signed by the treating physician was sent to 21 potential participants, explaining the study, and inviting them to participate (Appendix 1a). The potential participants were informed on invitation that their decision regarding participation in the study would not affect their ongoing care. Women who wanted to participate were given the opportunity to inform the researcher in person, or by mail, phone, or email. Women who did not respond to the initial invitation were not contacted again about this study.

Twenty one women were initially invited to participate in the study, with a list of another twenty eligible women kept aside, in case the response rate from the first mail out was low. For the study, a sample of 10-15 women was considered adequate to explore the experience of sexuality and body image. Most qualitative studies often involve only a small number of participants. However, the depth of information elicited needs to be sufficient to describe the phenomena (Fossey et al. 2002).

The age range of the women invited to participate was between 25 and 80 years, with an equal distribution of women invited from metropolitan, regional and rural NSW. Ten out of 21 women responded to the invitation, 8 by returning the "permission to be contacted for this study" (Appendix 1b), and 2 women made phone contact with the researcher. Eleven of the 21 women sent an invitation to participate, did not respond, with one invitation sent back as 'not known at this address'. Later in the study, at an outpatient follow up visit, one woman was approached by her treating physician and asked if she would like to participate, despite her positive response at the time, she later declined to be interviewed. Interestingly, both the youngest woman aged 25 and the oldest, at 80 years of age, who were invited to participate, did not respond to the invitation.

Participant Characteristics

The ten women who participated in this project ranged in age from 37 to 76 years, with a mean age of 58 years, at the time of interview. As the predominant mean age for women diagnosed with a vulvar cancer is 65 years (Hacker 2010), these women were on average, slightly younger than the usual. Six of the women interviewed were from rural areas, and four women lived in an urban setting. Eight had completed compulsory school education or less, and the other two women had completed post compulsory school education. None of the study group had a tertiary qualification. Four women were in full time employment, three were retired, and three women identified themselves as homemakers. In terms of cultural background, eight of the women described themselves as Anglo-Australian, and two women were of Southern European origin.

All of the women interviewed for this study had children, four had grandchildren. Six of the ten women still had children, either teenage or adult, living with them. Without exception, all women acknowledged currently having good support, either from their husbands, adult children, or a close female relative or friend. Seven of the women had a sexual partner, all of these seven women reported being sexually active at the time of the study. Three women lived alone and had not been sexually active for some time. Only one of these three women had resumed sexual intercourse following surgery, but she had subsequently divorced and not been sexually active since then.

Treatment Characteristics

The women participating in this study had undergone various degrees of surgical excision. Three women had either an anterior or posterior vulvectomy, only one of these having had a radical anterior vulvectomy with a resection of her distal urethra. The other seven women in the research group had a one sided radical local excision or wide local excision. As previously described in chapter 2 radical local excision involves a wide and deep excision of the primary tumour, maintaining a 1cm clear surgical margin, but leaving the rest of the vulva intact. In contrast to this, radical vulvectomy involves the dissection of the tumour, contiguous skin, subcutaneous fat, and the vulva.

One of these seven women had undergone multiple vulvar procedures to treat recurrent vulvar intraepithelial neoplasia (VIN). Across all of the participants, half had groin node dissections, with three of these being performed on only one side. Eight of the ten women had maintained an intact clitoris. One woman had her surgery just over 12 months prior to being interviewed, three others, between 18 months and three years. The other six women were interviewed more than three years after their treatment. At the time of interview only two women were pre menopausal, with only one of the eight post menopausal women taking hormone replacement therapy.

Participant Interviews

To explore the experience of the phenomenon of sexuality and body image after surgery for vulvar cancer, individual semi-structured in-depth interviews were conducted. Ten women participated in recorded interviews for this study over a five month period, from April to August 2009. Prior to commencement of the interviews the lead up conversation involved ascertaining that the participant was comfortable and clear about the focus of the research and explicit consent was obtained to tape record the interview. The interviews commenced by reviewing demographic information with participants, and then gradually led into more specific discussion of the research topic. This was beneficial in making the participant comfortable and establishing rapport, prior to discussing more intimate topics. The participants were also reassured prior to commencement of the interview they could terminate or adjourn the interview at any time. The tape recorder was not used to record the lead up conversation but was switched on at the commencement of the semi-structured interview.

The focus in a semi-structured interview is usually maintained through the use of an interview guide, which includes a list of broad questions and prompts intended to steer the interview in a 'focused, yet flexible and conversational manner' (Fossey et al. 2002:727). For this reason an interview guide (Appendix 2) was developed from a review of the appropriate literature and from the clinical experience of caring for these women. This guide was also developed in consultation with a psychologist who specialised in this subject. The interview guide defined the areas to be covered, based on the objectives of the study. It allowed for initial questions or comments to define the topic, with further questions being determined as the information was provided by the participants (Britten 2006). Probes were also added to the interview guide to assist in eliciting further information.

The use of open ended questions promoted participant response by inviting them to talk, encouraging the free flow of conversation (Taylor, Kermode & Roberts 2006). The interview guide included questions reviewing demographics, including the participants social support network. Demographic information collected prior to interview, from the participants medical record included:

- stage of disease
- type of surgery
- time since treatment
- age at time of treatment

- current age
- residential location (metropolitan, regional or rural)

At the time of interview other demographic characteristics elicited included:

- relationship status
- living situation
- education
- employment
- menopausal status
- use of hormone replacement therapy

Participants were then encouraged to describe their experience, initially starting with two open questions;

- How did you cope with your diagnosis and surgery?
- How do you now feel about your diagnosis and your treatment for vulvar cancer?

The interview guide included four other main questions;

- Has anyone spoken to you before about the impact of treatment on your sexuality?
- Can you tell me about the place that sexuality has in your life/ relationship?
- How has the treatment for vulvar cancer affected your sexual life?
- Have you noticed any change to how you feel about your body since surgery?

Additionally, the guide included several probes to expand on these main questions;

- Have you noticed any altered sensation?
- Have you noticed any changes to your ability to achieve orgasm?
- Have you noticed changes in your sexual relationship since surgery?

- What has been your partner's response to you sexually since your treatment?
- Do you feel your partner's attitude changed following your treatment for vulvar cancer?
- Do you think the frequency of sexual activity has changed?

The order of the interviews was dependant on the participant, the sequencing and asking of the questions was flexible. For those women who said they were not sexually active some of these questions were omitted. The conversation of the participant was used to direct subsequent questions and the interview followed a conversational, rather than an interrogative style (Van Manen 1990). Probing questions were directed by what the participant had said, and the women's own vocabulary was used when framing further questions (Britten 2006). Additionally, the interview guide assisted by providing clear direction during the interview process (Taylor, Kermode & Roberts 2006), and allowed further follow up of emergent ideas or issues (Fossey et al. 2002). Following the first two interviews some issues emerged that were incorporated as questions into the subsequent interviews, these questions are not evident in the original interview guide but are detailed below;

- Did you look at your wound/vulva after the surgery?
- How long after your surgery before you looked at your vulva?
- Do you remember receiving information about the surgery and what you would experience afterwards?
- When do you think would be the most appropriate time to be provided with information about sexual activity?
- Have you discussed having vulvar cancer with others?

All of the interviews were conducted at the participant's convenience and in a place of their choosing. Four interviews took place in a private office of the

Gynaecological Cancer Centre, five in the participant's home, and one, on a headland overlooking a popular beach, in regional New South Wales. None of the interviews were conducted in the evening or on weekends, even though the researcher was willing to do so. This was attributed to the intimate and private nature of the research. The women could be assured of privacy when partners and children were out of the home.

It was important to be flexible for the women, with one interview being conducted standing outdoors on a headland. What was not obvious at the time, but later became clear, was the impact background noise would have when transcribing taped data. The noise of the wind, and the seagulls in the background almost drowned out the participant's voice. This transcription took much longer than others, as the interview recording had to be repeatedly rewound, and played back, in order to decipher the participant's words. The lengths some women went to participate in this project was humbling, with one woman flying to Sydney to be interviewed, another making a four hour return train trip, accompanied by her husband. One participant, from remote NSW, arranged a visit to family in Sydney in order to be involved in this research project.

All the participants who were interviewed in their homes appeared relaxed and made the researcher welcome. Two of the four women who chose to be interviewed in a private office of the Gynaecological Cancer Centre, were nervous and initially hesitant. One of these women cried at various points throughout the interview, but refused an offer to terminate the interview. This participant stated she always got upset when she talked about her cancer. On the whole the interviews were not distressing to the women, and laughter was threaded throughout the conversation, with the women often using humour to describe their experiences. At the conclusion of the interview any of the women who displayed any signs of distress during the interview were offered the assistance of the Psychologist in the department. None of the women felt the need to take up this offer.

Overwhelmingly, the participants were grateful someone was taking an interest in vulvar cancer, as they all felt it was a ‘neglected’ cancer. Several of the women thanked the researcher at the conclusion of the interview, stating they had enjoyed the experience. Subsequently a few of the participants have indicated a desire to be included in any future research.

Notes were taken prior to commencement of the interviews to document the participant’s responses to the demographic questions, and again at the completion of the interviews, to record any information provided by the participant, once the tape recorder had been turned off. Because several of the women knew the researcher in the role of Clinical Nurse Specialist, there were times in the interview when some women sought clarification on treatment issues. It was important to answer the women’s questions as they arose and then guide the interview back to their experience. These interruptions were minimal and did not affect the data collection.

Data Analysis

A review of the literature revealed a selection of techniques to analyse data from a qualitative perspective. Van Manen proposed the aim of the analysis of qualitative data was to achieve insight into the ‘essence’ of a phenomenon. He argued that to understand the experience “involves a process of reflectively appropriating, of clarifying, and of making explicit the structure of meaning of the lived experience”. Ultimately this meaning can be communicated through the construction of text, this text developed from the analysis of the thematic aspects of an experience (1990:79). Theme has been described as a component of an experience which occurs often in the text, describing an aspect of the focus or structure of lived experience (Van Manen 1990:87). Thematic analysis is a method of analysis that identifies these themes or essences (Van Manen 1990; Taylor et al. 2006; Douglas et al. 2009), and was selected as the most appropriate analysis method for this research project. For the present study thematic analysis was a process of inductive categorisation of what the women had said to understand the essence of the experience of sexuality and body image following treatment for early stage vulvar cancer (Pope & Mays 1995).

Data Management

At the end of each of the interviews, and prior to transcription each interview recording was reviewed. Following this the researcher transcribed verbatim the raw data from each of the participant interviews into Microsoft word, including pauses and laughter. The participant's own words were essential to understanding themes and the subsequent analysis. Verbatim transcription of the participants own words also allowed for acknowledgement of their voices in the proceeding analysis and interpretation (Fossey et al. 2002).

Following transcription of the audiotapes, the interview transcriptions were cross checked with the original interview recordings. At this time the transcriptions were edited to delete names and other distinguishing features, and a number code, 1-10 was applied to each transcription. Meticulous records of transcribed data were maintained. Standardised file formatting, and clear labelling of the files and the transcriptions, facilitated access to the data during analysis (Pope & Mays 2006).

Thematic Analysis

Firstly, multiple copies of the coded interview transcriptions were made, with the original stored with the participant identifying details recorded on them. At this time a copy of the de-identified interview transcriptions was made available to the researchers' supervisors. Prior to starting the analysis, the researcher reacquainted herself with the relevant literature and the aims of this research project, so as to be receptive to any subtle notions present in the data which might otherwise be ignored (Taylor et al. 2006; Douglas et al.

2009).

The analysis process involved listening to the audiotaped interviews several times, and the reading and rereading of each of the interview transcripts, to get an overall sense of the interview. Following this, the next step in the analysis involved a selective reading approach as described by Van Manen (1990). During repeated readings of the interview transcripts, statements or phrases that seemed crucial or revealing about the experience of sexuality and body image were highlighted. A 'colour coding' method was used (Taylor et al. 2006:463), this involved the use of an assortment of coloured pens to highlight words and ideas in the text that appeared to be connected to the experience.

After having amassed these groupings, the next step in the analysis was to identify and code recurrent or common themes, within the data from each participant. By the same process, across all participant data, comparing and contrasting was used to identify common and divergent themes (Fossey et al. 2002; Taylor et al. 2006). Initially there was a broad range of coded categories including, but not limited to: information, getting on with life, libido, arousal, orgasm, fear, support, the wound, changes in sensation, it's not breast cancer, not coping on discharge, lymphoedema, looking at the wound, and privacy. At this point, themes were combined that were similar and those that were different were assigned their own category. Through this technique, the 'essential themes' of the phenomenon were identified. Essential themes have been described as themes that fundamentally belong to a phenomenon, that if deleted from the data the phenomenon would not be visible (Van Manen 1990:107). Likewise, these essential themes cannot fit into other categories without losing their meaning (Taylor et al. 2006).

Additionally, to improve the analysis of this project, a review was undertaken to locate data that contradicted or was disparate to the emerging findings.

This attention to negative cases improved and refined the qualitative analysis (Mays & Pope 2000). From this the essence of the phenomenon of sexuality and body image following treatment for early stage vulvar cancer was revealed. The findings from this analysis are presented and discussed in Chapters 4 and 5.

Ethical Requirements and Participant Protection

In order to ensure the protection of the rights of the participating women, and before recruiting any women to this study, ethical approval was obtained. Initially, approval to access the data base in order to develop a list of potential participants (Appendix 3) was obtained from the Director of the Gynaecological Cancer Centre.

Following this an ethics application was submitted to the South Eastern Sydney and Illawarra Area Health Service Human Research Ethics Committee (SESIAHS HREC), concurrently with a submission to the University of New England Human Research Ethics Committee (UNE HREC). At this time a copy of the Invitation to Participate (Appendix 1) the Interview guide (Appendix 2), the Patient Information Form (Appendix 4), and the Patient Consent Form (Appendix 5) were also provided to the Ethics committees. Following some minor amendments ethics approval was obtained from both committees (UNE HREC approval no: HEO8/011; SESIAHS HREC approval no: 08/152).

Several discussions took place early in the research process between the researcher and her supervisors about potential conflict of interest caused by her dual role as a nurse specialist and researcher. As a large number of patients are managed by the gynaecological cancer centre and none of the selected participants were undergoing treatment, it was agreed that the project did not have a conflict of interest in her dual roles. This view was upheld by the ethics committees at UNE and SESIAHS respectively.

Consent in writing was sought from all participants prior to interview including consent to be audiotaped. Before the interview commenced potential participants were informed of their right to refuse to answer any question, and their right to suspend or withdraw from the research project at any time. Additionally, the planned dissemination of the study findings was discussed with the participants prior to commencement of the interview. Respondents were informed the results from the analysis of their interview would be written up in the form of a thesis, and an article for submission to a peer reviewed journal. Assurance was given that their confidentiality would be maintained throughout this process.

Confidentiality was maintained throughout data collection by the removal of all identifying material. Audiotapes of interviews were numerically coded, one to ten. Similarly, names were deleted from the interview transcriptions and these were assigned the same code as the audiotapes. Only the researcher was aware of the assigned codes, ensuring the participants are non-identifiable to all but the researcher, as per the NHMRC guidelines (2007:29). The de-identified, coded data, in the form of audiotapes and transcriptions of interviews were stored in a locked cabinet in the researcher's office. Only the researcher and her supervisors had access to the de-identified interview transcriptions. Computer files were accessed through a password known only to the researcher.

Rigour and Trustworthiness of the Study

A way of determining the worthiness of research is its 'rigour'. Rigour is the way in which a project has been conducted to ensure the trustworthiness of the results and the analysis (Taylor et al. 2006). Ryan-Nicholls and Will (2009) contend that rigorous research strengthens the argument the researcher makes when trying to demonstrate the validity of their findings. They described rigour as part of "the iterative, self correcting nature of research"

(p. 71). Rigorous research is transparent in that it allows others to examine it for accuracy (Taylor et al. 2006). In quantitative research replication of research findings are important as it assists the process whereby ideas are modified or replaced as more accurate information is identified. Validity and reliability are the words generally used to describe 'rigour' in quantitative research. Validity in quantitative research refers to the extent to which the methods used to collect and analyse data do what they were supposed to do. Within this research paradigm methods are considered reliable if sufficiently free of bias to consistently provide the same results given similar circumstances (Taylor et al. 2002; Collingridge & Gantt 2008). Qualitative research uses different concepts to demonstrate the rigour and trustworthiness of research studies including; credibility, auditability and respondent validation (Taylor et al. 2006). These concepts and their application are discussed below.

Credibility

There is no one standardised test for rigour in qualitative research, but one of the ways to determine rigour is credibility. Credibility has been defined as the degree to which participants and readers of the research identify the lived experiences depicted in the research as comparable to their own (Taylor et al. 2006). This research project was conducted in such a way that the results would be found to be credible. This was done initially by having the interview guide reviewed by a Psychologist and a colleague, who are both experts in this area, and by the researcher's supervisors, who collectively have extensive research experience. The rationale for doing this was to ensure that issues related to this topic were not overlooked. Additionally, during both the data collection phase and during the analysis of this research project the assistance of the researcher's supervisors was maintained. Another advantage to eliciting this type of input is the opportunity it provided for testing the strength of the emergent themes (Cutcliffe & McKenna 1999).

Further validation of this project was sought by presentation of this study to fellow post graduate students and academics. Additionally, this research study has been presented locally, on several occasions at multidisciplinary meetings. Presentation at these meetings provided the opportunity for feedback from academics, senior clinicians and the researcher's peers. This allowed a critique of the study process and an exploration of other aspects of the research project, which might otherwise have eluded the researcher (Cutcliffe & Mc Kenna 1999).

Another technique used in this research project to ensure rigour in the analysis, was the use of purposive sampling. This type of sampling approach purposively includes 'outliers' to reveal the diversity within the study population. This sampling technique improves sample coverage, providing a framework for analysis, avoiding bias (Barbour 2001:1115)

Auditability

Auditability is another way to achieve rigour in qualitative research. It is generally achieved through the development of a decision trail, which can be examined by other researchers to establish the extent to which reliability has been maintained in the research project (Taylor et al. 2006). The auditability of this research project was strengthened by the transparency of the data collection and analysis. This was done through the maintenance of meticulous records and the reporting of the research process (Mays & Pope 1995). It was further strengthened by presenting the findings in the participant's words, through the use of quotations, assisting the reader to evaluate the authenticity of the analysis interpretation (Mays & Pope 2000; Fossey et al. 2002). The assistance of the researcher's supervisors to independently judge the credibility of the interview process and verify analysis findings was also instrumental in guarding against researcher bias. Similarly, debriefing with expert colleagues was also used to address researcher biases which might affect objectivity of the research.

Respondent Validation

Further validation was sought by sending each of the participants a copy of the transcription of their interview, to verify if this was an accurate account of their experience (Pope & Mays 2006). Of the ten transcriptions sent, six of the participants responded. All six felt the transcription was an accurate representation of their interview. None of these participants suggested any changes to the transcript. Consequently, the subsequent analysis can be considered to be a valid representation of the respondent's experience (Cutcliffe & McKenna 1999).

Summary

The purpose of this study was to understand the experience of sexuality and body image following treatment for early stage vulvar cancer, and to determine what meaning and importance women attached to this experience. Phenomenology was used as the philosophical basis for this research project, as its function is to understand phenomena from the perspective of those who experience it (Collingridge & Gantt 2008:393). The use of the semi-structured interview allowed for exploration of this phenomenon and the focus of the interviews was maintained through the use of an interview guide. Data analysis was achieved using thematic analysis as a technique to generate themes, and issues pertaining to sexuality and body image that were relevant to these women. Rigour of this study was achieved through the established means of credibility and auditability.

CHAPTER 4

STUDY FINDINGS

Introduction

This chapter details the findings of the research study. The data elements were organised into common themes regarding sexuality and body image and then grouped together to form clusters of themes or sub-themes. Some strong common themes also emerged that were not directly related to the concepts of sexuality and body image, but were so important to the women's overall experience that they were retained in the analysis. From this data four essential themes were identified that described the structure of the experience of these ten women. These themes together illuminate the experience of sexuality and body image following treatment for early stage vulvar cancer. It is important to note that the essential themes and their sub-themes were identified as unique to this experience, but no one theme was considered more or less important than any other. The four essential themes comprise: information limitations, sexuality, body image and a private cancer. These four essential themes incorporate several sub-themes. These sub-themes are: coping with vulvar cancer, sexual information, fear, changes in sensation, the sexual relationship, the vulva is not visible, and lymphoedema. In the following section each of the key themes and the related sub-themes are described.

Theme 1: Information Limitations

Coping with Vulvar Cancer

During the data collection phase of this study, the initial introductory questions that were used to build rapport, prior to addressing the more sensitive sexual topics, revealed the women's experience of coping with the diagnosis and subsequent surgery for vulvar cancer as traumatic and anxiety laden. Each of the women interviewed had a vivid recollection of her experience of being diagnosed with vulvar cancer. For these women a diagnosis of vulvar cancer, not unlike any other potentially life threatening illness was a significant life event. It evoked fear, anxiety and even for some, a sense of isolation. Initial access to information and support had a significant effect on how the women coped with their diagnosis of vulvar cancer, most particularly the time between diagnosis and surgery.

For some women in this study their emotional response to a diagnosis of vulvar cancer was exacerbated by a lack of available information and in some instances, ignorance of the disease, treatment options and prognosis by the primary health care provider. During the time from diagnosis to consulting with a specialist gynaecological cancer team, women lacked access to basic information, support and counselling. Consequently, the women sourced information from electronic resources, and occasionally cancer support groups. Not all of this information was beneficial, even in some instances exacerbating already heightened levels of anxiety and fear.

In some cases the women felt their fears were acknowledged, and the information and support they were given alleviated some of these fears, however, a few of the participants expressed feelings of anger and frustration at being left to seek and decipher information on their own prior to their surgery. One woman was so distressed by the lack of information and support given to her that she sought referral to another gynaecological oncologist. She described her experience:

> *I came to you from another hospital, I didn't like the way I was treated at that hospital because they weren't caring, it was as if they didn't realise what was wrong with me, they were treating me as if [long pause]. I felt like I had been in and had a termination! That's how I felt I was being treated. So when I saw the Psychologist here that you*

> *organised that day I felt so much better when I walked out of her office because I was able to sit there and talk about everything to her and then I felt, I felt good you know [laughter]* (**Participant 1,** 56 year old woman, 22 months following her surgery).

Another of the women described how she searched for information in a bid to understand what was ahead for her. Through the internet this participant made contact with a gynaecological cancer support group. However, the negative information she was given exacerbated her anxiety. She described not coping well:

> *I didn't cope real well because I didn't understand the concepts, I did research on the internet, but there wasn't enough information for me to grasp it, and like I said to you before, I did contact an association that deals with gynaecological cancers, I wasn't empowered. She told me negative stuff about a 36 year old woman…, you know how it was invasive and she told me I had to be assertive with doctors. She told me very negative things… she talked about mutilating surgery… I was really confused, I didn't know what to expect.*

Q. She told you very negative things?

> *Yes it was it was very negative, she talked about mutilating surgery. I was really confused, so when I went in I was really confused; I didn't know what to expect. Before I went up, it was a month of hell, I didn't cope, I just cut everything, I was a mess and everything. I would have been better if I had known more* (**Participant 4,** 37 year old woman, just 12 months since surgery).

Despite most of the women in this project being provided with detailed verbal information on the extent of the excision to treat the vulvar cancer, and the time it would take for the wound to heal, some women felt unprepared for the discomfort they experienced, and how this would disrupt their lives. This was most evident for women who had a groin node dissection. Additionally, for some, the use of a diagram provided them no insight as to the extent of the surgical excision, with even a few of these women still uncertain of their vulvar anatomy. One older participant explained her lack of understanding of her genital anatomy:

> *Body parts were not an issue when I grew up, you had boobs, and you had a waist and things like that, but you didn't understand any sexual parts of your body it just wasn't done* (**Participant 5,** 76 years old, 31 months since surgery).

One of the younger participants also described her lack of understanding of where the vulva was:

> *My friends are nearly 50 and they didn't know where the vulva was [laughter]… I didn't know where the vulva was, so uneducated in that area, women know the clitoris and the vagina don't we?* (**Participant 4)**

Several women interviewed remembered being drawn a diagram of the vulva by their oncologist, two of these women did not find this beneficial; one woman commented:

> *It is hard from a little diagram, it is like a map, you know; Sydney is here and Brisbane is there, you can see but it is not a reality* **(Participant 5)**.

For women in this study having undergone radical local excision of their vulvar cancer, their expectations of the extent of their vulvar excision were generally much greater than the reality. Of the ten women in this project, three had never been able to look at their vulvar wound and will not now look at their vulva. The seven women who did view the vulvar wound experienced mixed reactions, ranging from shock and disgust at the sight of it, to being surprised that the wound was not as extensive as expected. Unanimously, for these women, viewing the wound was a private experience and was done at a time when they felt ready. Being offered a mirror by nursing staff post operatively, although well intentioned was not helpful to the women. One participant with the more extensive surgical excision described her reaction to looking at the wound for the first time about two months post operatively:

> *Well I think I was rather pessimistic about it [the wound] more or less thinking it is all done and dusted and with a bit of luck I won't get any more cancer, if that's what it takes, that's what it takes. It was worse than what I thought it was quite invasive and quite nasty* (**Participant 5)**.

Another described her feelings when she said;

> *I was really shocked, I think at just what it looked like, yeah I couldn't really see what had been taken'* (**Participant 9,** 64 year old woman, interviewed 64 months after surgery).

Contrary to this some of the women's expectations of their vulvar excision were far worse than the reality:

> *After I had the surgery the nurse said, 'would you like a hand mirror to have a look', but I didn't want to. It was when I came home, I have a built in wardrobe and I sat at the end of the bed and I looked and I went oh ok. Yes it didn't surprise me, I didn't go, oh yuk! I probably thought it was going to look worse than it actually did. Yes probably because of what that woman had said [from gynaecological cancer support group] I was expecting this complete butchering…* (**Participant 4)**.

Coping with the healing wound was difficult for the women, most particularly for those few women having had more radical vulvar surgery and/or removal of their groin nodes. The women were unprepared for the impact that this had on their lives in the first few months post operatively. One woman interviewed described an experience she had post operatively as one of the worst experiences of her life, one she would never forget:

> *After the surgery it was pretty horrendous, I was well looked after and I am a patient person so I just laid back and did what I was told. There is one thing that just blew me away... I had been using bed pans while on bed rest, but when the day came where they said 'come on you can hop up and go to the toilet', I think I had one of the worst experiences I have ever had. I was sitting on the toilet and when I got up I found my urine was going up the wall! I had no idea that I would spray my urine like a cat, I felt like*

> *a tom cat spraying all the walls* (**Participant 5,** having had the most radical vulvar excision).

Likewise, this participant felt the reality of the recovery from this type of surgery was significantly underplayed, she described her feelings:

> *I didn't think I would be so disabled down there. I didn't think I was going to be changed so much. I just went into it with my head held high, I am going to get better and I don't suppose I even wanted to know what was going to happen to me. Once I found out what had happened to me the shock started to come in, even in hospital I couldn't have a look. This is what you have to do to treat the cancer and hope it won't come back again and so if it is all a bit of a horrible mess down there… well it just has to be a horrible mess doesn't it.*

Another described the ongoing discomfort until the wound healed, she described '*sunning*' the wound was the only thing that afforded her some relief from the pain:

> *Oh yes it was the only way I can get any relief and the sun is such a great healer, because it is such an uncomfortable area you can shower and shower but the moisture is still there so I just do 10 minutes in the sun a couple of times a day* (**Participant 6,** 50 year old, just under 10 years since surgery).

Additionally, for the two women who developed a lymhocyst[2] following their groin node dissection, the experience of having daily dressings and packing of the lymphocyst, compounded the distress they experienced:

> *I still remember the lymphocyst, having the packing and everything like that it was very deep, they would have reams of stuff [packing] that big [holding hands wide]. I used to think that couldn't get into my leg but it did, the smell of it was obnoxious, it was pretty putrid, the lymphocyst it was pretty putrid…* (**Participant 5)**.

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[2] Lymphocyst is an early postoperative complication of the groin node dissection. It is a collection of lymphatic fluid in the area around the groin node dissection. Lymphocysts occur in about 40% of women and usually develop within one to four weeks after surgery. They generally require drainage and daily dressings, but once resolved do not recur.

The experience of being discharged back into the local community for dressings and packing of the lymphocyst was described by one of the women as a distressing experience. This participant struggled with trust in the community nurses who attended each day to attend her dressings:

> *And when the nurses are coming here to do the dressing and she said 'oh I can't pack the wound anymore' and I said oh you have to. She said 'no it is good, it is closing up', and you feel horrible because you feel they don't have knowledge, and that is what really puts you off because you worry they are not knowledgeable…, yes the community nurses don't know a lot about vulvar cancer, when I was readmitted [back into hospital] the nurse that did the dressing was excellent but sometimes the packing can be really unpleasant* (**Participant 4**).

Sexual Information

At the time of diagnosis the women were focused on the diagnosis of their vulvar cancer, and their treatment options. As a consequence, women generally didn't remember being given any sexual information. On the other hand, women who had undergone groin node dissection had excellent recall of the information and education they had being given on the risks, preventative techniques and the management of lymphoedema. For participants who did recall receiving information on sexual intercourse it was either; too basic, or given at a time when they were not receptive to receiving information of a sexual nature. One participant responded when asked if she had received any written or verbal information about sexuality;

> *No I don't think about the sex part, no. I know he [Doctor] said something but I just can't remember, he did say you have to wait a certain time, I can't even say what that was. It is probably because it wasn't on my mind at the time. It wouldn't even have been something I thought about* (**Participant 4)**.

One participant did remember being given some information but described it as very basic when she said:

> *It was very basic [information], there was something now*

> *when I think about it that said your partner needs to be understanding, but when I think about it there should be something for the partner, there really should, on what to expect and not to expect. They will think 'Oh I will hurt her', but if they had something that told them what had happened to the passage, and something to tell them that it would be different to before and how to circumvent it would be very beneficial* (**Participant 5)**.

Another described being sent a booklet in the mail on Sexuality and Vulvar Cancer following a phone call she made to the Cancer Council asking for information. She described her feelings when she read this:

> *I actually chucked it away! It was like I had told them my diagnosis and I expected more from them, I don't know why I felt like that, probably because you hear about the Cancer Council so much I expected more from them. This was all before my first visit [pause]… I was reading it when I was waiting for my first visit with you and [Gynaecological Oncologist]. I thought they might have contacted me, a phone call or something. I thought, what is this going to help me with!... I put it in the bin* **(Participant 4)**.

The women interviewed had varied opinions on when was the best time to receive information about sexual intercourse. Overall, they suggested within the first 6 months; with some suggesting preoperatively, others immediately post operatively, or up to 12 weeks following surgery:

> *Yes if I had my time over I would like more information in that first 6 months. Before I have the treatment; what I am going to deal with, what I am going to find, what sex is going to be like. More counselling for 6 months, what is it going to be like afterwards* (**Participant 6)**.

In contrast, for some women initial preoccupation with diagnosis and prognosis precluded them from absorbing information on sexual issues, with one woman describing her feelings:

> *I think initially you are delving into what cancer you have and what stage it is. I think maybe once I have recovered from my surgery at the first post operative visit I could have spoken about it then. Because then it was time to think I can engage in sexual intercourse* **(Participant 2,** 64 year

> old woman, 23 months since surgery).

Theme 2: Sexuality

Fear

Sexuality for each woman after treatment for vulvar cancer was a uniquely individual experience, but across all the data common themes occurred. Fear was a predominant emotion associated with several experiences. For the younger women there was fear associated with the potential for removal of, or disruption to their clitoris. Similarly, for most sexually active women fear was a prevalent emotion linked to the resumption of sexual intercourse after their surgery. Women feared pain and the potential for disruption to sexual intercourse and approached it with trepidation. For this reason some women postponed sexual activity for many months after recovery, others resumed sexual activity as soon as they felt their wound had healed, albeit with a degree of anxiety.

Most of the women in this study had recommenced sexual activity between two and seven months following treatment for vulvar cancer, with only one woman not having sexual intercourse for '*about 12 months*' after her surgery. All of these women expressed fear and anxiety leading up to this first sexual encounter. Overwhelmingly, they expected their first post operative sexual experience to be painful. One woman described her fear:

> *I was very nervous, I was very nervous about it all splitting because you know the muscle and the material in your vagina is you know [long pause] I thought if its got a scar which would be a massive cut, which it would have been, it is not going to give, and so I was really nervous the first couple of times I was hanging on for grim death you know* (**Participant 1**).

Another woman admitted fear of what sexual intercourse would be like for her and her partner, she described her feelings:

> *You know leading up to it I was worried what was going to*

> *happen, how it was going to feel, like I said, I was nervous the first time* (**Participant 2)**.

Fear of painful sexual intercourse prevented three of the women from initiating sexual intercourse for more than six months after their surgery. One of these women responded when asked about resuming sexual intercourse: *'Not for 12 months, I was too scared that it would hurt'* (**Participant 9,** 58 year old woman, 64 months since the surgery). Another described it being at least seven months before she felt '*comfortable*' enough psychologically to have sexual intercourse (**Participant 3**, 48 years old, 48 months since her surgery).

The two women, who had not resumed sexual intercourse following their surgery, both expressed nervousness at the concept of sexual intercourse. They divulged that they had not participated in any form of sexual activity since their surgery, including experiencing any sexual thoughts or feelings. Both of these women had undergone removal of the clitoris. One woman described her thoughts of participating in sexual intercourse when she said:

> *Knowing how I feel down there if I was inclined to experiment and see if I could enjoy sex, I would feel that it would have to be very very gentle, even feeling if you could have anyone penetrate you* **(Participant 5)**.

Only one woman interviewed expressed no anxiety about resuming sexual intercourse, she described her feelings: *'No I didn't feel bothered, I didn't have any hang ups about it'* **(Participant 10,** 62 year old woman, interviewed 39 months following surgery). The women's fear of this first sexual encounter was generally unfounded, with most of the women experiencing no discomfort. For the few women who did experience discomfort due to decreased vaginal and genital lubrication, subsequent use of a personal lubricant, alleviated this problem.

Similarly, fear of losing the clitoris was a prominent concern for a few of the women, mainly the younger women interviewed. These women felt reassured when informed by their surgeon that the clitoris could be preserved and grateful post operatively their clitoris was intact. One of the younger women interviewed was so fearful that her clitoris would be removed that on the second night after her surgery, she described masturbating to reassure herself that her clitoris was still intact:

> *I remember waking up after the surgery and I can remember having the calf compressors on pumping up, and I was in so much pain, [husband] was there and they gave me a little bit more morphine, and I was so afraid that they had taken my clitoris that I actually masturbated that night [laughter]* (**Participant 6)**.

However, for this participant there is the ongoing fear that the clitoris will be eventually removed during repeated procedures she undergoes for recurrent Vulvar Intraepithelial Neoplasia (VIN)[3]:

> *It bothers me because at different stages over the last 10 years I have had various surgeries and… [Doctor] has said to me he will try to save the clitoris, so that has played on my mind. I don't know what that would be like; you know some cultures do that to their daughters.*

In contrast, the oldest participant expressed feeling no fear preoperatively at the thought of losing the clitoris; she described her feelings, when asked: *'no not really I think I took it as part and parcel of it all'* (**Participant 5).**

Changes in Sensation

A prevalent theme for all but one of the women interviewed, including those women who were not sexually active; was changes to sensation over the excision site on the vulva. These changes in sensation ranged in area directly proportional to the size and position of the excision. The women described the changes to sensation in various ways; '*numbness*', '*an odd feeling*', an '*unpleasant sensation*'. One woman, having had the most extensive vulvar surgery described her initial reaction to touching the vulva:

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[3] Vulvar Intraepithelial Neoplasia (VIN) is a cellular abnormality of the vulva which is confined to the epithelium; for further explanation see the section headed 'Vulvar Intraepithelial Neoplasia' in Appendix 6.

> *I didn't want to touch the area down there to wash myself, it felt so strange. I felt it is like touching a wound, whether it is on your hand or anywhere you just want to be protective of it, even now I am not too good at it [touching the vulva]. It is a place on your body that is fragile we think of it as fragile, it most probably is not. It is probably as tough as anything but it did take me a while before I could touch it, it feels so strange, it still feels strange* **(Participant 5)**.

For some of the other younger women interviewed these changes were not as troubling, as they simply avoided touching the '*numb*' area during sexual foreplay. However, three of the seven sexually active women, all post menopausal did admit to increased difficulty in achieving orgasm since their surgery. Only one participant was certain that her orgasmic difficulty was attributable to the changed sensation in her vulva. For this woman subsequent changes to positioning during sexual intercourse have compensated for this and she can now achieve orgasm as before:

> *It's different...ohhh I suppose a different movement to get a climax I suppose, I was lucky I didn't have the clitoris removed, so we have just made positional changes* **(Participant 10)**.

One other woman, who had reported difficulty achieving orgasm, was unsure if the sensation of numbness around the area of excision on the vulva, or her psychological state were responsible for this; she described this when asked about sexual intercourse since her surgery:

> *I just feel it is different I don't know when you have foreplay with your husband and everything you just feel phhhhh, less sensation, where the wound is. It is an unpleasant feeling, orgasm is hard! But I think really it is to do with my mind, I am too busy trying to think of what I should, you know, trying to relax and everything, but it has changed a lot* (**Participant 2)**.

The other woman **(Participant 9)** who acknowledged not being able to achieve orgasm since the surgery, had maintained an intact clitoris, and was the only participant to not experience any altered sensation to the vulva.

Although reluctant to discuss orgasm, she admitted (when asked) to not making any attempt to rectify this, it was simply how it was.

'Nothing has changed' was the response of the younger two participants interviewed. Both women described sexual intercourse as being the same as before their surgery for vulvar cancer despite their concern that it wouldn't be, one woman described this:

> *Nothing has changed in that area, you know leading up to it I was wondering what was going to happen, how was it going to feel. I was nervous the first time [laughter]… it was fine, I was lucky because [husband] is such a good person, he didn't make me feel like I was an alien or I was any different. It was the same it wasn't any different* **(Participant 4)**.

Three of the sexually active women, all post menopausal, described a reduction in their desire for sexual activity since their treatment. Two were reluctant to attribute these changes to vulvar cancer; one described her feelings about sexual activity:

> *To be truthful I couldn't care less if I had sex or not and I don't know whether that is menopause or what. I know that before I had the operation it was very painful then and I thought that was just menopause, so it seems that for a long time I have been scared and in pain and expecting it to hurt. Since the operation I have started to shop around and I found this stuff called Sylk [personal lubricant] which is kiwi fruit or something and occasionally I will use that it makes me feel a lot more relaxed about things* **(Participant 1)**.

However one of these participants did attribute her decreased libido and long periods of no sexual activity to repeated irritation from ongoing VIN; she described this:

> *There have been long periods in between these surgeries of no sexual activity. I think it is a combination of irritation from the VIN and a lack of libido. I don't feel as turned on and as hot as I used to* (**Participant 6)**.

The two participants who had not maintained their clitoris, both without a sexual partner, expressed a lack of desire for any sexual activity: one described her feelings, when asked; *'It feels numb all the time, I have no sexual thoughts, no, no nothing like that'* (**Participant 7**, a 63 year old woman who had her surgery almost five years ago). When asked, both of these women said they would not pursue another sexual relationship; this is discussed in the following sub-theme.

The Sexual Relationship

Despite any functional sexual changes, all but one of the sexually active women reported satisfaction with all aspects of their relationship with their partner, sexual and otherwise. All of these women described their marriages as happy, and valued the support they had received from their partners during their treatment for vulvar cancer. The one participant who acknowledged some disappointment at one aspect of her sexual relationship with her partner, had undergone multiple vulvar procedures to treat recurrent VIN, and thought that her husband's reluctance to perform cunnilingus was due to fear he would '*catch something*', despite this they maintained a satisfying sexual relationship. In contrast to this, of the three women in this study who were not sexually active, two directly attributed their relationship breakdown to their having being treated for vulvar cancer. Neither of these women had started new relationships.

Women expressed feelings of satisfaction at the sensitivity displayed by their partners in allowing them to resume sexual intercourse when they felt they were ready, none felt pressured by their partners to do so. One of the women when asked about how her husband reacted to not resuming sexual intercourse for six months, she responded; *"No, no, he left it all to me… he has been fantastic, very good"* (**Participant 2)**.

Only two of the sexually active women reported any changes to their partners' sexual behaviour towards them since their surgery. One of the participants described sexual intercourse as unchanged but did volunteer that her husband had never touched the excision side of her vulva. She had never asked him about this, and was not at all bothered by it; she described this:

> *Nothing has changed no, but he [husband] has never touched that area, he has never touched that area. I was expecting a change but it hasn't. This [surgery] has had no impact. No… he takes an interest when I ask him things, like how does it look in these pants, can you notice any change, but he doesn't make me feel different, everything is the same [smiling]* (**Participant 4)**.

As mentioned previously, there was one other participant who when interviewed described feeling bothered by the fact that her husband would no longer perform oral sex on her; She explained this:

> *You know [husband] won't perform cunnilingus or anything like that anymore because I think he has got a mindset that he might get something in his mouth or something like that. I can understand why, yeah, I can understand why he might have that hesitation you know. He has seen it in war and peace! You know peace has gone so I can understand that [laughter]* (**Participant 6,** who had undergone multiple procedures for recurrent (VIN)).

Only one of the seven women involved in a sexual relationship expressed initial concern at her partners' response to her having surgery to the vulva:

> *I was worried about [husband] and I asked him before I had the surgery would it matter having the vulva gone. I was thinking I am going to have my vulva removed, how is that, image wise, going to look… what is he going to think?* (**Participant 4)**.

Familiarity of the long term relationship appeared to be sexually protective for one of the women, she expressed this when she said:

> *No I didn't have any problems, [husband] he is not a demonstrative person, but in his way he has been caring. I never felt like I had lost my womanhood. I don't know how I would feel if I had to go out and have sex with someone*

> *else, with all the tightness and worrying and so on [laughter]. So in that way I felt comfortable with my husband* (**Participant 1)**.

All three of the participants who were not sexually active had been divorced for some time prior to their interview. Two of these three women directly attributed the disintegration of their marriage to their diagnosis and treatment for vulvar cancer. One of these women described her husband's reaction to her vulvar cancer:

> *My husband was a strange fellow for the fact that he hated illness of any description. When the kids were ill you would never see him. I don't know why, he had this thing about illness [pause] I think he thought cancer is death. I actually think he started up his relationship with my girlfriend while I was still in hospital. From the time I got out of hospital the marriage started to fall apart…. We stayed together for five years after that, it was still sexually active but he wasn't there you know* (**Participant 8**, 63 year old woman, over 10 years since her surgery).

The one other participant whose relationship had also ended after her surgery for vulvar cancer, also due to her husband's infidelity; expressed her reluctance to pursue another sexual relationship:

> *I might have another relationship but I wouldn't have a sexual relationship, I don't think so, no. I guess much of it is how much [husband] hurt me* (**Participant 7)**.

The other participant without a partner who underwent the most extensive surgery expressed good fortune that she did not have a sexual partner; she remarked:

> *Feeling so strange in that area I don't know if I would even have the urge to have any sexual activity… [laughter] but it hasn't happened and I haven't been placed in that position but in thinking about it, and I haven't given it a lot of thought, but I am thinking about it now, I just wonder having had the vulvectomy and feeling so strange down there I don't know if I would have any urge to participate. Well even sitting here now I have to sit in the right way, if I don't I have to get up and adjust myself, so*

> *there is definitely that big change and I guess I have been lucky in not having a partner that might want sex and I am not the least bit interested in it…. [more laughter]* (**Participant 5)**.

Theme 3: Body Image

It appears that following treatment for early stage vulvar cancer many women maintain a positive body image. Women having had the most radical vulvar excision and multiple vulvar procedures struggled more with disruptions to their feelings of femininity and body image. Interestingly, all women felt some protection from the invisible nature of their surgical excision, with some perceiving that mastectomy to treat breast cancer would be more visible, therefore, making it harder to deal with.

The Vulva is Not Visible

The theme of the vulva being hidden and not readily visible to others seems to be protective of body image for the participants in this study; one woman described this:

> *I would rather have my vulva removed than my breast, it would be so inconvenient to put in a prosthesis. I would hate that! I would be really conscious about that. Who sees there, no one, the gynaecologist, your husband, no one. It hasn't been as big an impact as what I thought it was going to be when I was first diagnosed* (**Participant 4)**.

Likewise, another of the participants who also described noticing a disparity in size from one side of the vulva to the other was not concerned due to it not being obvious to others:

> *No, I don't feel any different in regards my femininity and body image, it doesn't worry me. I can stand and look in the mirror and think oh I look different, but I swim, I get into cossies, no one would know* **(Participant 10)**.

One other participant who had experienced several excisions and laser procedures for recurrent vulvar intraepithelial neoplasia identified struggling from time to time with feelings of femininity and her body image. Despite this she remained positive and only felt embarrassed when exposing the vulva:

> *One of the most embarrassing things is going to have a Brazillian wax prior to surgery and I have an absolutely lovely lady that does it for me but it is still that presentation. However she is very professional but when I have to wax before I have something taken off [VIN] I get quite embarrassed. But self image I think you just have to work on it each day, but when I look in the mirror it looks the same to me…* (**Participant 6)**.

The participant who had the most radical surgical excision, a radical anterior vulvectomy, including removal of her clitoris, identified the negative impact to her body image. Although she commented she did not feel less feminine, she did describe the feeling of being '*neutered*' following the surgery:

> *You don't like to think you have done something to yourself that neuters you I suppose. I don't feel less feminine I feel that my body is not the same. I suppose it would be in some ways the same as women who have lost a breast. A friend has just lost a breast and she was saying how strange it felt to wash that breast or that spot, she found it a little different and that is the way it is for me. Fortunately you don't have to worry about people seeing it, it is strange, it has left me with feeling my body is not right…* (**Participant 5)**.

Overall, the participants interviewed who had not had a groin node dissection described very positive self image, with most of them remarking that once the wound had healed and they resumed their 'normal' lives they experienced no significant changes to body image. Some participants when asked about their body image and if they felt differently about themselves since their surgery simply responded *'no, I don't feel any differently'*. Other women were more expressive and justified their feelings:

> *No no I still dress the same and behave the same, no I don't feel any different. I guess because I have just been in and had an operation and come out, I haven't done anything else. It might have been different if I had to have chemotherapy and radiotherapy and all that I think that would be different* **(Participant 3)**.

One of the younger women interviewed, who had a one sided vulvar excision actually described preferring the look of her vulva on the operated side, she responded when asked about her body image:

> *I always feel there is a flat side, I say there is an up and down. I am always aware there is more on one side. Yes I always feel when I am getting ready, or when I am towelling myself, you always know it is there, I am always aware it is there and even in pants sometimes it can look a bit raised, I was showing you at the last visit that the unoperated side now looks raised in my underpants. Not that I worry about it, [pause] I worry more about the lymph nodes and that, but it is there you know it's there. I am absolutely fine with it, I wish the unoperated side was flat. I wish when I shower myself you really notice a difference I think the other side is in the way I just like it flat, I like the feeling of it being flat. Yes, I just like the cosmetic appearance of it and the flatness of it* (**Participant 4)**.

Lymphoedema

For the four participants in this study who had removal of their groin nodes there was an ever present worry associated with the threat of developing lymphoedema. Only one of these women had at the time of interview not developed some degree of lymphoedema. All of the women reported being well informed about the possibility of developing this condition, and all of the women were aware of techniques to prevent or minimise it. Unanimously, all four of these participants acknowledged some detrimental effects to their body image, or how they felt about themselves since having the groin nodes removed. The women attributed this to either; having to change their style of dress to cover swollen lower limbs, worry about developing the condition and adhering to preventative techniques, or for one respondent, feeling '*incomplete*' since having '*negative*' nodes removed.

The participants who experienced the most disruptions to body image were those three women having developed lymphoedema as a consequence of their groin node dissection. These participants felt compelled to cover the swollen affected limb so it was not visible to others, and found this distressing. When responding to the question: Do you see yourself differently now since your surgery? One of the women responded: *'Yes only because I have the swelling in the leg, only one leg and it bothers me'*. She went on to describe feeling the need to wear ¾ leggings when she swam so no one would notice her swollen leg **(Participant 3)**.

Another of the participants who described feeling '*ok*' about her body image, conversely described covering up the lymphoedema for the comfort of others:

> *I don't have any ankles, I have terrible skin! Look can you see [pulling trousers up to expose ankles]. You just dress differently, you wear pants a lot and long skirts, I can put up with my legs the way they are, the way they look, but I don't think other people should have to (laughter)…* **(Participant 8)**.

One other respondent when asked about her body image again identified changes to her wardrobe as an issue, she described this when she said:

> *It might just have taken it away that I can't wear nice straight leg trousers. I have to wear those with a bit of stretch in them and as you can see this one is much bigger than the other one [points to right leg]. That is the only thing, I don't think it really concerns the image, only the clothing, and also I can't sit in anything that is tight, it really hurts, really hurts. There is no way you could wear a bikini or a G string [wry laughter]* (**Participant 5)**.

The women in this study who had a more extensive surgical excision described having to make changes to their underwear to accommodate the surgical excision. This generally resulted in the women having to wear loose cotton underwear but unanimously they saw this as a minor issue, even somewhat amusing. This appeared to have no negative impact on body image, unlike the changes that needed to be made to cover swollen lower limbs.

Theme 4: A Private Cancer

A sense of vulvar cancer being an intimate or extremely personal experience for the women emerged during the in depth interviews. Women generally perceived it to be too intimate to bring up, or discuss socially. The majority having never discussed their cancer with anyone other than their specialist gynaecological cancer team, partners and close female relatives and friends. Many of the participants had not told their teenage or adult children they had been treated for vulvar cancer. The women described this as protecting their children from reality, or saving them the embarrassment of knowing their mother has cancer of such an intimate area. One participant described how supportive her family had been to her, but revealed that she had given her daughters only limited information:

> *I had good support from two girlfriends, they were very supportive, and my family [long pause] are supportive in their own way, but I was protecting my daughters! I didn't really want them to know. They are 24 and 26 now I didn't really want them to know how bad it could have been… so you know I didn't say too much to them but they were caring because Mum had been in hospital [smiling]* **(Participant 1,** with both adult daughters still living at home).

One other woman interviewed felt it was preferable to let her son think she had been treated for cervical cancer, rather than afford him the embarrassment of knowing his mother had vulvar cancer, she said:

> *My son, who is 30 he just thinks it was cervical cancer. I have never bothered to enlighten him (long pause and then a gentle smile) no he is really quite shy'* (**Participant 7,** divorced, with a very supportive adult son).

Another described restricting or censoring information she provided to her sons:

> *My sons don't really know a lot, they know I had a lump*

> *down there but I didn't really go into it with them. I am open with them, they know they can talk to me about anything, but I didn't really want to go into it with them, I was protecting them.* (**Participant 4,** mother of teenage boys)

One other woman described the experience of being treated for vulvar cancer as a difficult topic to bring up, she said:

> *I would be happy to talk to other women just like I am sitting talking to you about it, but you can't just go down to the club you know and say, I will have a vodka and soda and by the way this is the way my fanny looks, [laughter] you know what I mean? I would be happy to talk to them but it is a private area, private business, it is private, but if anyone wanted to know I would tell them about it* (**Participant 6**, also a mother of teenage children).

With another of the women remarking:

> *It was too private, I never said anything, I don't say anything to anyone. I don't want it to be known [teary, dabbing eyes with a tissue]. I don't want to discuss it, I don't feel comfortable…* **(Participant 3)**.

Many of the women compared their experience of having surgery for vulvar cancer to breast cancer. In this instance, the comparison to breast cancer was a negative one, with most women describing breast cancer as a more common and less intimate cancer; therefore, more socially '*acceptable*'. Some of the women interviewed felt they would be more likely to talk about their cancer if it was breast cancer. Not all women commented positively when comparing vulvar cancer to breast cancer, with one woman expressing hostility at the interest and support that breast cancer generated. She described her feelings following a talk she had given on her experience of vulvar cancer, at a local Women's Health Centre, she remarked:

> *Everyone was embarrassed and I thought what am I doing here if you are all going to hide your heads. I think they thought I was going to talk about breast cancer [angry tone, shaking head]… you know I am so angry with the support that breast cancer gets…* (**Participant 7)**.

During the interviews the participants acknowledged knowing no one who had been treated for vulvar cancer; however, most had friends or relatives with breast cancer. Overwhelmingly, the women all expressed a desire to meet and talk to someone having been treated for vulvar cancer and to be involved in a vulvar cancer support group. One woman's response when asked if she would like to be involved in a support group for vulvar cancer was:

> *Yes I would, because I don't know anyone else with vulvar cancer up here, only breast cancer… a lot have had their breasts off* **(Participant 9)**.

It was evident from the interviews that the intimate nature of vulva cancer was somewhat isolating for the women, as treatment of cancer in such an intimate area precluded the women from discussing their experience with all but a few close family members, and trusted female friends. Ultimately, this limited their access to the support available to other's diagnosed and treated for cancer. This applied equally to women from both metropolitan and regional/rural areas.

Conclusion

The themes identified in this chapter together comprise a description of the experience of sexuality and body image from the perspective of ten women following treatment for an early stage vulvar cancer. For some women information limitations impacted on their ability initially to cope with their diagnosis of vulvar cancer and to deal with their wound post operatively. Information on sexual function and the possible implications of treatment on sexuality was either, not given, or given at a time when women were not interested in receiving it.

Within the essential theme of sexuality, resumption of sexual intercourse evoked fear and anxiety for most women. Changes to sensation on the vulva were evident in almost all women, but this was only a problem for a few women. However, older women experienced more disruption to orgasm and desire. The relationship with the partner was a significant feature for all women, and was an important factor for women in determining satisfaction with their sexual relationship. Removal of the clitoris and the absence of an interested partner was linked with women not resuming sexual intercourse following treatment for vulvar cancer.

The theme body image incorporated the vulva as not visible to others, affording some of the women protection from disruption to their body image. However, also within this theme, was the experience of lymphoedema, which had a more detrimental effect on body image. Finally, for all women the diagnosis and treatment of vulvar cancer is a private experience, shared only with a select few. In the following chapter these themes will be discussed in the context of the relevant literature.

CHAPTER 5

DISCUSSION

Introduction

The purpose of this study was to identify and understand the experience of sexuality and body image for women following treatment for early stage vulvar cancer. Specifically, to understand the experience and to determine the meaning, and importance, women attached to this experience. The objective of this research was to contribute to the limited body of knowledge available, describing the psychosexual outcomes for women following treatment for early stage vulvar cancer. A qualitative approach based on interpretive phenomenology was used to interview a purposive sample of 10 women who had previously been treated for an early stage vulvar cancer. Data was generated from verbatim transcription of the semi-structured interviews. The experience of sexuality and body image following treatment for early stage vulvar cancer was revealed through this interpretive phenomenological study. Thematic analysis of this data revealed themes that were essential to the experience. These essential themes and their sub-themes conveyed the structure of the experience of sexuality and body image following treatment for early stage vulvar cancer.

This chapter presents a discussion of the study findings in relation to the literature relevant to the four essential themes identified. These themes comprise: information limitations, sexuality, body image and a private cancer. These themes have several dimensions in the form of sub-themes, which are also discussed in this chapter. Implications for future nursing practice and other clinical practice are then identified. Finally, the limitations of the study are acknowledged and recommendations for future research made.

Discussion of the Themes

This section focuses on discussion of the key themes (described in the previous chapter) in the context of available literature. A significant amount of the literature referred to in this chapter has previously been described in chapter 2. However, in order to broaden the discussion, most particularly in relation to emergent information within two of the key themes, information limitations and a private cancer, it was necessary to refer to literature not previously discussed in this thesis.

Theme 1: Information Limitations

The findings of this study concerning how the women dealt with their diagnosis and treatment for vulvar cancer were interpreted and themed as information limitations. Information limitations was a recurring theme throughout the women's experience of vulvar cancer, encompassing women *coping with vulvar cancer*, and receiving *sexual information.*

Coping with Vulvar Cancer

Vulvar cancer is a rare cancer, and women diagnosed with this disease are presented with particular challenges. One of these challenges can be the lack of information available to women and their families about the disease, treatment options and prognosis. Additionally, many women may experience a delay from their diagnosis to a specialist consultation; due to the necessity to be referred to a tertiary referral centre[4]. This may involve women travelling long distances to access specialist care. In this current study, these factors contributed to the burden of distress experienced by some of the participants. During the time from their diagnosis to a consultation with a gynaecological oncologist (between two to four weeks), the participant's information needs,

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[4] Modern management of vulvar cancer necessitates an experienced, multidisciplinary team approach, which is available only in tertiary referral centres (Hacker 2010:546).

most specifically regarding their disease, prognosis, and implications of treatment were not met. Women attempted to search for this information themselves but there was a lack of appropriate information available to them.

Similarly, Jefferies and Clifford (2009:33) recently published the findings from their qualitative study of British women with vulvar cancer. They also reported women 'searching for information' between their diagnosis of vulvar cancer and their consultation with a gynaecological oncologist. They suggested that during this time the health care professionals involved in the care of these women had not made information available to them. Likewise, the one other Australian study of women having undergone surgery for vulvar cancer, also found these women to have 'high information needs'. Furthermore, the authors found there was a lack of written information readily available to women diagnosed with vulvar cancer, other than that usually provided by doctors, nurses and other health professionals in a consultation (Janda et al. 2004:187). Research concerning women with gynaecological cancer has also described a strong correlation with the lack of available information and associated high levels of distress. As discussed in chapter 2, an earlier quantitative study by Corney et al. (1992) found that for women diagnosed with a cervical or vulvar cancer, the period of most distress usually correlated with the period of most uncertainty. This was either between the development of symptoms, and the diagnosis of cancer; or between the diagnosis of cancer and surgery.

An extensive review of the literature into other rare cancers revealed almost no discussion of the informational needs of these patients. A recent publication of the Australian Nursing Journal devoted their entire December 2009 issue to the discussion of four rare cancers: carcinoid, vulvar, gastrointestinal stromal tumours and multiple myeloma. Despite this, it was only in the editorial by Krishnasamy (2009) that mention was made of the difficulties faced by these patients in accessing information. However, it has also previously been shown for patients with various other forms of cancer that during the time from diagnosis to consultation, lack of information has caused some patients a 'fear of the unknown', which significantly contributed to their psychological morbidity (De Lorenzo et al. 2004:721). Likewise, patients from remote and rural locations can also experience similar problems accessing information following their diagnosis of cancer. The findings from a qualitative study of colorectal cancer patients has shown that patients, from rural locations in the United Kingdom, experience more hurdles acquiring information before reaching the specialist referral centre, than those from urban locations (Bain & Campbell 2000). In contrast, an Australian study conducted to determine the needs of women diagnosed with breast cancer found although these women had high information needs, there were no differences between urban and rural women in accessing relevant information (Girgis et al. 2000). An explanation for this could be that as breast cancer is the most commonly occurring cancer in women, significant work has been done by agencies such as; the National Breast Cancer Centre, The Cancer Council and other bodies in raising awareness about breast cancer. For this reason, cancer information is readily accessible to both urban and rural women.

In the present study some participants described they had difficulty understanding the information they had been provided at their preoperative consultation. Others had disregarded, or forgotten information, that was not relevant to them at that point in time. Many of the participants reported a lack of understanding of the surgical excision and the time it would take for the wound to heal. Additionally, a few of the women had difficulty visualising what would be excised during their surgery, even some women unsure what the vulva actually incorporated. These findings are consistent with those previously described in chapter 2. Following their study of the psychological effects of vulvectomy, Stellman and colleagues (1984) reported that approximately half of the respondents could not describe which body parts had been removed at surgery. Likewise, most participants in the study by

Andreasson et al. (1986) had no concept of what their genitals would look like after vulvectomy, with more than half of them believing the result of the operation to be worse than they had expected. Certainly, the participant in this current study who had the most radical surgical excision (a radical anterior vulvectomy) was shocked by the size of her wound. However, for a few of the women having had a less radical surgical excision their vulvar excision was less than they had perceived it would be.

Although it was beyond the scope of this research project to determine how much information these women had been provided, it is known that all of the women in this study participated initially, in a lengthy consultation with their Gynaecological Oncologist. At this time they would have been provided both verbal and written information. One component of this information is a drawing of the proposed surgical excision on a professionally printed diagram which identifies the vulvar structures and the position of the lymph nodes in the groin. This diagram is then given to the women to take with them. However, the current results show that not all women benefited from this type of information. Some women did not recall the diagram and a few found it of no benefit at all. Other studies have also previously found cancer patients report a lack of understanding and poor recall of the information they are given in medical consultations (Knox et al. 2002). Various information recall studies have been performed over the last 30 years. Ley (1982) conducted a summary of evidence related to recall of information amongst various cohorts of patients, with results indicating that heart surgery patients could only describe about 30% of the information provided to them. Likewise, cancer outpatients forgot more than 30% of the written information they had received.

A further review of the literature did not reveal any studies specifically investigating recall of information for gynaecological cancer patients. However, the availability of adequate information for women diagnosed with vulvar cancer has previously been discussed in the literature investigating the psychosexual consequences of treatment. In contrast to the results from this current study, Andersen and Hacker (1983) found the majority of women in their study felt they had been adequately informed as to the surgical details of their operation to treat their vulvar cancer. However, similar to the findings from this current study, Danish investigators found approximately 25% of their participants thought the information they received regarding surgery to treat their vulvar cancer was either inadequate or nonexistent (Andreasson et al. 1986). In accordance with this, Weijmar Schultz and colleagues (1986) described only half of the ten women interviewed for their study estimated the information they received to be sufficient to adequately address their information needs.

It was not possible within the framework of this research project to determine what influenced or enhanced the participant's recall and understanding of the information they had been provided. However, the literature has previously determined there are various factors which influence patient's uptake of information, such as the patient's attitude to having cancer, and the strategies they used to cope with cancer (Leydon et al. 2004). It is also well recognised by health care professionals that some patients 'switch off' when given distressing news, or when they hear the word 'cancer' (Allen 2003:599). For this reason, Cimprich (1992) also found recall of information provided to patients at the time of diagnosis was limited. An interesting finding from a survey of Australian prostate cancer survivors was that men who had received their diagnosis and information more recently, seemed to not remember receiving information. In comparison, those participants further away from their diagnosis (approximately 2 years), appeared to have better recall of having received information. The authors suggested that these patients may not recall information given to them early in their diagnosis, due to their psychological state. However with time, anxiety levels are reduced and the information is recalled (Sharpley & Christie 2009). It may also be that over time, information is repeated and this aids recall.

Other factors that were described in chapter 2 as influencing patient's understanding of information; included the use of difficult medical terminology by health professionals, patient education levels and the mode of information presentation (van der Meulen et al. 2008). Sharpley and Christie (2009) found that participants rated their most valuable form of information was that provided by their oncologist, second to this was the information booklet. The clinician's ability to effectively communicate with the patient has also been implicated as a factor affecting how patients understand information (Gattelari et al. 1999). In this context, ovarian cancer patients have been shown to benefit from an additional consultation with a specialist nurse, as well as the medical consultant. In addition to this, the timing, the amount, and the delivery of information were also considered important to patients (Jefferies 2001). Several of the participants in the study by Janda et al. (2004) suggested it would be beneficial to vulvar cancer patients if additional consultations, which included the partner or family member, were provided prior to surgery. This could facilitate the patient's understanding of, and preparation for, treatment related side effects.

In a study of men with prostate cancer the context in which information was given was determined to be equally important. Participants in this study evaluated information provided to them more positively if they perceived it to have been given with warmth and empathy (Nanton & Dale 2009). Furthermore, Ley (1982), described several communication techniques which might influence information recall, these were; simplifying the information provided, repetition of information, and providing specific rather than general recommendations. In accordance with this, an interesting finding from the current study was that participants who had undergone groin node dissection had excellent recall of the information and education they had been given on the risks, preventative techniques and the management of lymphoedema. Information on lymphoedema is provided to these women by the gynaecological oncologist at the initial consultation, and reinforced by nurses and physiotherapists on several occasions both before and after surgery. Women are also given a bookmark which has printed on it a brief description of lymphoedema and specific suggestions on how to prevent it developing. Therefore, this positive result could be due to the information on lymphoedema being provided in a simple format, specific to one topic only and repeated at several time points.

An interesting approach that is now being taken in some oncology departments is the use of the DVD or video cassette to prepare patients for threatening medical treatments (Thomas et al. 2000; Schofield et al. 2008). This is considered beneficial as it allows the patient to continue the 'learning process', outside of the hospital environment (Thomas et al. 2000:1536). Two randomised controlled trials to assess the benefits of video taped information for patients undergoing treatment for various forms of cancer were described earlier in chapter 2. The first study of British patients found the information video cohort to be more satisfied with the information they had been provided, than the group who did not receive video information. In addition to this the information video cohort reported lower levels of anxiety than the non-video cohort (Thomas et al. 2000). In the later study of Italian cancer patients, comparing information booklet only, to information booklet plus video, the videotaped information was considered 'quite' or 'much' more comprehensive than the booklet (De Lorenzo et al. 2004:721). Despite the proposed benefits of the DVD or video taped information, this does not yet appear to be widely practised. In Sharpley and Christie's recent study (2009), only 8% of the 237 prostate cancer patients had received an educational video. Likewise, none of the participants in the current study had received this type of information.

Sexual Information

The other component of the theme information limitations was *sexual information*. Several participants in the current study had little recall of receiving sexual information. Most of the participants could not recall receiving a booklet providing information on sexuality, despite this being routinely included in the written information provided to them. Earlier in chapter 2 lack of information regarding sexual outcomes of treatment was also described as an issue for patients following treatment for a gynaecological cancer (Andersen & Hacker 1983; Andersen et al. 1988; Crowther et al. 1994). Even some of the women in Andersen and Hacker's (1983) study reported that the sexual information they had been provided was falsely reassuring. These women would have preferred a more realistic description of likely genital numbness.

Similarly, a few of the participants in the current study found the information they received to be inadequate, or provided at a time when they were not interested in receiving it. One participant even described throwing away the information booklet on sexuality and vulvar cancer she had received prior to her first consultation. This participant felt this type of information was of no benefit to her at that point in time. These are by no means new findings. A study by Luker et al. (1996) examining the information needs of women treated for breast cancer, determined that at the time of diagnosis, for the majority of women, the priority information need concerned survival. These authors proposed that information given to women prior to treatment about other issues, such as the impact of surgery on sexuality, may not be retained by the patient, who is in a heightened state of anxiety and concerned primarily with survival issues (Luker et al. 1996). Some of the women in the current study described this very concept when they expressed initial preoccupation with their diagnosis, and the stage of their vulvar cancer precluded them from taking in, or even wanting, information on sexual issues. In accordance with this, Luker et al. (1996) have previously suggested that it would be more prudent for health professionals to be strategic when providing information, by assessing the patient's informational needs at different time points thereby, limiting the burden of information which patients are unable to recall at a later date (Luker et al. 1996).

There were various suggestions by the participants in the current study as to the most appropriate time for sexual information to be provided. The overall consensus was that it should be within the first six months. However, the various time points suggested by the women were; preoperatively, at the first post operative visit, or some time within the first 6 months. Certainly, some of these women were not interested in sexual information being provided at the initial consultation. It would appear that for these participants providing sexual information to them at this time is inappropriate. However, other participants in the present study were receptive to receiving it preoperatively. In addition, some of these participants felt their partners should be included more in discussion about sexual issues, with one participant suggesting that partners should also be provided with sexual information relevant to them about the changes they might notice. The determination of appropriate time points for the provision of sexual information has previously been discussed in chapter 2. These recommendations are similar to those suggested by the women in this present study, with Gamel et al (2000) determining that women needed sexuality information at three time points, which coincided with specific events in the disease trajectory. These three time periods were: 'diagnosis and treatment period; recovery and first intercourse; the period of rebuilding sexual life' (p. 678).

It should also be mentioned that the lack of sexual information, although not surprising, was a somewhat disappointing finding from the current study. There was a 'preconception' of the researcher and her colleagues prior to conducting the current study that women who had been treated in this hospital would describe more positively their experience of being provided with sexual information. Knowledge of the literature describing the lack of provision of sexual information, and the inadequacies of some health professionals to address sexuality, had led the department in which the researcher works to promote psychosexual adjustment as an important component of the care of women treated for a gynaecological cancer. Additionally, all women treated in this department are provided written information on sexuality and the opportunity to speak to a psychologist. This information is generally provided at the initial consultation, and the women are visited by the psychologist while in hospital recovering from their surgery. Furthermore, this topic is broached post operatively at routinely scheduled follow up visits, and the women have the opportunity to discuss any issues they have with a specialist nurse who is experienced in this area.

Possibly, the focus of this department has been too narrowly fixed on functional sexuality, for example; the resumption of sexual intercourse, and not on the broader concept of sexuality. Much of the literature discussing sexuality and cancer is absorbed by this very functional assessment of sexuality. Hordern and Street (2007) found from their patient interviews that most participants were searching for a more patient centred style of communication from their health care provider. Indeed, many participants in their study were disappointed by the lack of support, and practical strategies provided to them by health care professionals, to help them live with the sexual and intimate changes they had experienced.

However, as health care providers are encouraged to raise the topic of sexuality and to encourage discussion of sexual issues with their patients, there will always be a proportion of patients who are uncomfortable discussing sexual issues. Some of the reasons suggested by patients for their not approaching the topic of sexuality were described earlier in chapter 2. These may include: feelings of shame, or fear of being viewed negatively by the clinician. Some patients may consider sexuality not relevant to their medical condition. Others may believe there is nothing that can be done about their sexual issues and subsequently never bring the topic up (Brandenburg & Bitzer 2009). Additionally, time constraints and a lack of privacy have also been cited by women as preventing them from broaching sexual issues with their practitioner (Sarkadi & Rosenqvist 2009). Approximately 23% of the 15 vulvar cancer patients interviewed by Janda et al. (2004) did not wish to talk about sexuality with a doctor. The authors provided no explanation for this but did describe a significant number of these women, all over 65 years, did not consider sexuality important.

It was also described in chapter 2 that the personal characteristics of the physician were shown to significantly influence female diabetic patient's willingness to discuss sexual matters. Many of these women considered their general practitioners personal characteristics, before consulting with them about sexual issues. Some women felt their GP was 'too shy' or 'not the type' to discuss sexuality with. Many expressed a preference to see a female gynaecologist, who was also of a similar age to them (Sarkadi & Rosenqvist 2009:163). In accordance with this were comments made to the researcher conducting this current study. In the lead up conversation prior to their in-depth interview, three of the participants commented that sex and sexual issues were topics they were uncomfortable discussing and rarely, if ever, did so. Even with two of these women commenting at the conclusion of their interviews, that their decision to participate had been determined by the trust they had in the researcher and their feeling confident they would be able to discuss such a sensitive topic with her.

However, the literature discussing cancer patient's preferences for information on sexuality generally report the majority of patients do want this type of information. Certainly, the majority of women in the current study wanted this type of information. As described earlier, a recent Australian study conducted to determine issues of sexuality and intimacy from the perspectives of both cancer patients and health professionals, reported many patients were disappointed with the sexual information and support they had received from health professionals (Hordern & Street 2007). Prior to this, another study was conducted also assessing the attitudes and behaviours of health professionals towards discussion of sexual issues with 15 women being treated for ovarian cancer. Results revealed that no woman had received written information on sexuality, and only two had received verbal information. Eleven of these women felt that verbal information should have been conveyed to them (Stead et al. 2003). Another quantitative study, of long term survivors of vaginal and/or cervical cancer, also reported that 62% of the 221 participants had never discussed sexuality with their health care team, despite 74% of these women feeling it would be beneficial to them to do so (Lindau et al. 2007).

It must be concluded from the results of the present study that this department still does not adequately address these women's information needs. For the women in this current study it is difficult to determine all of the factors which contributed to their experiencing information limitations. However, it needs to be considered that the format, the timing, and the quality of the information provided were not acceptable to all women. Likewise, it is important to remember that the literature given to patients is generally quite broad, so as to provide information to the majority. Some patients might have difficulty deciphering from this the information that is relevant to their own situation. It is challenging to all health care professionals to address the provision of information in such a way as to effectively meet the informational needs of the individual patient.

Theme 2: Sexuality

The second essential theme from this study, sexuality, incorporated a combination of emotional, physical and relationship aspects. For each of the women in this study sexuality was a uniquely individual experience, but across all the data common themes were found. These included issues grouped under the three sub-themes of; *fear, changes in sensation*, and *the sexual relationship*. All of which were linked to the women's experience of sexuality.

Fear

For the women in this study fear was associated with several experiences. For the younger women fear was associated with the potential for removal of, or disruption to, their clitoris. None of the postmenopausal women in this study described experiencing this emotion in relation to the potential for removal of their clitoris. Fear of removal of the clitoris has not previously been articulated in the literature pertaining to vulvar cancer. Similarly, for most sexually active women fear was a prevalent emotion linked to the resumption of sexual intercourse after their surgery. Women feared pain and the potential for disruption to sexual intercourse and approached it with trepidation. Although fear in relation to sexual activity following a gynaecological cancer has previously been discussed in the literature, this has generally been in relation to women fearing transmission of their cancer to their sexual partner (Stellman et al. 1984; Corney et al. 1992), or a recurrence of their cancer exacerbated by sexual activity (Stead et al. 2001).

Fear experienced by women leading up to the resumption of sexual intercourse was previously identified by Zegwaard and colleagues, who interviewed Dutch women and their partners following treatment for cervical cancer. Comparable to the experience of women in the present study, these women also vividly recalled their fear. The women described fearing the unknown, some afraid they would not become aroused, or what sex would feel like following surgery (Zegwaard et al. 2000 cited in Gamel, Hengeveld & Davis 2000:678). Fear of resuming sexual intercourse was also experienced by Australian women following treatment for cervical and endometrial cancer. Results from this qualitative study indicated that some women were frightened to resume sexual intercourse post operatively because they feared painful intercourse, or they feared their own sexual response would be reduced. Also some of these women feared their partners would no longer wish to have sex with them due to the cancer (Juraskova et al. 2003). Interestingly, none of the participants in the current study expressed fearing sexual rejection by their partners. This may be due to all seven of the sexually active women in this current study describing being involved in a committed and supportive intimate relationship. This is discussed in greater depth in the section on *the sexual relationship*.

The partners of the women in both the earlier Dutch study and the current research project allowed the women to take the lead in the resumption of sexual intercourse. Consequently, it would appear that women were given the time to recover both mentally, as well as physically, before attempting sexual intercourse. Likewise, Juraskova et al. (2003) also found that couples who discussed their feelings about sexual issues were able to resume a more satisfying sex life. This type of understanding and support from partners has also previously been shown to be crucial for breast cancer survivors to resume and maintain healthy sexual relationships (Pelusi 1997). However, it has also previously been suggested that some men withdraw from making sexual requests of their partners following surgery for breast cancer, due to feeling disturbed by their partners changed physical appearance, or in response to their partner’s anxiety and altered body image (Hanson 2002). For the women in the present study it was described more simply, it was about their partners respect and support for them, giving them time to heal and come to terms with the surgery.

Changes in Sensation

Findings from this study determined that only women over 55 years reported disruption to orgasm. However, orgasmic disruption did not appear to be attributable to the women’s age, but rather as a consequence of the surgical excision. Several authors report on findings from studies of healthy women from the general population, comparing sexual function across various age groups. Most of these suggest that older women report decreased lubrication, decreased sexual desire and decreased sexual activity compared to their younger counterparts (Howard et al. 2006; Lindau et al. 2007). As discussed in chapter 2, sexual response has been said to decrease in older women due to diminished sexual hormone production. This can cause a delay in arousal response rates, and a decrease in intensity of orgasm (Masters & Johnston 1980). Despite this, it appeared that the women who experienced disruption to orgasm in this study had experienced excision of vulvar tissue abutting the clitoris, and the volume of vulvar tissue excised was greater than that for women who reported no disruption to orgasm. For most other women in this study having had a radical local excision, the changes to sensation on the vulva as a result of the operation were generally described as 'numbness' over the area of excision. Only one of these participants commented that this had initially disrupted her ability to achieve orgasm during sexual intercourse. However, upon determining that a positional change during subsequent sexual activity allowed her to achieve orgasm as before, this was no longer an issue for her. For the other women in this study this area of 'numbness' has had no impact on sexual arousal, or their ability to achieve orgasm. These women described simply avoiding that area during sexual foreplay.

These findings are in accordance with those from previous studies, described earlier in this thesis. Results from these studies indicated that women with more genital disruption experienced more sexual difficulties, most particularly with the desire and resolution phases of the sexual response cycle (Andersen et al. 1988; Theusen et al. 1992). However, these results differ to those of Green et al. (2000), who found no relation between sexual dysfunction and the type of surgery (radical or simple vulvectomy), or the volume of tissue removed in women after treatment for vulvar cancer. Likewise, and also in contrast to the findings from this current study, Stellman et al. (1984) found no differences in sexual function or satisfaction between women who had undergone simple or radical vulvectomy, suggesting that loss of sexual function was related more closely to psychological issues than to anatomical deficits. It has been suggested it might be more reasonable to assess the sexual issues of women in terms of their sexual relationship, as it appears that for women there are many sources of sexual satisfaction, such as, feelings of intimacy, love, friendship, physical closeness and sensuality (Bos 1986).

The Sexual Relationship

Overall, this study found that following treatment for vulvar cancer, all women who were involved in a committed and supportive relationship, resumed and maintained a satisfying sexual relationship, irrespective of their age or the extent of excision. This was despite a few women reporting increased difficulty achieving orgasm since surgery, and others experiencing a decrease in sexual desire. This supports findings from an earlier qualitative study from the Netherlands, where despite only five of the ten women interviewed reporting being able to achieve orgasm up to 2 years following their treatment for vulvar cancer, all women reported satisfaction with their sexual relationship. The authors concluded from this that the intimate aspects of a sexual relationship are more important predictors of sexual rehabilitation after vulvar cancer (Willibrord et al. 1990). Similarly, Weijmar Schultz and colleagues also ascertained after interviewing women and their partners following vulvectomy that; “motivation for sexual expression, closely related to extent of mutual affection felt, might be more important for sexual rehabilitation than any physical restrictions imposed by the surgery” (Weijmar Schultz et al. 1986:126).

However, these results are not unique to women with cancer, Bancroft and colleagues (2003) also determined when studying sexuality in healthy women from the general population, that the more important determinants of sexual distress for the women studied were, experiencing negative emotions during sexual interactions, rather than any physiological sexual responses. Likewise, Hayes and Dennerstein (2005) proposed that as women age relationship factors can become more important than physiological factors. They suggested women are less likely to become distressed about sexual changes as they get older. For many women, being in a relationship and the quality of the relationship are most important. Certainly all the participants in the current study, who were involved in a relationship, indicated the quality of their relationship as being more important to them overall than any 'minor' sexual issues. This is not to say that sexual function was not important to these women, but rather only one component of their sexuality.

Two of the three participants interviewed who were not sexually active, had never resumed sexual intercourse following their treatment for vulvar cancer. Both of these women had undergone a more radical surgical excision compared to the other women in this study, including the removal of their clitoris. Neither of these participants referred to the removal of their clitoris during their interviews, but described determination to not pursue another sexual relationship, neither sure they could participate in sexual activity, most particularly penetrative vaginal intercourse. However, during regular follow up both women can comfortably tolerate a pelvic examination, including the insertion of a vaginal speculum. Therefore, despite no physical barrier to sexual activity these women continue to experience psychological impediment, suggesting that it is not only lack of availability of a sexual partner that reduces sexual interest in women following radical vulvar surgery. Certainly one of these two participants indicated that she had been too emotionally hurt by her former husband to ever be involved in another sexual relationship. Andersen and her colleagues (1988) identified a similar reluctance of women to initiate relationships with new partners following vulvectomy. However, these authors attributed this to the women's discomfort with their perceived genital changes. The literature has also previously suggested that the most common reason for a reduction in sexual interest in this group of women was the lack of availability of a sexual partner (Springer 1982; Andersen & Hacker 1983).

It is not possible to determine from the results of the current study if age was a factor in these two participants not pursuing another sexual relationship as this issue was not probed. Likewise, the one other participant who was no longer sexually active following her divorce also stated she would never pursue another sexual relationship. All three of these women were aged between 60 and 76 years. The Global Study of Sexual Attitudes and Behaviours collected data from 27,500 men and women, aged between 40 to 80 years, in 29 countries around the world. From this data the authors concluded that, sexual desire and activity for middle aged and elderly women was widespread and persisted into old age (Nicolosi et al. 2004). Therefore, it might be more likely that these women were simply not interested in pursuing another sexual relationship and their age was not a factor. Certainly, during their interview these participants did not indicate any distress at not being involved in an intimate relationship, sexual or otherwise. This would be in accordance with the findings from the previously discussed research by Corney et al. (1992) and Janda et al. (2004). These authors reported results which indicated that the majority of older women who did not resume sexual intercourse after treatment for cervical or vulvar cancer, were not at all concerned by this abstinence (Corney et al. 1992; Janda et al. 2004).

An important factor that seems to decrease psychological distress for those involved in a relationship is feeling supported within that relationship (Wilmoth 2001). It has previously been reported that satisfaction with the relationship, most particularly the level of support, was positively associated with psychological wellbeing (Pistrang & Barker 1995). Similarly, a study by Sheppard and Wylie (2001), assessing sexual difficulties in men after treatment for testicular cancer, determined that being in a committed relationship protected these men from sexual problems. This was despite the presence of body image disturbances and sexual dysfunction, these men's perceived partner support appeared to reduce their impact. Likewise, the importance of the relationship in determining sexual satisfaction is also evident for well women from the general population. The results from an Australian study, The Melbourne Women's Midlife Health Project, indicated that previous sexual function and the status of the relationship were the most important predictors of levels of sexual satisfaction for the women participating (Dennerstein, Lehert & Burger 2005).

Despite most of the participants in this current study being involved in a supportive relationship, it must be acknowledged that two of the ten women interviewed directly attributed their relationship breakdown to their having had treatment for vulvar cancer. The literature acknowledges that the stress of cancer and its treatments can exacerbate already existing marital tensions (Hughes 2008). In studies of women with breast cancer, relationships have been shown to experience considerable distress. In one study of breast cancer patients, 35% of women felt their partners to be emotionally distant, and 12% experienced a separation (Walsh, Manuel & Avis 2005 cited in Sheppard & Ely 2008:179). Similar to this, in the much earlier study of women with cervical and vulvar cancer, 16% of women reported a significant deterioration in their marriage since their treatment (Corney et al. 1992).

It has been suggested that the longer relationship would have a greater chance for survival following a diagnosis for cancer; the assumption being that the couple have already dealt with many life stresses together (Springer 1982). More than 30 years ago, Sewell and Edwards (1979) found in a study of gynaecological cancer survivors, that older women in longer relationships experienced less relationship problems than younger women who had been in a relationship for a shorter time. In contradiction to this, both women in this study whose marriage broke down following their treatment for vulvar cancer, had been married for many years and considered their relationship to have been strong. However, one of these women did describe her former husband's complete inability to cope with illness, even to the extent that when their children had been ill, he would absent himself from the family home. It came as no surprise to her that he was unable to deal with her vulvar cancer. For those couples that are able to surmount the relationship challenges associated with cancer, there is the possibility for mutual growth, and a deepening and strengthening of the relationship (Fergus & Gray 2009). Indeed, some of the other participants in this study did describe very positively their partner's support for them during their treatment for vulvar cancer and the subsequent strengthening of their relationship.

Theme 3: Body Image

The third essential theme described in the previous chapter relates to body image. For the most part, the findings from this study indicated that women experienced little to no long term disruption to their self concept and body image, following conservative surgical excision, for an early stage vulvar cancer. The factors that contributed to women experiencing negative emotions were radical vulvar excision, multiple vulvar procedures and/or the development of lymphoedema. Although only one participant in this study had undergone a radical vulvectomy, her experience suggests that radical vulvectomy has a more detrimental affect on body image than the more conservative surgery. For this participant, changes to her urinary stream, and a feeling of being 'neutered', contributed to her changed concept of body image. However, she described that by knowing this surgery was required to rid her of vulvar cancer she was able to deal with the inevitable psychological effects. Similar findings have been reported in the literature from studies of women treated for breast cancer. These studies show that the fear of breast cancer is greater than the fear of losing a breast (Fallowfield et al. 1990; Luker et al. 1996). In the study by Luker et al. (1996) neither breast surgery, nor the removal of a breast, was rated as a higher information priority than survival. Further from diagnosis survival issues were still a concern, with the risk to family members getting a breast cancer also showing a significant increase in importance. Body image and sexual attractiveness information needs were rated as much less important at all time points.

A positive finding from this current study was that several women expressed surprise at the pleasing cosmetic result from their surgery, with only women having had the more radical excision expressing dismay when they viewed their wounds. This has not previously been identified from earlier, quantitative or qualitative studies. In addition to this, the generally positive results from this current study in relation to body image are in contrast to those from several earlier studies of women with gynaecological cancer. In Andersen and Hacker's study (1983) there was major disruption to body image for women following vulvectomy. Likewise, in another American study to determine the psychological effects of vulvectomy, compared to hysterectomy for endometrial cancer, women who had a vulvectomy were more likely to experience depression, and harbour feelings of sexual guilt than women who had a hysterectomy (Stellman 1984). Additionally, a study of Danish women reported more than half of the women described a lack of respect for their own bodies, and a feeling of not being a 'proper woman' since their vulvar surgery (Andreasson et al. 1986:7). Not surprisingly, Green and colleagues (2000) did find that women who were depressed post operatively were more likely to have body image disturbances. However, as in their findings for sexual dysfunction, body image disturbances did not appear to correlate with the extent of the vulvar excision.

Similar conflicts in the literature have also been identified when comparing women receiving breast conserving surgery with women having had a mastectomy to treat breast cancer. Ganz and colleagues reported fewer body image disturbances in women having had breast conserving surgery, than women having had a mastectomy (Ganz et al. 1998). However, Nissen et al. (2001) found no differences in well being between women having had breast conserving surgery, compared to mastectomy. In a study by Marshall and Kiemle (2005) examining the impact of breast reconstruction on patients, it was shown that women, who felt that their sense of femininity and womanhood were related to their breasts, had more body image adjustment problems.

It is not possible to determine if age was protective of body image for women in the current study. However, the literature does identify that for some middle aged and older adults, body function and cardiorespiratory fitness, were the factors directly related to women's satisfaction with their body appearance. As described in chapter 2, Reboussin and colleagues found that older age was more positively related to measures of body satisfaction. The authors concluding from this and previous reported data, that somewhere in the mid 50's, the attitude to one's body began to improve and that older adults may value body function more than appearance (Reboussin et al. 2000).

Lymphoedema

A sub-theme of body image was determined to be lymphoedema, as it was particularly disruptive to these women's perception of self, with women having to adjust their style of dressing to cover up lower limb lymphoedema (LLL). These were expected findings as this is well described in the literature. Ryan and colleagues (2003) following their study to determine the incidence and prevalence of LLL in women treated for a gynaecological cancer, reported that lymphoedema impacted on 'appearance, mobility, finances and self image' for those women affected (p. 417). Additionally, these authors found that 79% of women identified having to make major changes to their wardrobe to disguise the appearance of swollen legs. Another qualitative study, investigating women's experience of living with LLL, also indicated negative effects to body image. This study found that LLL evoked anxiety in women, who feared developing larger bodily proportions (Frid et al. 2006).

Similarly, breast cancer survivors with lymphoedema of the upper extremity experience anxiety and adjustment problems (Lockwood-Rayermann 2007). Furthermore, in a recent study conducted by Ahmed and colleagues, it was determined that for breast cancer survivors with arm lymphoedema, health related quality of life was lower than for those women who had not developed lymphoedema (Ahmed et al. 2008). One of the factors affecting health related quality of life for these women has shown to be the effect of lymphoedema on their family and leisure activities. Radina (2009) found women who had developed arm lymphoedema following breast cancer treatment, either modified or restricted their participation in family leisure activities. This was evident for some of the participants in this current study, with one participant describing limiting water activities with her teenage children due to the need to wear compression garments. Likewise, another participant was unable to pursue her love of walking, most particularly during the summer months, due to increased swelling in her affected limb. It is not surprising then, that following their study of women with vulvar cancer, Janda and colleagues (2004) found LLL to be the most frequently reported symptom, negatively influencing several aspects of quality of life. Similarly, in a study conducted by Farrell (2009) the effect of complete lymphadenectomy on quality of life was a negative one in 37% of women with vulvar cancer (R. Farrell 2009 pers. comm., 2nd February).

The Vulva is Not Visible

Seemingly protective of body image for the participants in the present study was the hidden nature of their surgical excision, even for women with more extensive surgical excisions. The idea that no one, other than partners and health professionals involved in their care saw the vulva, afforded them protection from feelings of self consciousness. Some of these participants attributing less importance to their vulvar scar than a disfigurement which would be obvious to others, such as mastectomy to treat breast cancer, or swollen limbs from lymphoedema. This concept has previously been explained by Cash and Szymanski, who contended that the importance placed on a self ideal discrepancy, determines the psychological impact it will have on an individual (Cash & Szymanski 1995 cited in White 2000:186).

Lawrence et al. (2004) hypothesised that individuals with socially visible scars, such as facial scars, relative to hidden scars, would experience more stigmatisation. They described stigmatisation "consists of labelling a person as possessing an attribute that is so negative that it overshadows all other attributes of that person" (p. 26). This stigmatisation ultimately leads to lower self esteem and body image. However, for those whose scars are hidden, such as for the women in this current study, some level of protection from being stigmatised is afforded to them. Similarly, a study exploring chemotherapy related hair loss, determined that this visible side effect of treatment can lead to the stigmatisation of the individuals experiencing it. Ultimately this led these participants to feeling socially discredited, or diminished in their interactions with others (Rosman 2004). In accordance with this, Ryan's (2005) qualitative study of 30 women with ovarian cancer showed participants had an awareness of 'feeling different'. This was most evident when their bodies exhibited signs of being different, such as hair loss or baldness from their chemotherapy treatment (p. 213). Another study, evaluating women's perception of the cosmetic results of their breast conserving surgery, found that half of the respondents reported moderate to severely visible scars which significantly influenced their self rating of body image. Consequently, such obvious scars were shown to be related to adverse psychological effects in these women (Hoeller et al. 2003). However, although the impact of 'hidden scars' on body image may be more subtle, concealed scars may be particularly burdensome in intimate situations (Lawrence et al. 2004:26).

In this current study, the very conservative nature of the vulvar excision could also mean that for some of the women, given time for the vulvar wound to heal, the amount of vulvar tissue removed had resulted in a vulvar appearance that is not radically different to before surgery. In one instance, the excision of labial tissue was perceived by a participant as an improvement when compared to the other side, which she felt was too ‘droopy’. This participant described finding the aesthetic appearance of the operated side an improvement, even jokingly asking if the other side could be ‘trimmed’. This belief in some women that their labia are abnormally large or asymmetrical is not uncommon in the general population, and has led to a demand for labial reduction surgery (Likes et al. 2008:213). The amount of genital tissue removed in this aesthetic labial surgery is similar to the amount of tissue removed in the treatment of preinvasive conditions of the vulva, and in vulvar cancer (Liao et al. 2010:23). However, from a cancer professional viewpoint it is hard to imagine what leads women to undergo this type of vulva surgery, if it is not required to treat a cancer. Several studies have been conducted in an attempt to understand women’s reasons for undergoing cosmetic surgery for labial reduction. As described in chapter 2, these studies concluded that women believed their genital appearance before surgery was ‘odd’ or made them look like ‘freaks’, and these women strived for ‘normality’ (Bramwell, Morland & Garden 2007:1495). Additionally, one of the most commonly cited reasons for doing so derived from a woman hearing jokes made at her expense, usually by her partner, during oral sex. Understandably this resulted in a lack of self confidence, lower self esteem and lower sexual libido for these women (Giraldo, Gonzalez & de Haro 2004). However, it should be mentioned that the participant in the present study who commented on the size of her labia, did comment that her partner had never indicated to her that he considered her genitalia in any way abnormal.

Theme 4: A Private Cancer

The final theme discussed in Chapter 4 relates to vulvar cancer being a private cancer. Comparable to the findings of Anderson and Hacker (1983) from almost 30 years ago, participants in the current study described discomfort discussing their vulvar cancer with anyone but the most intimate family members or friends. This fact alone contributed to some of these participants experiencing a sense of isolation due to the rare and private nature of vulvar cancer. Consequently, the rarity or isolating nature of vulvar cancer also determined that these women rarely, if ever, spoke to other women with vulvar cancer, compounding their sense of isolation. Previous studies of women with gynaecological cancer have made reference to this, with authors describing women who expressed a sense of 'being the only one' or 'isolated' (Janda et al. 2004:87; Jefferies & Clifford 2009:35). In Jefferies and Clifford's study, through the participant's search for information about vulvar cancer, the authors detected a sense that these women were communicating a need to raise awareness of vulvar cancer through improved availability of relevant information (2009). Similar experiences of isolation were described by participants in a much earlier study by Wortman and Dunkel-Schetter (1979). These researchers studied 55 patients to find what they considered beneficial or unhelpful to their coping with cancer. The author's findings indicated that respondents often experienced feelings of rejection and withdrawal, and difficulty communicating with others about their cancer. Likewise, a comparative study of women with breast cancer with disease free individuals, also reported similar experiences in the breast cancer cohort. Seventy-two percent of the 100 respondents in this group reported they were treated differently after people became aware they had breast cancer, 52% felt they were avoided, and 14% felt pitied by others (Peters-Golden 1982).

It has been proposed that certain types of cancers such as gynaecological or colorectal cancer may generate an element of shame that makes revealing or discussing the cancer, or its treatments, difficult (Hughes 2008). Many of the women interviewed in the current study had not told their teenage or adult children they had been treated for vulvar cancer. The women described this as protecting their children from reality, or saving them the embarrassment of knowing their mother has cancer of such an intimate area. A study of colorectal cancer patients reported a range of specific problems associated with quality of life, one of these issues was difficulty talking to others about their cancer (Schag et al. 1994). Equally, cancer in genital organs can have certain sexual connotations which may lead to shame (Bos 1986). Feelings of shame have also been associated with lung cancer patients. These patients have described often feeling blamed for the contraction of their lung cancer due to their history of smoking (Chapple, Ziebland & McPherson 2004).

The culture, in which a woman has been raised, as well as the culture in which she now lives, may also impact on her ability to discuss sensitive issues (Hughes 2008). Some women may find it hard or even rude to mention their genital organs. Furthermore, in general conversation words such as vulva, vagina, or clitoris are often avoided. Certainly this was described by several of the participants in the current study. These women felt vulvar cancer was 'too intimate' to talk about socially. In a survey to gather knowledge and attitudes to the word vagina, more than 75% of the female respondents agreed that although society is more comfortable discussing these areas, it is not a common subject. What is more, about 30% of these women thought that discussions involving the vagina should not be held in public (Nappi, Liekens, & Brandenburg 2006). One might assume this study would reveal similar results if the word vagina had been transposed with the word vulva.

Most of the participants in the current study also expressed a desire to talk to someone else with vulvar cancer, or to be involved in a vulvar cancer support group. As mentioned in the literature review this was previously identified by Weijmar Schultz and colleagues (1986), and Corney et al. (1992). Corney and her group described, one third, of the 105 women they interviewed following treatment for gynaecological cancer would have liked to talk to someone else, preferably another woman, who had surgery. Similar to this, in their much earlier study, Weijmar Schultz and colleagues reported that, seven of the ten respondents thought it would be beneficial to be put in contact with another vulvectomy patient. However, only five of these participants thought involvement in a support or discussion group would be beneficial to them (1986). Likewise, in a later study by Pistrang and Winchurst (1997) to examine gynaecological cancer patient's attitudes towards psychological services, slightly less than half of the 35 participants said they would currently use either one of three types of psychological services, which were: individual counselling, a support group and couple counselling. However, these 35 participants showed no preference for one type of support service over another.

In the past breast cancer support groups have been identified as benefiting women physically, socially and psychologically following treatment for breast cancer (Michalec 2005). Likewise, peer support programs for women with breast cancer have also been effective in alleviating many of the physical and emotional effects of breast cancer (Power & Hegarty 2010). In a previously mentioned study of breast cancer patients, Lugton (1997) identified that involvement with other women in the same situation, either through peer support programs, or support groups, decreased these women's feelings of isolation. For women with vulvar cancer, involvement in a vulvar cancer support group might be beneficial in decreasing their sense of isolation, or feelings of being the 'only one'. However, there is very little evidence in the literature to determine women's attitudes, or preferences for this type of psychosocial support, following treatment for vulvar cancer.

It is apparent that women are isolated by their experience of vulvar cancer and the challenge here would be to change these women's perception of being uncomfortable discussing vulvar cancer. As clinicians we have an ethical responsibility to provide these women with appropriate information, support and counselling throughout their disease trajectory. Nurses and other health professionals should help these women to develop and maintain their own formal or informal support networks.

Study Limitations

There were a number of limitations in this present study that should be acknowledged. The participants were all Caucasian, either Anglo-Australian, or of Southern European origin, none had tertiary qualifications. Also participation in this study was limited to only English speaking women. These factors prevent comparisons of cultural and social diversity within the study population. Likewise, this study only included heterosexual women, limiting the exploration of experiences of other women with different sexual orientation. Also, as the youngest patient in this research project was 38 years of age, the experience for women from a younger demographic has not been adequately explored. Likewise, the oldest demographic is also under represented in this study. The only participant in this study older than 70 years had not participated in any form of sexual activity since her surgery. Therefore, the description of the experience for this age group is limited. In addition to these factors, the study numbers were too few to make comparisons between rural, regional and metropolitan women. This needs to be explored further, most particularly in relation to the unmet information needs that were described by the study participants.

This study included women only one year from treatment, up to many years after treatment for vulvar cancer. This precluded comparisons in sexuality and body image at different time points from diagnosis. A longitudinal approach, with a greater number of participants, might allow for this type of exploration. Other issues that may impact on sexuality and body image, such as comorbidities, medications and the sexual partner were not specifically addressed in this study. These should be given consideration in subsequent work.

The retrospective nature of some areas of the interview process, asking comparative questions, cannot determine if time alters the perspective of the participant’s experience. However, the parallels between the essential themes generated from this study, and the findings from other studies, allows for confidence in the strength of the data and the subsequent data analysis (Leydon et al. 2000:912). Additionally, the intimate and personal nature of this research, combined with a recruitment process where women ‘opt in’, could conceivably only recruit participants who are interested in, and comfortable talking about sexuality. There may well be a group of women who are too embarrassed to ever participate in, and discuss sexual issues face to face. These women may be better served by a less confronting quantitative research approach, such as a survey modelled on the issues eventuating from the present study. Alternatively, the participants’ willingness to participate in this research project and discuss this topic could also reflect a need on their part to confront and discuss sexual issues.

Nevertheless, despite these limitations, this study is only the second Australian study to investigate women’s experience of sexuality and body image, and one of only a few studies to look exclusively at psychosexual issues for women with early stage vulvar cancer. The findings from this present study may serve as a relevant platform for the development of future research into the psychosexual outcomes for women diagnosed and treated for vulvar cancer.

Suggestions for Future Research

The data generated from this study offers a preliminary basis for a broader exploration of the experience of women treated for vulvar cancer. The results of this current study have identified information needs as a priority area to be addressed in future research. A survey to explore two of the essential themes developed from this current study, that is; information limitations and a private cancer, is being planned for August this year. This will be incorporated into a vulvar cancer support day planned in collaboration with a Psychologist who specialises in this subject. The proposed survey of these women will aim to determine the barriers and limitations they encountered in accessing information and support following their diagnosis of cancer. From this, a much larger study will be developed in collaboration with other gynaecological cancer departments, to adequately determine the information and supportive care needs of these women. A multi-centre approach will boost sample size and facilitate generalisability of the data. In order to examine the efficacy of providing various types of information to vulvar cancer patients a comparative study of verbal and written information, compared to DVD or audiotaped information would be beneficial. Women's preferences for this information should be explored. More research is also needed to determine strategies for ensuring these patients are able to understand and comprehend the information imparted to them. This research will then lead to interventions that are directed by patient needs and patient preferences.

Future studies in this area should involve women having been treated for all stages of vulvar cancer, including women treated for Paget's disease of the vulvar[5], and for vulvar intraepithelial neoplasia (VIN). Treatment for both Paget's disease of the vulvar and VIN, can involve multiple surgical procedures, not unlike the treatment for vulvar cancer. However, there is little in the literature describing the psychosexual outcomes for these women, with only two studies identified and referred to in chapter 2 (Andersen et al. 1988; Likes et al. 2007). The findings from these studies in relation to quality of life and psychosexual adjustment following surgery are conflicting. There is obviously a need to explore this further. There is also a need to compare the psychosexual outcomes for women treated with surgery and radiotherapy, to women treated with surgery alone, as it is unknown if these women experience greater psychosexual morbidity. In this instance a longitudinal study across different time points from treatment might be beneficial to identify if there are certain points in the recovery process where interventions

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[5] Paget's disease of the vulva is an uncommon non squamous intraepithelial lesion of the vulva.

may be more beneficial to these women. A longitudinal study would allow for relevant physiological changes to arise, stabilise and retreat. This would allow the course of psycho-sexual adjustment to be established (Juraskova 2003:355).

Equally important for future research would be the inclusion of women's partners, as this would allow for different perspectives on sexual issues. Additionally, research exploring the unmet needs of these women and their partners, including their preferences for the provision of sexual information, would be beneficial to clarify the level of support required. It is also interesting to note that most of the studies conducted to determine patient's satisfaction with sexual information have involved quantitative tools, such as the questionnaire or cross sectional survey. There has been very little qualitative investigation of this topic. Using a mixed method approach for future research would also provide a more detailed investigation of the experiences and changes to sexuality following treatment, for both women and their partners (Gilbert, Usher & Hawkin 2009). It is also important for future research to include lesbian women, as Connolly (2005) suggested there is evidence in the context of cancer that lesbian relationships, when compared to heterosexual relationships, differ in the domains of communication, attachment and conflict resolution. These issues may be relevant to research on sexuality and cancer (Gilbert et al. 2009).

Additionally, a comparative study based on demographic location, to elucidate whether isolated patients are disadvantaged, or indeed have different needs which require further attention, should be included in future research. Collaboration with other gynaecological cancer departments would be beneficial to more broadly investigate these issues, as it would allow access to greater numbers of women who had been treated for vulvar cancer. Likewise, collaboration with other departments from across Australia would also allow for a cross section of women, from a range of social and cultural backgrounds. It would be important to include women from a range of cultural backgrounds where sexuality may have a disparate meaning to those described in the current study (Gilbert et al. 2009).

Implications for Practice

The findings from the present study and those mentioned previously, highlight the difficulties faced by health care professionals in knowing not only the extent and complexity of information to give patients and the time to impart it to them, but how to assist them to understand and recall information. More attention needs to be placed on ensuring these women receive and comprehend the information provided to them. A particular emphasis of this department has always been to encourage women to bring with them a family member when presenting for their consultation, to not only offer support, but to assist them in recall and understanding of the information presented. The findings from this present study indicate more needs to be done. The literature reveals that providing patients with a DVD or audiotape of their consultation is beneficial. Discussions have commenced as to the feasibility of developing an information DVD. The idea is to make a range of these DVD'S covering all of the gynaecologic cancers available to all women treated for a gynaecological cancer. An application will be submitted to The Cancer Institute of NSW for an Innovative Services Grant to fund this. In the interim, with the patient's consent, each patient will be supplied with an audiotape of their consultation with their gynaecological oncologist.

More focused attention should be placed on supporting these women from the time of their referral. This department has initiated a system whereby each patient who is referred to the department with a vulvar cancer is contacted by a nurse and provided with verbal and written information. These women are given the opportunity to ask questions and have some of their fears alleviated. They are also put in phone contact with their gynaecological oncologist if they wish to speak with them at this point. Where possible for regional and remote women optimising their access to local services during this waiting period could be achieved through collaboration with their primary health provider. However, as this is only one department, this type of intervention will only benefit a proportion of the women diagnosed with vulvar cancer. Therefore, it would be prudent to make this information more widely available to gynaecologists, non-specialist nurses and general practitioners, so that patients could more easily access this information.

Currently the Clinical Cancer Networks, a division of The Cancer Institute of NSW, is collaborating with the gynaecological cancer centres in NSW to develop an online cancer services directory. Data from this department has recently been submitted. This directory will contain details of all gynaecological cancer services available in NSW, including; treatment centres and their outreach services, and the relevant cancer support services. The contact details of all key health care professionals involved in the care of women with gynaecological cancer will be included on this website. In addition to contact details, a brief description of the various health professional's roles and specialist skills will be provided. When all the data from across NSW is submitted it will be made easily accessible through an internet website. In order to ensure that all health professionals are made aware of this service, a bulletin in electronic format will be sent to all stakeholders including; hospitals, gynaecologists, general practitioners, cancer nurse coordinators, generalist nurses, community health nurses and community health centres and allied health practitioners. This website will include links to information on each of the gynaecological cancers, to provide consumers with a lay version of each treatment and its side effects.

The majority of the women in earlier studies, and in the current study, said they would be more than willing to talk to other women about their experience of vulvar cancer. It would be beneficial therefore to develop a list of women who are willing to be contacted by other women newly diagnosed, or undergoing treatment for vulvar cancer. This information could be made available to Cancer Council Connect. Cancer Council Connect matches patients with cancer, with volunteers who have experienced a similar cancer experience. This might go some way to alleviating the feelings of isolation experienced by some of these women following their treatment for vulvar cancer. Of course some of the isolation experienced by women diagnosed and treated for vulvar cancer is attributable to having cancer of a genital organ. Unfortunately, vulvar cancer has no media or public profile which continues to ensure it remains a cancer with a social stigma. The public continue to be made aware of breast cancer through the media and high profile women who have experienced breast cancer. These women continue to ensure that breast cancer remains a public and political issue (Beaver & Booth 2007:415). One suggestion to develop public awareness of vulvar cancer would be to organise a national vulvar cancer day. To achieve this, collaboration with government organisations such as, Cancer Australia and The Cancer Institute would be imperative to facilitate access to media support.

On a much smaller scale, a vulvar cancer support day is scheduled for August this year. The aim of this support day is to not only provide these women a relevant platform to ask questions and address some of the issues they have faced since been diagnosed with vulvar cancer, but assist them to develop and maintain their own informal support networks. Initially, due to limited resources, this will involve only women treated at this centre. However, our aim for the future is to combine with The Cancer Council to arrange these events across rural and urban areas of NSW.

Addressing Sexuality

The assessment and treatment of sexual functioning should become a routine aspect of care for women following treatment for vulvar cancer (Wilmoth & Spinelli 2000). Improvement in the assessment of sexual difficulties is important for the development of clinical interventions and referral pathways

(White 2008). Dialogue about sexuality is essential from the time of diagnosis and should continue through the cancer care trajectory. This dialogue should be initiated irrespective of whether or not the woman has a current sexual partner, as anxiety about sexuality may impact on future sexual relationships (Burke 1996). Often women do not need extensive interventions for sexual concerns; what is needed is for their concerns to be aired and normalised (Sheppard & Whiteley 2006). The literature suggests clinicians should identify those within the oncology team who are educated in, and willing to discuss sexuality with these women.

Providing information and educating patients is accepted as an integral part of nursing practice. However, the reality of the clinical environment is that even if ward based nurses had the necessary knowledge and skills to discuss all the patients sexual informational needs, they are restricted in the time they have available to them to do so. Specialist gynaecological oncology nurses are uniquely placed to provide this information, as they are in frequent contact with patients, and are routinely involved in offering guidance and counselling (Robertson 2005; Burke 1996). These nurses are usually involved with women in a variety of settings, including hospital, outpatient departments and in the community. They are in contact with these women from initial consultation, through both acute and chronic care. As such, these nurses are well placed to include both a sexual assessment and where required, include sexual issues in a care plan (Katz 2002). Additionally, by addressing this topic from diagnosis should help women to discuss and deal with any issues as they arise (Hughes 2008).

An organised approach is important for nurses to assess a patient's understanding of sexuality and body image, and to assist patients to take definite action in preventing or alleviating any sexuality issues (Pelusi 2006:36). For this reason, all patients should have incorporated into their plan of care a basic sexual assessment. This sexual assessment can be conducted by a specialist nurse in a quiet and private place within the outpatient department. Additionally, the development and implementation of evidenced based intervention strategies to assist women in the prevention or minimisation of negative effects on sexuality and body image are described subsequently.

Intervention Strategies

The first level of intervention should involve a basic sexual assessment. There are several supportive framework models to assist in conducting sexuality assessments, such as the PLISSIT, ALARM, SCHOVER, and BETTER Models (Krebs 2006; Mick 2007). As previously described in chapter 2, these models are useful in guiding assessment and education about sexuality, and assist health professionals to differentiate between problems that require simple interventions, and those that require more specialised expertise (Robertson 2005; Wilmoth & Spinelli 2000).

Once sexual function has been assessed, interventions to promote adaptation can be achieved by education of the patient (and partner, if appropriate). The following general interventions have been adapted from the work of several authors. (Andreasson et al. 1986; Green et al. 2000; Robertson 20005; Krebs 2006). The recommended interventions include:

- Educating the patient about her vulvar anatomy, and identifying what will be removed at surgery.
- Providing factual information about the potential direct effects that treatment may have on sexuality.
- Assisting women with the “desensitisation” to touching and viewing their scar.
- Giving practical suggestions regarding future sexual activity such as, when to resume sexual intercourse. There is no normal time to resume sexual intercourse, for each woman this is an individual and personal thing, but these women require information that sexual intercourse

should not cause them pain. Equally, information about the role of vaginal lubricants and/or topical oestrogen creams should be provided.

- The changes to sensation in the region of the surgical excision should be described to the patient. These are relevant to both everyday life and sexual life. There is no therapeutic option to this except, information and guidance, such as advising women about changes to underwear and for advice about finding alternative areas for erogenous sensation.
- Identifying available cancer support services

Specific Suggestions

The second level of intervention should be problem focused, based on the presence of a sexual dysfunction, and may be addressed by suggesting strategies or alternatives to alleviate specific problems. For example: women might find that certain sexual positions are more comfortable and arousing than others. If a woman is experiencing pain with sexual intercourse, it is important that she have control over the depth of penetration and the rate of thrusting, in this instance the female superior position is often optimal (Karpenter & Andersen 2005). Women who experience more complex or persistent sexual problems such as, hypoactive desire disorder or sexual arousal disorder, require more intensive therapy. Based on the needs of the woman and or her partner, the specialist nurse is in a position to provide referral information, or organise a referral to a trained sexual therapist or psychologist (White 2008). In recognising the range of sexual changes that these women may experience, and acknowledging the legitimacy of the topic of sexuality with women, assists them to deal with this relevant quality of life issue (Hughes 2000:99).

Conclusion

This study is one of only two studies focusing specifically on Australian women with vulvar cancer. The findings from this study extend beyond the original questions on sexuality and body image, to a broader description of the experience. These findings enhance our understanding of the experience of sexuality and body image for these women. While the results of this study cannot be generalised to wider populations, they do present us with each woman's view of their own experience.

The identification of themes common to the experience for all of the women in this study adds to our understanding of the experience of sexuality and body image following treatment for early stage vulvar cancer. This experience involved disruption to some of the more functional aspects of sexual intercourse; this is most predominant in post menopausal women having had a more extensive surgical excision. For younger premenopausal women having had a conservative surgical approach to treat their cancer, once overcoming initial fears in relation to resumption of sexual intercourse, experience no adverse long term sexual effects. It is also evident that for all sexually active women, intimacy and relationship status are more important to them than physical arousal. A small number of women never resume sexual intercourse after treatment and this appears to be related to the absence of a committed sexual partner and a more radical surgical excision. However, there may be other reasons why these women never resume sexual intercourse after surgery.

The women experienced little to no long term disruption to their self concept and body image, following conservative surgical excision. The women, who underwent more extensive removal of vulvar tissue, multiple vulvar procedures, and those who developed lymphoedema, were those who experienced detrimental effects on body image. These results highlight the improved psychosexual outcomes for women whose vulvar cancer is treated with a more conservative surgical approach. These findings support the current emphasis on management of these women by performing the most conservative operation, consistent with cure of their disease.

Overall, the findings from this study add to the existing body of knowledge available, and have implications for health professionals attempting to meet the needs of women with gynaecological cancer. Although unintentionally, it appears that as health professionals we have failed to some degree, in the provision of information and support to women diagnosed and treated for vulvar cancer. This is evident, not only from the time of their diagnosis to treatment, but throughout their survivorship. The results also indicate that from the women's viewpoint there is still a necessity to improve communication about sexual issues. These study findings provide an insight into the care requirements that need to be considered.

Nurses can be instrumental in providing these women with the information, education and support they require, to adjust to the diagnosis and subsequent treatment of their vulvar cancer. Additionally, by discussing and including sexuality in these women's care will validate to them that sexuality is considered an important component of their recovery. The challenge now for us as health professionals is to address these issues and improve our care of women diagnosed with vulvar cancer.

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Appendix 1a

AN INVITATION TO PARTICIPATE IN RESEARCH

Women's Experience of Sexuality and Body Image Following Treatment for Early Stage Vulvar Cancer

23rd February, 2009

Dear

I am writing to introduce to you a research project that will be undertaken by Ellen Barlow, Clinical Nurse Specialist in the Gynaecological Cancer Centre at the Royal Hospital for Women. Ellen is conducting this project as part of her Honours thesis for a Master of Nursing she is currently undertaking at the University of New England. This study will assist us to identify the long-term effects of surgery for vulvar cancer on sexuality and body image. Little is known about women's experiences following treatment. You are receiving this letter because you have been treated for early vulvar cancer in the Gynaecological Cancer Centre at The Royal Hospital for Women.

This research will provide us with information which will help us to better understand your experience, enabling us to provide more appropriate information and counseling to women like yourself, both prior to and following treatment for vulvar cancer.

Involvement in this study would include your participation in a confidential in depth interview with Ellen Barlow, the research nurse from our unit. This interview would take approximately 60- 90 minutes of your time, and would be tape recorded. The interview would be conducted at a time and location convenient for you.

If you would like to discuss this study further with, Ellen Barlow, please let her know by completing the next page and post back it to her in the enclosed reply paid envelope. Alternatively, you could telephone Ellen directly on 02- 93826184, or email her on ellen.barlow@sesiahs.health.nsw.gov.au.

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Yours sincerely

[redacted]

Neville F Hacker
Professor of Gynaecological Oncology, Conjoint/ University of New South Wales
Director, Gynaecological Cancer Centre, Royal Hospital for Women

Appendix 1b

Women's Experience of Sexuality and Body Image Following Treatment For Early Stage Vulvar Cancer

PERMISSION TO BE CONTACTED ABOUT THE STUDY

I …………………………………………………………………..[NAME]

of

………………………………………………………………………………………

…………………………………………………………………….[ADDRESS]

have read and understood the "*Invitation to participate"* for the above named research study. I agree to be contacted by the researcher, Ellen Barlow to be given more information about the study.

I am best contacted on………………………………….[TELEPHONE NUMBER(S)]
on………………………………….[DAYS]
on………………………………….[TIME]

NAME………………………………

SIGNATURE………………………….

DATE __/__/_______

Royal Hospital for Women, Gynaecological Cancer Centre, version 1, 11th August 2008

Appendix 2. Interview Guide

Establishing Rapport:

Before asking questions about sensitive sexual matters it is important to ensure trust, privacy, and a safe environment to allow free communication, and to establish rapport with the participant. The participant will be told they can terminate or adjourn the interview at any time.

This will take place by:

- Reviewing demographic information
- Explaining that for some women this topic is a difficult one to discuss openly.
- Reinforce to the participant this interview is confidential
- Eliciting the participants emotional response to cancer diagnosis and treatment

Questions:

- How did you cope with your diagnosis and surgery?
- How do you now feel about your diagnosis and your treatment for vulvar cancer?

Questions regarding the participants social support network:

- Do you live alone or with family/friends?
- Do you feel you have good support from family and/or friends?
- What leisure activities do you enjoy?

In order to establish if a partner exists, and the status of the relationship.

Questions

- Are you currently involved in a relationship?
- How long have you been involved in this relationship?
- Are you currently sexually active?

Sexual Function:

Open with a normalising statement such as: many women who have had surgery for vulvar cancer find that it has an impact on their interest in sex and sexual functioning.

Appendix 2 continued

Useful Questions:

- Has anyone spoken to you before about the impact of treatment on your sexuality?
- Can you tell me a little about the place that sexuality has in your life/ relationship?
- How has the treatment for vulvar cancer affected your sex life?

Questions to probe this topic

- Have you noticed any altered sensation?
- Have you noticed any changes to your ability to achieve orgasm?
- Have you noticed changes in your sexual relationship since surgery?
- Do you see yourself as different sexually since surgery?
- What has been your partner's response to you sexually since your treatment?
- Do you feel your partner's attitude changed following your treatment for vulvar cancer?
- Do you think the frequency of sexual activity has changed?

Body Image:

Statement: Many women following treatment for vulvar cancer 'feel different' about their bodies.

- Have you noticed any change to how you feel about your body since surgery?
- Could you tell me more about what changes you have experienced since your treatment?
- (If so) have you had difficulty adjusting to theses changes?
- (If so), has this had an impact on your feelings of sexuality?

The Royal Hospital for Women, Gynaecological Cancer Centre, version 3, 29th December, 2008.

Appendix 3

RHW

24th May, 2007

I agree to allow Ellen Barlow, Clinical Nurse Specialist in the Gynaecological Cancer Centre at the Royal Hospital for Women, to access the information database of patients treated for gynaecological cancer in this department.

I understand Ellen will use this information to develop a list of potential participants, for a research project she is conducting as part of a Master of Nursing honours thesis, she is currently undertaking, at the University of New England.

Yours sincerely

[redacted]

Neville F Hacker
Professor of Gynaecological Oncology, Conjoint/ University of New South Wales
Director, Gynaecological Cancer Centre, The Royal Hospital for Women

Appendix 4

UNE
THE UNIVERSITY
OF NEW ENGLAND

RHW

INFORMATION SHEET FOR PARTICIPANTS

Women's Experience of Sexuality and Body Image Following Treatment For Early Stage Vulvar Cancer

You are invited to participate in a study to help us learn more about the long-term effects of treatment for early stage vulvar cancer on sexuality and body image. In this study, we hope to gain a better understanding of your experience of sexuality, and perception of body image following your treatment. This study has been developed as part of a Master of Nursing research honours project, presently being undertaken by the Research Associate Ellen Barlow at the University of New England, Armidale, NSW,

You were selected as a possible participant in this study because you have been treated for an early stage vulvar cancer at the Royal Hospital for Women. The information you could provide will assist us in understanding your experience, allowing us to provide more appropriate information and counselling for women like yourself to help to minimise the difficulties that might arise.

If you decide to participate: –
You will be asked to be involved in a confidential in-depth interview with the Research Associate Ellen Barlow. The estimated duration of the interview would be approximately 60-90 minutes. The interview will be tape recorded with your consent and later transcribed by the interviewer, Ellen Barlow.

This interview will involve you describing your experience of sexuality and body image since your treatment. We acknowledge that this interview will require your discussing topics of an extremely personal nature, and every effort will be made to prevent you any embarrassment or discomfort. This confidential interview will be arranged at a time and location agreeable to you.

We would also like to collect information from your hospital medical records about your treatment follow-up and other medical conditions. This information will remain confidential.

We do not predict that you will receive any direct benefits from this study. However, your participation may assist in making future changes in the care and support offered to women who like_you, have had treatment for vulvar cancer**.** Should the interview raise difficult issues for you, you will be offered counselling support by the gynae/oncology psychologist Rosalind Robertson and referrals will be made if you wish for ongoing assistance in your local community.

Any information about you that is obtained in connection with this study will remain confidential and will be disclosed only with your written permission. However, the findings from this study may be published or disclosed to other people in a way that will not identify you. The data from this study will be coded and stored in a locked filing cabinet for 7 years and then shredded and computer or disc, erased. There will not be any costs associated with your participation.

Appendix 4, continued

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OF NEW ENGLAND

RHW

INFORMATION SHEET FOR PARTICIPANTS

This project has been approved by both the Human Research Ethics Committee of The University of New England and the Human Research Ethics Committee of the South Eastern Sydney Area Health Service (UNE HREC approval no: HEO8/011; SESIAHS HREC approval no: 08/152). Should you have any issues concerning the manner in which this research is conducted, please contact the Research Ethics Officers at the following addresses: Research Services, University of New England, Armidale, NSW 2351. Tel: (02) 67733449, Fax: (02) 67733543, Email: Ethics@.une.edu.au. Ms Marie Malica, Manager, Research Support Office, South Eastern Sydney and Illawarra Area Health Service HREC Northern Sector, Tel: (02) 9382-3587, Fax: 93822813, Email marie.malica@ sesiahs.health.nsw.gov.au

Whether or not you decide to participate will not interfere with the care you will receive from any of the staff at the Royal Hospital for Women or any other facility. If you decide to take part in the study you will be given the option to withdraw from the study at any stage.

If you have any questions at any time please contact Ellen Barlow on (02-9382-6184), A/Professor Rafat Hussain on (02) 67733678, or Dr Glenda Parmenter on (02) 67733683 who will be happy to answer them.

You will be given a copy of this form to keep.

The Royal Hospital for Women, Gynaecological Cancer Centre, version 3, 29th December, 2008

Appendix 5

UNE
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RHW

CONSENT FORM

Women's Experience of Sexuality and Body Image Following Treatment For Early Stage Vulvar Cancer

1. I ....of ……………………………………..
   agree to participate as a subject in the study described in the Information sheet for Participants set out on page 1 and 2.

2. I acknowledge that I have read the information sheet for participants, which explains the research project including possible risks. I acknowledge that I am aware, and agree to this interview being tape recorded.

3. Before signing this consent form, I have been given the opportunity of asking any questions relating to any possible physical and mental harm I might suffer as a result of my participation and, if I have asked such questions I have received satisfactory answers.

4. I understand that I can withdraw from the study at any time without prejudice to my relationship with The Royal Hospital for Women or any other facility required for my care.

5. I agree that research data gathered from the results of the study may be published or presented, provided that I cannot be identified.

6. I agree that relevant information pertaining to my treatment and ongoing care at the Gynaecological Cancer Centre in the Royal Hospital for Women, may be obtained from my medical records for the purposes of this study.

7. This Consent form is being signed in duplicate and I acknowledge receipt of a copy of this Consent Form and the Information Statement for Participants.

Signature of Participant	Signature of Researcher
______________________________	______________________________
Please PRINT name	Please PRINT name
______________________________	______________________________
Date ______________________________	______________________________

The Royal Hospital for Women, Gynaecological Cancer Centre, version 3, 29th December, 2008

Appendix 5, continued

THE UNIVERSITY
OF NEW ENGLAND

RHW

REVOCATION OF CONSENT

Women's Experience of Sexuality and Body Image Following Treatment For Early Stage Vulvar Cancer

I hereby wish to WITHDRAW my consent to participate in the research project described above and understand that such withdrawal WILL NOT jeopardise any treatment or my relationship with the Royal Hospital for Women or my medical or nursing attendants.

Signature	Date

Please PRINT Name

The section for Revocation of Consent should be forwarded to Ellen Barlow, Gynaecological Cancer Centre, The Royal Hospital for Women, Barker Street, Randwick, 2031.

The Royal Hospital for Women, Gynaecological Cancer Centre, version 3, 29th December, 2008

Appendix 6

Further Biomedical Information

Pre-invasive Diseases of the Vulva

Lichen Sclerosis: Is a non neoplastic condition of the vulvar skin of unknown etiology, which causes severe pruritis. Although it is seen in women of all ages, lichen sclerosis more commonly occurs in post menopausal women (Hughes & Handscomb 2001). The long term risk of a woman with lichen sclerosis developing vulvar cancer is low. However, there is an increased risk if accompanied by hyperplasia (Hacker 2010).

Vulvar Intraepithelial Neoplasia (VIN) is a cellular abnormality of the vulva which is confined to the epithelium. The term VIN applies to histologic high grade squamous intraepithelial lesions. There are now two categories of VIN: VIN, usual type (subcategorized histologically as warty, basaloid, or mixed). VIN, usual type, encompasses VIN 2, VIN 3, and the previous older histologic terms: Bowen's disease, bowenoid papulosis, dysplasia, and carcinoma in situ. These lesions are usually associated with HPV. Invasive squamous cancer of the warty or basaloid type is associated with this type of VIN.

VIN, differentiated type; appear less commonly, are seen most particularly in older women, and are not associated with HPV. This type is usually apparent in a background of lichen sclerosis (Campion 2010:20; Hacker 2010:537). VIN has generally been considered to have a low malignant potential. However, in 2005 Jones, Rowan and Stewart reported a series of 405 cases of VIN 2-3 seen over a 40 year period in Auckland, New Zealand. The authors found that 10 of 16 (62.5%) women with persistent untreated VIN had progressed to malignant disease.

Paget's Disease of the Vulva

Paget's disease of the vulva is an uncommon non squamous intraepithelial lesion of the vulva. It predominately affects post menopausal white women, and presents as vulvar pruritis and soreness. The lesion usually begins on the hair bearing areas of the vulva, but may extend to the mons pubis, thighs and buttocks. It may manifest in an underlying adenocarcinoma of a skin appendage, or of vulvar glandular origin (Hacker 2010).

Staging of Early Vulvar Cancer

The role of cancer staging is to identify the tumour location, local and regional spread and metastases. This staging not only allows for treatment planning, but provides clinicians with a universal language to communicate about the disease, its treatment and prognosis (Hughes & Handscomb 2001). Staging for vulvar cancer is based on a surgical pathological staging system (Ansink, van der Velden & Collingwood 2006), therefore is established after surgical treatment. The current criteria for early stage vulvar cancer based on the International Federation of Gynecology and Obstetrics (FIGO) staging for vulvar cancer (2008) is:

- **Stage 1** Tumour confined to the vulva.
  - **1A** Lesions ≤ 2cm in greatest diameter, confined to the vulva or perineum, and with stromal invasion ≤ 1.0mm, and no nodal metastases.
  - **1B** Lesions greater > than 2 cm in size or with stromal invasion 1.0 mm confined to the vulva or perineum, with negative nodes.
- **Stage 11** Tumour of any size with extension to adjacent perineal structures (1/3 lower urethra, 1/3 lower vagina, anus) with negative nodes

(Hacker 2010:668).

Routes of Spread of Vulvar Cancer

Vulvar cancer spreads locally by direct extension to adjacent organs, including the vagina, urethra, and anus, and by lymphatic permeation to regional lymph nodes (Hacker & Van der Velden 1993). The lymphatics from the vulva drain mainly to ipsilateral (one side) inguinal and femoral nodes, and to the iliac and paraaortic nodes (Rouzier, Haddad, Atallah, Dubois & Paniel 2005). Lymphatic metastases may occur early in the disease, usually to the inguinal lymph nodes. Metastases to the pelvic nodes are uncommon, with an overall reported frequency of about 9%. In vulvar cancer hematogenous spread to distant sites such as the lung, liver, and bone are rare, and usually occur late (Hacker 2010:543).

Background to the Current Management of Vulvar Cancer

Almost 30 years ago, Hacker introduced the concept, previously suggested by Taussig, of using separate incisions for the groins, and the vulvar excision, in an attempt to decrease post operative morbidity (Stehman & Look 2006). As early as 1981, Hacker et al. (1981) reported improved healing and decreased post operative hospitalisation (mean = 19 days), in a series of one hundred patients who underwent radical vulvectomy and bilateral inguinal lymphadenectomy, through separate groin incisions. Ghurani and Penalver (2001) also identified the use of separate groin incisions in suitable patients, as contributing significantly to decreased postoperative morbidity and improved quality of life. Similarly, in a study of 67 patients treated with modifications to radical vulvectomy and groin dissection, compared to 15 women having had en-bloc vulvar resection and groin dissection, it was found en-bloc radical vulvectomy, radical vulvectomy (with separate groin incisions) and radical hemivulvectomy were associated with vulvar wound complications in 47%, 15%, and 8% respectively. The rate of wound complications decreased significantly with the use of separate groin incisions and one sided groin dissections. It was also determined that lymphocyst formation and lymphoedema were not reduced by the modifications to the groin dissection employed (Lin, DuBeshter, Angel & Dvoretsky 1991).

In a retrospective analysis of 160 patients treated for vulvar cancer, Rodriguez et al. (1997) identified no difference in minor wound breakdown rates, but significantly fewer major wound breakdowns in the conservatively treated group. They also found that the frequency of wound breakdown correlated significantly with the number of clinical risk factors. In contrast to these findings a study focusing on postoperative complications after modified radical vulvectomy and inguinofemoral lymphadenectomy (removal of the inguinal and femoral lymph nodes) identified high morbidity despite the use of the separate groin incisions, preoperative antibiotics, and post operative thrombotic prophylaxis. The most significant morbidity in this group of women was associated with the groin dissections, with complications in 59% of women younger than 65 years, and 72% of the women older than 65 years. However, these findings were not correlated with clinical risk factors such as smoking, hypertension, diabetes, obesity and other co-morbidities (Gaarenstrom, Kenter, Trimbos, Agous, Amant, Peters & Vergote 2003).