THE LIVED EXPERIENCE OF YOUNGER WOMEN WITH CANCER OF THE VULVA: A PHENOMENOLOGICAL STUDY

by

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Abstract

Cancer of the vulva is a comparatively rare cancer that requires radical surgery. Whilst the physical effects of the surgery can readily be described, little is known about the psychological, emotional and social impact of this condition. A review of the literature showed a paucity of studies (Andersen and Hacker 1983; van de Wiel 1990; and Green et al 2004) and produced limited insights into the wider impact of this disease. The question driving this work is ‘What must it be like to be diagnosed with, and have surgery for, a vulval cancer?’ The purpose was to gain an understanding of the women’s own perspectives of their care and to inform the development of clinical nursing practice.

An interpretative phenomenological approach was taken based on the work of Heidegger and van Manen (van Manen 1990; Mulhall 1996). Thirteen women were identified by purposive sampling and interviewed. The women were all below 50 years of age and had surgery to remove the cancer between 6 months and 5 years prior to the interview. The data was analysed using framework analysis (Ritchie and Spencer 1994). Four key concepts emerged from the data, Searching, Aloneness, All Change and Professional Connectivity, and were shown to be incorporated within the four existentials of the everyday world, Lived Body, Lived Relationship, Lived Time and Lived Space (Van Manen 1990). The lived experience is described in its entirety by the concept of Invisibility which reflects the challenges the women faced in living with a condition that is not recognised or widely discussed, a factor that impacts on the way in which these women can share their experience with family, friends and the health care professionals. The study concludes by making tentative suggestions as to how the insights gained could be used to improve the care of women with vulval cancer in the future.
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**Glossary**

**Bartholin’s gland carcinomas:** Bartholin’s gland carcinomas are mostly adenocarcinoma. Adenocarcinomas may also arise in the vestibular glands or the sweat glands. They represent 2-3% of all vulvar cancers.

**Basal cell carcinoma, BCC:** This is a relatively rare type of cancer of the vulva, accounting for 2-4% of cases.

**Bilateral Groin Node Dissection (BGND):** A bilateral groin node dissection involves the removal of the lymph nodes in the groin. They are removed because they may be at risk or clinically suspicious of metastatic disease. The procedure may be performed either through a separate groin incision or en-bloc with the vulva.

**Carcinoma in situ (CIS):** The cancer is confined to the epithelial layer only. The stage of cancer may also be called stage 0. It may also be referred to as VIN 3 (see below).

**Dyspareunia:** This term refers to pain on sexual intercourse.

**Early Stromal Invasion (ESI):** This term refers to a tumour that has begun to invade beyond the epithelial layer of the vulva and extends deeper into the stromal layer.

**Hemi-vulvectomy:** This operation involves removing half of the vulva, either as an anterior hemi-vulvectomy or posterior hemi-vulvectomy. Anterior hemi-vulvectomy usually includes the removal of the clitoris.

**Human Papilloma Viruses (HPV):** HPVs are small DNA viruses, and to date over 1000 types have been isolated. HPVs associated with the genital tract are divided into the high risk types, 16, 18, 31, 35, 45 and 56, and low risk types, 6 and 11 which are associated with genital warts. The high risk types are associated with the development of cancer of the vulva and also cancer of the cervix.

**Ipsilateral Groin Node Dissection (IGND):** Ipsilateral groin node dissection involves the removal of the lymph nodes from one side of the groin only.

**Lichen sclerosis:** Lichens sclerosis is a benign inflammatory disease of unknown aetiology resulting in patchy white changes on the vulva with associated itching (pruritus). It may develop into vulval cancer in some cases.

**Radical vulvectomy (RV):** A radical vulvectomy is the removal of the primary vulval cancer, together with contiguous skin, subcutaneous fat, labia majora, labia minora, clitoris and perineal body. It may be tailored according to the extent of the disease, for example when there may be involvement of the urethra. It may be performed with separate incisions to remove the lymph nodes, which is known as a triple incision, as there are three separate incisions or en-bloc, when there is one incision to include the vulva and the groin nodes.
Squamous cell carcinoma (SCC): Squamous cell carcinomas are the most common malignant lesions found on the vulva. They vary from small flat lesions, to shallow ulcers to large fungating lesions. The vast majority of squamous cell carcinomas are well differentiated, grade 1 tumours.

Total pelvic exenteration: This operation may be carried out on women who have a recurrent cervical tumour, and occasionally an endometrial cancer. The surgery involves the removal of the rectum and distal sigmoid colon, the bladder, vagina, cervix and endometrium and ovaries (if they are present) and necessitates the formation of both an ileal conduit and colostomy.

Triple incision: This involves the removal of the inguinal nodes in both groins, and a radical vulvectomy through three separate incisions.

Vulvar intraepithelial neoplasm (VIN): Vulvar intraepithelial neoplasia is an abnormality affecting the intraepidermal pathology of the vulval skin or mucosa. It ranges from mild atypia to severe abnormalities. VIN is graded according to the depth of the abnormality and severity. VIN 1 affects the lower one third of the mucosa, VIN 2 is confined to the lower two thirds and VIN 3 affects the full thickness of the epithelium. VIN mainly affects the labia minora and the perineum. The most common symptoms are itching, soreness and burning. The lesions may be unifocal or multifocal. Women with VIN 1 and 2 are treated by observation only while VIN 3 may be treated by local excision or laser vaporisation. VIN 3 may also be referred to as carcinoma in situ, CIS and leads to invasive cancer in 3-7% of women. Cigarette smoking is associated with 60-80% of cases.

Wertheim’s hysterectomy: A Wertheim’s or radical hysterectomy is performed for early stage cervical cancer. It involves the removal of the uterus, cervix and the upper one third of the vagina, the parametrial tissue, and the pelvic lymph nodes. The ovaries may also be removed at the same time.

Wide Local Excision (WLE): A wide local incision is a wide and deep resection of the vulval cancer with a 1 cm margin and deep dissection to the level of the inferior fascia. It is primarily used for early stage disease, when the primary lesion is 2cm or less in diameter.
CHAPTER I
INTRODUCTION

Wisest is she who knows she does not know

(Socrates 470-399 BC)

1.1 Introduction

This research study is an exploration of the lived experience of 13 women, who were less than 50 years of age, and were diagnosed with cancer of the vulva and underwent surgical treatment. Cancer of the vulva is a rare condition, and to date there is a lack of awareness of the issues affecting sufferers since little research has been conducted. The purpose of the study is to address this gap in knowledge, by investigating the experiences of women following the onset of symptoms, diagnosis and treatment of vulval cancer. The wider context of their experience within their family and work environment may also be explored. This opening chapter focuses on the background to the study and details my interest in this group of women. An overview of this condition is presented at the outset to inform the work that follows.

1.2 Cancer of the vulva

Cancer of the vulva is a rare condition, accounting for between 3-5% of gynaecological malignancies or 1000 new cases each year in the United Kingdom. It commonly affects women aged over 70 years, but in recent years younger women are also being affected. The pre-disposing factors associated with a diagnosis of cancer of the vulva are shown in Table 1.
Cancer of the vulva may arise from a precancerous condition known as vulvar intraepithelial neoplasia (VIN 3) which may develop into carcinoma in situ and then invasive cancer over time. An increasing number of younger women are being diagnosed with multi-focal pre-invasive disease, due to the effects of the Human Papilloma Virus (HPV). This was confirmed by Joura et al (2000) who noted that the incidence of VIN in women under 50 has increased by 392% in the last decade. It has also been shown that a prior history of genital warts increases one’s risk of VIN (Al-Ghamdi 2002; Rusk 1991).

**Table 1: Pre-disposing factors associated with cancer of the vulva**

- Precancerous conditions, lichen sclerosis, VIN (Vulvar intraepithelial neoplasia)
- Multiple sexual partners
- Human Papilloma Virus (HPV), immuno-suppression and Herpes Simplex virus
- Smoking
- Genital warts
- Lower socioeconomic status

Lichen sclerosis is also a precancerous condition characterised by a diffuse white change to the skin. A diagnosis of cancer or precancer is made by obtaining a sample of the affected tissue and confirming it by histological examination.

The treatment for cancer of the vulva and for precancerous conditions is surgery to remove the affected area, together with a 1 cm area of healthy tissue. The extent of the surgery
depends on the depth of invasion of the tumour, which is defined as the measurement from
the epithelial-stromal junction of the most adjacent superficial dermal papilla to the deepest
point of invasion. The most common histological types are squamous carcinomas (85-
90%), but other types such as adenocarcinoma, melanoma and Bartholin’s gland cancers
may also occur. The International Federation of Gynecology and Obstetrics (FIGO) uses
surgical information to stage the tumour (see Appendix 2). The stage of the disease allows
insight into the prognosis, for example 65-90% of women with stage 1 disease may expect
a 5 year survival. The stage identified also assists in making a decision regarding adjuvant
therapy post operatively. Further information on the aetiology, anatomy, and physiology
of the vulva, and treatment and nursing care of women with cancer of the vulva may be
found in Appendix 2 and 3.

The care of patients with any form of cancer has been an increasing priority for the British
Government in recent years. The rapid referral system was instigated as part of the
Department of Health NHS Cancer Plan (2000) whereby any patient suspected of having
cancer must be seen within 14 days. Women with rare cancers, such as cancer of the
vulva, are referred to cancer centres which are located around the UK and may be a
distance from the patient’s home. The benefits of cancer centres are that multidisciplinary
teams can develop and maintain the necessary skills and expertise (Junor et al 1994). In
addition, 34 cancer networks were established in September 2000 to help to implement the
NHS Cancer Plan (2000). They were identified as the organisational model for cancer
services and brought together health service commissioners and providers, the voluntary
sector and local authorities within regional areas, with the aim of improving the patients’
experience of care and ensuring that the appropriate information was provided throughout the patient’s journey.

1.3 Background to the study

As a Clinical Nurse Specialist caring for women with a gynaecological cancer, I have noticed that over the past few years increasing numbers of younger women were being diagnosed with vulval cancer and admitted to hospital for radical surgery. This can be a life-changing event for women of any age, but as younger women were being treated for this condition, they have a longer lifetime ahead of them to become accustomed to the consequences of their diagnosis and treatment. I began to reflect about this particular group of women with a specific question in mind: ‘What must it be like to be diagnosed and treated for cancer of the vulva?’ I understood the physical effects of the surgery involved, but I started to consider how this might affect them from a psychological, emotional and social point of view.

There appeared to be a lack of holistic advice for women when they were discharged from hospital care, and at follow-up appointments although many aspects of the patient’s well-being were addressed, I noticed that questions about any psychological concerns or sexual rehabilitation were rarely asked. Neither did there seem to be any care for the woman and her partner as a couple. I came to the conclusion that I had a ‘snap shot’ view of their time in hospital, but had no real understanding either of the time from the onset of their symptoms until their diagnosis had been made, or of the consequences for a woman and her partner following her surgery for vulval cancer and subsequent rehabilitation. This is shown diagrammatically in Figure 1.
This issue arose from the perspective of my role as a Clinical Nurse Specialist and may lead to anecdotal awareness.

1.3.1 Anecdotal awareness

As I have been employed as a Clinical Nurse Specialist for a number of years, I have cared for a number of these women. Many of them recalled the time before their diagnosis was confirmed. They had spoken of numerous visits to various doctors before their treatment was started and the frustration of having to endure unpleasant symptoms for some time.
They also mentioned their shock on being told they had cancer and the profound impact this had had on them and their families. In particular, the care of a 28 year old vulval cancer patient who had young children had a lasting impact on the nurses involved in her care. Her disease was at an advanced stage before she was diagnosed and thus I was aware of the value of alerting women of the presenting symptoms of vulval cancer and the importance of seeking prompt medical advice. I also wanted to know if they had received verbal and written information that was appropriate to their needs at every stage of their journey of care.

Following the women’s surgery, I had helped to plan their discharge from hospital care, including referrals to the physiotherapist and lymphoedema specialist nurse, and contacting the district nurses to arrange home visits. I wondered how they coped when they had left the hospital environment and returned to their own homes, and questioned how long it had taken for them to recover physically and to be able to return to work.

An integral component of nursing care is to provide empathy and understanding towards the patients in one’s care. I began to reflect on this particular group of women, and began to think how I would feel if it happened to me.

1.3.2 As a woman

Cancer has been described as the ‘most frightening disease of all’ (Herzlich and Pierret 1987) and Bailey (2001) notes that the way people with cancer are cared for may be shaped by what we feel about cancer, reflecting on our views if this experience was personal to us. There appear to be several components. Firstly there would be the diagnosis of cancer
itself and coping with a life-threatening illness, and the fears over a possible recurrence. I would be concerned for myself with the worry that my life would be curtailed, and also for my family left behind. There would also be feelings of anticipatory loss: that I may not be able to see my children marry or enjoy prospective grandchildren. There would also be the component of coping with the illness itself, which would require surgery on a very intimate part of my body. I thought I would be embarrassed, but that may have been partly as I knew the doctors on a professional basis. My thoughts were:

- What must it be like to develop symptoms affecting a sensitive part of one’s body?
- What would be the impact of a diagnosis of cancer on one’s emotions?
- How would one feel if one had cancer of the vulva?
- What must it be like to have radical surgery on an intimate part of the body?
- How would one’s life be affected subsequently?
- What does it mean to be living with a disease that may recur at any time in the future?
- How would one’s husband/partner be affected by this illness?
- What effect would this have on one’s family?
- Would one’s life style change following this experience?

These thoughts informed my thinking in developing this study and are explicated further in chapter 3.

It is known that women, who require surgery for benign gynaecological conditions, may face sexual dysfunction such as loss of libido, lowered self-esteem and concerns about loss of femininity (McQueen 1997). It follows therefore that women requiring surgery for a
gynaecological cancer will be similarly affected. It is also likely that one’s body image may be affected if an organ that inherently makes one feminine is affected by an illness such as cancer.

To explore this, my initial task was to undertake a literature review which is described in chapter 2.

1.4 Research question

The question driving this work is ‘What must it be like to be diagnosed with, and have surgery for, a vulval cancer?’ I wanted to ask the women in my study to tell me their stories about what it is like, what their feelings are, and their understanding of the events following their diagnosis. I wished to capture a sense of their lived experiences by asking ‘What was it like for you?’ The time frame included the time that the women first became aware of the presenting symptoms, in order to incorporate their perceptions of life prior to the diagnosis, and how it is now. The impact of the woman’s diagnosis and treatment on her husband/partner and their family was also considered. The purpose was to gain insight into the patient experience by allowing the women to voice their experiences just as they were (Jardine 1990). It was anticipated that this would aid the development of nursing practice by adding to the body of nursing knowledge.

By researching the lived experiences of the women with cancer of the vulva, the wider context of her experience may also be explored. For example, suggestions about how their care could be improved in the future may also be identified. Good quality of care must be based on an understanding of the needs, desires and expectations of patients and until we
know what it is like to have this type of cancer and to receive treatment for it, we cannot understand the women’s needs, or know what is required to care for them. This is important as the only study on British women with cancer of the vulva was published over 16 years ago, and thus does not reflect contemporary health care today.

Given the paucity of literature regarding women in the UK, a decision was made to generate this insight utilising an interpretative phenomenological approach based on the work of Heidegger (Heidegger 2005) and van Manen (1990) which is discussed in chapter 3. In all, semi-structured interviews were conducted with 13 women who had been identified by purposive sampling. I hoped that by using my writing and language skills I would be able to describe, show and interpret the experience of having a cancer of the vulva, while remaining true to the women in my study. By being as perceptive, insightful and discerning as possible, I aim to disclose the phenomenon in all its fullest richness and greatest possible depth (van Manen 1990) and illuminate the perceptions that these women experienced from pre-diagnosis onwards (Crotty 1996).

It is anticipated that the knowledge acquired would enable other nurses and other health care professionals to ‘see’ something that would enrich their understanding (van Manen 2006). It was also hoped that the research will, as van Manen (1990, p32) states, ‘bring into nearness that which tends to be obscure’. I hope that by writing about these experiences, I will enable the reader to understand the significance of the experience of the participants, thus informing nursing practice and health care.
The findings from the study may have the potential to identify these women’s needs and to plan future care. Wider and larger-scale studies could also be guided from an informed starting point (Jasper 1994). I was aware that by seeking this knowledge, there might be an impact on the women studied, but it would allow them to voice their experiences just as they were (Jardine 1990). The study was organised in the following way.

1.5 Framework of the study

The framework of the study involved a review of the literature, development of the research design and subsequent interview schedule, selection of participants, analysis of the data, and report of the findings. It involved the step by step approach of:

- Background reading and thinking about women with cancer of the vulva
- Review of the literature
- Gaining an understanding of qualitative research methodologies in general and studying phenomenology as a philosophy and research method in depth
- Formulation of research question
- Development of the interview schedule
- Selection of participants
- Conducting and recording interviews with women who have had cancer of the vulva
- Listening to the tapes, reading and re-reading the transcripts and reflecting on what was seen and heard during the interview
- Developing and defining the key themes to emerge from the data
- Through analysis and by reflecting on the data, seeking to understand the experiences that the women have shared
- Developing concepts to describe the meaning of the women’s experiences
- Writing down these concepts
- Reporting the findings
- Making recommendations to improve the care of this group of women in the future.

Adapted from Reinharz (1983); Ritchie and Spencer (1994)

This study is presented in a series of eleven chapters. Chapters 1-4 focus on the context, literature review, research philosophy and design. The stories of the women who took part in the study are then provided in chapter 5, together with a description of the way the cancer presented. Chapters 6-9 are devoted to the four key concepts that arose from the data analysis. Chapter 10 builds on these, and discusses the ‘lived experience’ of the women who were studied. In conclusion, Chapter 11 notes the implications from the findings and final reflections.

In view of the qualitative nature of the research study and my own involvement as the researcher, I decided to use the ‘first person’ to reflect this throughout this thesis. Several authors have advocated this to increase the transparency of the research process (Webb 2002), and it enabled me to reveal my own opinions and thoughts in documenting the findings.
1.6 Summary

This chapter has described the background to the study, the reasons why I undertook the research and my research question. The organisation of the study from the initial idea to fulfilment of the thesis is given, together with an explanation of the individual chapters. By focussing on women who have undergone treatment for cancer of the vulva, it is hoped the findings will provide an insight into the experiences of the patients themselves and a better understanding of the impact of their disease and treatment. These findings may then be used by health professionals to inform delivery of health care to others with this rare condition.

The following chapter reviews the literature to set the scene for the research that follows.
CHAPTER 2
LITERATURE REVIEW

2.1 Introduction

The purpose of the review is to set the background to the study, gain an overview of the published findings by summarising previous knowledge, and to contextualise the meaning of the women’s experiences. The research databases of British Nursing Index, CINAHL, Medicine and Psychinfo were searched using the words ‘vulva or vulvar or vulva neoplasm, psychosocial or psychosexual, altered body image’. Since cancer of the vulva is rare, there are very few studies compared with research on other groups of cancer patients. There were 14 studies in total. The number of women in each study and overall, is small and the total number involved was less than 300.

Since there was a paucity of literature on women with vulval cancer, and as breast cancer affects an organ associated with femininity, I also considered the literature on this. In contrast there have been many studies on the impact of breast cancer and the subsequent sequelae of the surgery. This meant I was able to draw some comparisons between women who had breast cancer and those with vulval cancer, as will be seen throughout the thesis.

2.2 Review of the literature

The literature reviewed commenced from 1983, as the first paper to discuss the post treatment consequences following vulvectomy was published in that year by Andersen and Hacker (1983). The review included studies on women with the precancerous condition VIN 3, early stromal invasive disease or carcinoma in situ, and invasive cancer of the vulva. Women with precancerous conditions were included as they also undergo surgery,
as a wide local excision or anterior or posterior or hemi-vulvectomy to remove the affected tissue. It may be assumed that these women may undergo similar post operative consequences as women requiring surgery for vulval cancer and parallels may be drawn between their experiences. This was noted in studies by Andersen and Hacker (1983) and Likes et al (2007) who reported that women requiring surgery for pre-invasive disease and those requiring surgery for invasive disease were affected in similar ways.

The articles by Weijmar Schultz et al (1986); Green et al (2000) and Likes et al (2007) were described as pilot studies, while Andersen et al (1988) and Moth et al (1983) describe their papers as preliminary reports. Pockets of activity developed in the USA with two studies by Andersen and colleagues (Andersen and Hacker 1983; Andersen et al 1988), in the Netherlands with a series of three studies (Weijmar Schultz et al 1986; van de Wiel et al 1990; Willibrord et al 1990) and in Denmark (Moth et al 1983; Andreasson et al 1986; Thuesen et al 1992). Twelve studies were retrospective. The studies reported by Willibrord et al (1990) and van de Wiel et al (1990) were part of a larger prospective longitudinal study, investigating seven couples over a period of two years. Only one study involved women from Britain. This was conducted 16 years ago (Corney et al 1992). There is nothing in the current literature regarding women in the UK today who are suffering from this condition. This is important since the British National Health Service is different from the health care system in other countries, and this may impact on the meaning that women in this country give to their experiences of cancer of the vulva. A summary of all the studies is shown in Table 2.
<table>
<thead>
<tr>
<th>Year of publication</th>
<th>Authors</th>
<th>Country</th>
<th>Research Study</th>
<th>Methodology</th>
<th>Assessment Tools</th>
<th>Number of patients involved</th>
<th>Age of respondents</th>
<th>Timing</th>
<th>Findings</th>
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<tbody>
<tr>
<td>1983</td>
<td>Moth et al</td>
<td>Denmark</td>
<td>Preliminary Report</td>
<td>Retrospective Quantitative Questionnaire Interviews Gynaecological Examination Partners included</td>
<td>Questions from part of Danish Sexology Questionnaire</td>
<td>15</td>
<td>32-60</td>
<td>1-8 years</td>
<td>1. Almost all had sexual dysfunction 2. Changes in body image 3. Depression 4. Insufficient information provision 5. Partners were depressed</td>
</tr>
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<td>Year of publication</td>
<td>Authors</td>
<td>Country</td>
<td>Research Study</td>
<td>Methodology</td>
<td>Assessment Tools</td>
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<tr>
<td>1986</td>
<td>Andreasson et al</td>
<td>Denmark</td>
<td>Main study</td>
<td>Retrospective Quantitative Questionnaire Interviews Gynaecological Examination Partners included</td>
<td>Questions from part of Danish Sexology Questionnaire</td>
<td>25 partners</td>
<td>27-69</td>
<td>1-11 years</td>
<td>1. More than half had sexual dysfunction 2. Psychological problems. 3. Half the partners had psychological problems</td>
</tr>
<tr>
<td>1986</td>
<td>Weijmar Schultz et al</td>
<td>The Netherlands</td>
<td>Pilot study</td>
<td>Retrospective Quantitative Questionnaire Interview Gynaecological Examination Partners included</td>
<td>Questionnaire</td>
<td>7 partners</td>
<td>27-69</td>
<td>1-6 years</td>
<td>1.80% achieved complete or partial sexual rehabilitation</td>
</tr>
<tr>
<td>1986</td>
<td>Tamburini et al</td>
<td>Italy</td>
<td>Main study</td>
<td>Retrospective Quantitative Questionnaire Interview</td>
<td>MMPI Personality scale</td>
<td>21 partners</td>
<td>31-60</td>
<td>6 months – 12.5 years</td>
<td>1. Sexual dysfunction 2. Depression</td>
</tr>
<tr>
<td>Year of publication</td>
<td>Authors</td>
<td>Country</td>
<td>Research Study</td>
<td>Methodology</td>
<td>Assessment Tools</td>
<td>Number of patients involved</td>
<td>Age of respondents</td>
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<tr>
<td>1990</td>
<td>Willibrord et al</td>
<td>The Netherlands/ UK</td>
<td>Main study</td>
<td>Prospective Longitudinal study, before treatment, 6, 12, and 24 months post-op</td>
<td>1. Intimate Body Contact scale 2. Genital sensation List 3. Genital sensitivity test</td>
<td>7</td>
<td>37-69 Average = 49</td>
<td>Up to 2 years</td>
<td>1. Sexual dysfunction at 6 months, sexual rehabilitation at 12 months</td>
</tr>
<tr>
<td>1990</td>
<td>Van de Wiel et al</td>
<td>The Netherlands</td>
<td>Main study</td>
<td>Retrospective Quantitative Questionnaire Interviews</td>
<td>1. Intimate Body Contact Scale 2. Groningen arousability scale</td>
<td>7</td>
<td>37-60 Average = 49</td>
<td>12 months post-operatively</td>
<td>1. Sexual dysfunction regarding arousal and orgasm</td>
</tr>
<tr>
<td>1992</td>
<td>Corney et al</td>
<td>UK</td>
<td>Comparative study including cervical cancer patients</td>
<td>Quantitative Questionnaire Interviews</td>
<td>1. Hospital anxiety and depression scale 2. Visual analogue scale</td>
<td>28</td>
<td>Exact ages not given, between 20-75</td>
<td>6 months – 5 years Average = 31 months</td>
<td>1. Sexual dysfunction 2. Depression 3. Anxiety</td>
</tr>
<tr>
<td>Year of publication</td>
<td>Authors</td>
<td>Country</td>
<td>Research Study</td>
<td>Methodology</td>
<td>Assessment Tools</td>
<td>Number of patients involved</td>
<td>Age of respondents</td>
<td>Timing</td>
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<tr>
<td>1992</td>
<td>Thuesen et al</td>
<td>Denmark</td>
<td>Comparative study with women undergoing wide local excision and vulvectomy</td>
<td>Quantitative Questionnaire Interviews Gynaecological examination</td>
<td>Questions from part of Danish Sexology Questionnaire</td>
<td>18</td>
<td>20-55</td>
<td>3-11 years</td>
<td>1. Sexual dysfunction 2. Dyspareunia 3. Altered body image</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>No Control group Helsinki declaration respected</td>
<td></td>
<td></td>
<td></td>
<td>Average = 41.4</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2000</td>
<td>Green et al</td>
<td>USA</td>
<td>Pilot study</td>
<td>Quantitative Questionnaire Review of medical notes</td>
<td>DSM IV sexual function tool</td>
<td>41</td>
<td>25-98, Average = 60</td>
<td>Up to 5 years post-operatively</td>
<td>1. Increased sexual dysfunction, altered body image 2. Increased depression post-operatively</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>No Control group Ethical approval given</td>
<td></td>
<td></td>
<td></td>
<td>Average = 60</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2004</td>
<td>Janda et al</td>
<td>Australia/ USA/Austria</td>
<td>Main Study</td>
<td>Qualitative Questionnaire Interviews</td>
<td>1. ECOG performance scale 2. FACT-G</td>
<td>15</td>
<td>52-85, Average = 68</td>
<td>2 weeks-39 months</td>
<td>1. Reduction in physical, emotional, social and sexual functioning. 2. Altered body image.</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>No Control group Ethical approval given</td>
<td></td>
<td></td>
<td></td>
<td>Average = 68</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2007</td>
<td>Likes et al</td>
<td>USA</td>
<td>Pilot study</td>
<td>Quantitative Questionnaire Review of medical notes</td>
<td>1. Female Sexual Function Index 2. QLQ C- 30 3. Medical notes</td>
<td>43</td>
<td>19-75, Average = 47.6</td>
<td>2 months – 20 years, Average 29 months</td>
<td>1. The greater excision of vulval tissue causes greater sexual dysfunction and decreases quality of life.</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Ethical approval given</td>
<td></td>
<td></td>
<td></td>
<td>Average = 47.6</td>
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</table>
2.3 Research designs

This section considers the 14 studies identified in the literature. All the papers were critiqued using a framework that considered five elements, as shown.

Table 3: Research design framework

| 1. Identifying the research question |
| 2. Structuring the study |
| 3. Sampling |
| 4. Gathering the data |
| 5. Analysing the data |

Adapted from Parse et al (1985); LoBiondo-Wood and Haber (2006)

1. Identifying the research question

The research question was clearly identified in all the papers including aims to explore aspects of physical, psychological and sexual functioning of women after surgery on the vulva. Several studies sought to gain an overall picture of the post operative consequences of the surgery (Andersen and Hacker 1983; Stellman et al 1984; Corney et al 1992). The studies by Tamburini et al (1986) and Janda et al (2004) had similar aims and also sought to assess the effect on the woman’s quality of life post operatively. The remaining nine were specifically concerned with sexual functioning, comparing the time pre-operatively with the woman’s post operative functioning and the impact this had on her and her husband/partner (Moth et al 1983; Andreasson et al 1986; Andersen et al 1988; Weijmar

An assessment of the experiences of the partners of the women was included in the studies by Moth et al (1983); Weijmar Schultz et al (1986); Andreasson et al (1986); Willibrord et al (1990) and van de Wiel et al (1990). A number of authors (Andersen and Hacker 1983; Moth et al 1983; Andreasson et al 1986; Weijmar Schultz et al 1986 and Andersen et al 1988) incorporated an assessment of the information that the women had received from the health care professionals involved in their care.

2. Structuring the study

All the studies included an overview of what was already known about this group of women, highlighting the paucity of information and providing details to substantiate how the focus of the study emerged. However, only one published study referred to the background research methodology involved. Janda et al (2004) entitle their study ‘Vulvar cancer patients’ quality of life: a qualitative assessment’. The purpose was to develop a vulvar-cancer specific subscale tool to accompany the Functional Assessment of Cancer – General (FACT-G) questionnaire. The other studies took a quantitative approach but a weakness in these studies is that the background research design was not identified. Details pertaining to the research methodology are constrained by the methods of data collection rather than the philosophical basis.
Some studies took a comparative approach to evaluate two different groups of patients. For example Andersen and Hacker (1983) sought to compare their earlier findings with women who had a total pelvic exenteration, while Corney et al (1992) included women who had either a total pelvic exenteration or a Wertheim’s hysterectomy (See glossary). These patients are not comparable with women who have had cancer of the vulva as regards physical, psychological and sexual functioning. Women who have had a Wertheim’s hysterectomy are unlikely to experience any significant post operative sexual dysfunction as the vagina and vulva is not affected by the surgical procedure. Women who undergo a total pelvic exenteration lose their vagina as part of their surgery and intercourse is not possible unless a vaginal reconstruction has been undertaken which was not alluded to by Corney et al (1992).

Two studies identified a group of women with endometrial cancer as a comparative group, as the definitive treatment for this is a hysterectomy to remove a genital organ, the post operative radiotherapy may affect sexual function, and the five year survival rate is very similar to cancer of the vulva (Stellman et al 1984; Tamburini et al 1986).

Thuesen et al (1992) noted a change in the surgical management of women with vulval cancer which aimed to reduce the amount of vulval tissue removed, and wanted to describe the effect of these changes on the women.

of the meaning that the women gave to their experiences by asking them to compare their recollections of their physical, psychological or sexual functioning in the time before their surgery and how they felt subsequently. In this way, the women themselves served as their own control. However, retrospective data such as this is weak, as women may not be able to provide accurate details of the time prior to the onset of any symptoms that may have affected their functioning, or may only remember the positive aspects.

The study by van de Wiel et al (1990) involved an experimental design and was the only one which was undertaken in order to test a hypothesis. The hypothesis was that vulvectomy patients have a more problematic sex life due to their treatment compared with other women of a comparable age.

All the studies utilised more than one method to collect data and included postal surveys, interviews using validated assessment tools, gynaecological examination and a review of the medical notes. Questionnaires were used in all the studies, either by the women being asked face to face within a structured or semi-structured interview setting, or by utilising a paper and pen survey that was posted to the respondents. Both face to face interviews and self-report questionnaires were used by Andersen and Hacker (1983); Weijmar Schultz et al (1986); van de Wiel et al (1990); Willibrord et al (1990) and Corney et al (1992). The only studies that involved postal surveys without interviewing the respondents were those undertaken by Thuesen et al (1992); Green et al (2000) and Likes et al (2007).

The range of questionnaires used was diverse. For example in the group of studies from the team based in Denmark, the questionnaire was formulated for the study by Moth et al
(1983) who incorporated some questions from the Danish Sexological questionnaire (Jensen 1980). However it is not known how the questionnaire had been developed or if it had been piloted, as neither these details or the number of questions is included. This gives rise to concerns about its reliability and validity. Andersen and Hacker (1983); Tamburini et al 1986) and Likes et al (2007) included data collection tools that have been previously validated and used in other studies to assess the impact of cancer on post operative functioning. They were appropriate to answer the research question. For example, Likes et al (2007) utilised the Female Sexual Function Index (FSFI) (Likes et al 2006) which is a validated instrument used to assess sexual functioning in healthy women, women diagnosed with sexual dysfunction and in women who have experienced a vulval excision.

The number of questions was not recorded in the majority of studies, although Green et al (2000) used a survey composed of 88 questions including a multiple-choice component and Weijmar Schultz et al (1986) had 108 questions. Tamburini et al (1986) used the shortened version of the Minnesota Multiphasic Personality Inventory (MMPI), which had 370 questions in all. This may be significant as respondents may not answer all the questions if a large number is involved.

However none of the studies discussed how the questions were phrased or provided an interview schedule.

Stellman et al (1984) utilised a postal survey that was sent to 14 women. As the response rate was 50%, the authors also ‘briefly interviewed’ seven women in the clinic. A description of the findings from the interviews with four of the women was subsequently included as case histories. The use of interviews was not included within the study description and it is not known if the interviews were structured and used the same questions for each woman. Neither is it known if the interviews were recorded and if confidentiality and anonymity was assured, which is less easy in an out-patient clinic.

In some studies, interviews lasted between 45-90 minutes (Andersen and Hacker 1983; van de Wiel et al 1990), but in others this time was not recorded (Moth et al 1983; Weijmar Schultz et al 1986; Andreasson et al 1986 and Corney et al 1992).

3. Sampling

The method of selecting the participants was mostly by purposive sampling. However Stellman et al (1984); Tamburini et al (1986); and Janda et al (2004) did not record the method of identifying the respondents.

The number of participants in the studies ranges from 7 women (van de Wiel et al 1990; Willibrord et al 1990) to 43 women (Likes et al 2007). The studies on the women by Andreasson et al (1988); Thuesen et al (1992) and Likes et al (2007) also included women who had precancerous tissue disease and carcinoma in situ. As shown in Table 2, the age
range of the participants was between 19 years (Likes et al 2007) and 98 years (Green et al 2000), with the average age in most of the studies being 50-55 years. The study by Corney et al (1992) recorded that 4 women were aged under 50, 4 women were aged 51-64 years, while the remaining 20 women were over 65 years of age, although the upper age limit is not recorded. Janda et al (2004) also involved respondents who were older than those in other studies. They had an average age of 68 years (52-85 years), with 9/14 over 70 years of age. The respondents in the studies by Green et al (2000) had an average age of 60 years (25-98 years), but the precise age of each woman was not recorded.

The high response rate of participation in the research was noted, 76% by Corney et al (1992), 85% by Andersen and Hacker (1983) and 87% by Green et al (2000). Green et al (2000) attributed their high response to the women’s concern with their sexual function following their surgery and being able to respond to the survey anonymously at home. However the respondents received a monetary payment for participating, which could imply that the women were coerced in taking part in the study by this reward. If so, this is contrary to their basic human rights (LoBiondo-Wood and Haber 2006) but there is not enough information to comment on this. Willibrord et al (1990) and Likes et al (2007) noted the exclusion criteria for the eligibility of respondents in their studies, recording that those with a history of sexual dysfunction or psycho-emotional disorders were excluded.

The length of time between the respondents’ surgery and the reported study varied between two weeks (Janda et al 2004) and 20 years (Likes et al 2007). The long time frame is indicative of the challenges faced by researchers in achieving a sufficient sample size, but may have led to possible recall impairment. The average length of time between the
surgery and the time of the reported studies was mostly up to 5 years, although 6 studies did not provide this information (Andersen and Hacker 1983; Moth et al 1983; Stellman et al 1984; Andersen et al 1988; Green et al 2000 and Janda et al 2004). Willibrord et al (1990) conducted a longitudinal study and interviewed women on admission and again at 6, 12 and 24 months after surgery.

All research studies are committed to protect the human rights of the respondents taking part. This is achieved by ensuring that the local ethics committee approves the study, the respondents give their informed consent, and their right to confidentiality and anonymity is maintained (LoBiondo-Wood and Haber 2006). Six of the published studies (Moth et al 1983, Andreasson et al 1988; Thuesen et al 1992; Green et al 2000; Janda et al 2004; Likes et al 2007) reported that ethical approval and associated approval was obtained. The other studies failed to record this. This may reflect two issues. Either ethical approval was not given, or the recent change in editorial style has emphasised the importance of this being included by the authors.

4. Gathering the data

Most of the interviews took place in the hospital out-patient setting, although Janda et al (2004) do not record this and Corney et al (1992) state that the interviews took place either in the woman’s home or the hospital. The hospital environment may have been chosen as the women were attending for a routine appointment and it may have caused less inconvenience. However the principles of undertaking interviews in a quiet environment without interruption are not discussed and this may have been less easy to achieve within the hospital setting. It is not known in the majority of cases who conducted the interviews,
their professional background or interviewing skills. Corney et al (1992) reports that the authors undertook the interviews with the respondents, but by using four different researchers there may have been an element of bias.

Four studies incorporated a clinical gynaecological examination (Moth et al 1983; Weijmar Schultz et al 1986; Andreasson et al 1986; Thuesen et al 1992). The purpose of this appears to assess the women to ascertain if sexual intercourse was possible (Weijmar Schultz et al 1986). Other studies sought to compare the woman’s subjective estimation of her vaginal orifice which related to whether she was able to achieve intercourse, and the objective size of the vagina on examination (Moth et al 1983; Andreasson et al 1986 and Thuesen et al 1992).

Andersen et al (1988), Green et al (2000) and Likes et al (2007) undertook a review of the patients’ medical notes, in addition to collecting original data from the women. They recorded the number and sites of vulval excisions, for example the labia minora or posterior fourchette. The aim was to compare the area where the vulval tissue was removed and the size of the excision, with any post operative sexual dysfunction. However if the women’s medical notes are incomplete there may be issues of the records’ representativeness (Polit and Beck 2006). This seems to be relevant in the study by Andersen et al (1988) who noted that there was a low incidence of notations in the medical notes of post operative summaries regarding numbness, sexual problems and body image disturbances.
5. Analysing the data

Questionnaires used in postal surveys and interview settings recorded information that was described using nominal data. Moth et al (1983) and Andreasson et al (1986) conducted a postal questionnaire which provided quantitative data. Nominal data was used to describe changes in sexual functioning after vulval surgery. For example Moth et al (1983) noted that 7/15 and Andreasson et al (1986) reported that 10/24 did not have sexual intercourse after their vulval surgery. Tamburini et al (1986) provided numerical data in the form of percentages to note that 57% suspended sexual activity after surgery. However since Tamburini et al (1986) involved a small number of participants (n = 21), the use of percentages in the findings is precluded.

Other surveys utilised descriptive statistics to present the data. For example, Andersen and Hacker (1983) conducted semi-structured interviews with 15 women who also completed a questionnaire. The data was analysed using the Symptom Checklist-90 (Derogatis 1977) and Beck Depression Inventory (Beck and Beamesderfer 1974). The results were compared with standards expected for normal, healthy individuals and used to highlight the significance of the findings which were described in the discussion section. Van de Wiel et al (1990) conducted interviews in order to test the hypothesis that women who had undergone surgery for vulval cancer experienced changes in sexual activity, feelings of sexual arousal, sexual motivation and sexual satisfaction. The interviews were typed and the answers to each variable were scored on a five point scale. The results were compared with an age matched group, and Spearman’s correlation was used in order to make a quantitative presentation of the data. Although a statistical test was applied to the data, it was in order to compare the two groups, rather than to show statistical significance.
Janda et al (2004) conducted interviews with 15 women, which were then transcribed and analysed. The most frequent symptoms, for example lower leg lymphoedema, were measured according to the incidence and severity, and reported according to the mean value. As noted earlier, the aim was to develop a vulvar cancer specific qualitative assessment tool to be used in conjunction with the FACT-G (Functional Assessment of Cancer-General questionnaire). This was compiled on the basis of their findings and further work is planned to establish its reliability and validity.

Van de Wiel et al (1990) were the only authors to state that they used content analysis to identify themes to describe the women’s experiences. However, several authors sought to illustrate the meaning the women gave to their condition and derive understanding by including direct quotations (Andersen and Hacker 1983; Moth et al 1983; Stellman et al 1984; van de Wiel et al 1990; Thuesen et al 1992; and Corney et al 1992). The paper by Moth et al (1983) begins with a lengthy poem describing a woman’s feelings of aloneness and bitterness following her diagnosis.

To summarise, a review of the literature has shown that there are weaknesses in the design and analytical methods of the published studies, and they involved only a small number of women. There is also a lack of clarity in the analysis of the data. However, these studies provide an overview of the experiences of these women. This enables a picture to be built up of the challenges these women faced subsequently. It also illustrates the need for further work to be undertaken to explore these issues.
2.4 Findings in the literature

Despite the methodological limitations of the previous studies, there are collective trends which highlight some key issues which affected physical, psychological and sexual functioning following surgery for vulval cancer as shown in Table 2. The next section will discuss the findings in more depth.

2.4.1 Physical impact

The diagnosis of cancer of the vulva and subsequent surgical treatment had a direct impact on the women’s bodily functions (Andersen and Hacker 1983; Moth et al 1983; Tamburini et al 1986; Janda et al 2004; and Likes et al 2007). The women reported major disruption in terms of physical performance due to the development of lymphoedema which curtailed many activities such as shopping, cleaning, gardening, walking and housekeeping. Supportive hosiery offered partial relief and the women reported spending hours with their legs elevated to reduce the leg oedema. Janda et al (2004) also reported that the majority of women experienced a reduction in their physical functioning. It is not known exactly how many women experienced this, but it is noted that 3/15 of the respondents had had their surgery only two weeks before, which does not allow for a period of rehabilitation following the surgery. Six had developed post operative lymphoedema which impacted on their ability to fulfil their household chores. Post operative lymphoedema also caused a reduction in physical strength and tiredness (Moth et al 1983; Janda et al 2004).

The removal of fatty tissue around the perineum at the time of the surgery resulted in some women reporting a restriction in activities which involved sitting down for long periods, such as watching television, going to the cinema or taking trips in the car (Andersen and
Hacker 1983; Janda et al 2004). This also had an impact on the careers of the women in the study by Janda et al (2004) and they experienced difficulties in resuming their previous employment.

The surgery that was undertaken as an anterior hemi-vulvectomy or a radical vulvectomy also affected the women’s ability to pass urine. Micturition may be affected if the terminal end of the urethra is removed in conjunction with the vulval tissue. Several studies reported that when the women passed urine, it was described as a ‘spray’ or a stream with unpredictable direction with little control (Andersen and Hacker 1983; Moth et al 1983). Since this difficulty resulted in dampened clothing or leakage on to bathroom floors or carpets, it resulted in the women curtailing their social activities as they were reluctant to be away from home (Andersen and Hacker 1983; Stellman et al 1984; Janda et al 2004; Likes et al 2007).

Two studies reported the impact of the surgery on the clothes that were worn. Likes et al (2007) reported that women who had unilateral surgery reported their underwear fitting differently as one side of the vulva had been excised and the other side remained intact. This was described as a constant reminder of ‘not feeling whole’. In the study by Stellman et al (1984) one woman reported that she had ‘given up wearing slacks for fear that the absence of her vulva may be noticeable’.

In summary, the overall pattern following surgery for cancer of the vulva is one of deterioration in the women’s normal bodily functions such as passing urine, and a decline in everyday activities due to lymphoedema or the loss of fatty tissue around the perineum.
This had impacted on the women’s ability to enjoy her way of life as they had done prior to her diagnosis of cancer.

2.4.2 Psychological effects

Table 2 has shown that 8 of the reported studies noted psychological changes as a consequence of the diagnosis and surgery for vulval cancer (Andersen and Hacker 1983; Moth et al 1983; Stellman et al 1984; Andreasson et al 1986; Tamburini et al 1986; Andersen et al 1988; Corney et al 1992; Thuesen et al 1992; Green et al 2000). These were related to feelings of depression, which were manifested as feelings of anxiety (Moth et al 1983; Stellman et al 1986). Stellman et al (1986) illustrated the respondents’ feelings of guilt, isolation and aloneness post operatively by quoting from them directly. One woman is reported to have said ‘other women could not possibly understand what this surgery means’ (Stellman et al 1984). The feelings of isolation are linked to the rarity of the cancer, as some women reported the sense that they were ‘the only one’ with this condition (Janda et al 2004).

Several authors utilised standard data collection tools to record the effect of the diagnosis and surgery on levels of depression and anxiety. Andersen and Hacker (1983) noted that the women recorded substantial and significant levels of psychological distress and depression on the Symptom Checklist-90 (Derogatis 1977) and the Beck Depression Inventory (Beck and Beamesderfer 1974). This was supported in the later study by Andersen et al (1988). Moth et al (1983) attributed the feelings of depression to the fact that 6 women reported that the genital area looked far worse that they had imagined, and as a result experienced far greater problems than they expected. Anxiety was identified in the women studied by Corney et al (1992) who utilised the Hospital Anxiety and Depression
scale (Zigmund and Snaith 1983) to measure this. However in the absence of a pre-treatment assessment, this may be an indication that the anxiety was a continuation of pre-cancer distress rather than from the presenting symptoms of vulval cancer.

Depression was noted in 31% of women following their surgery by Green et al (2000) as determined by the PRIME-MD scale (Williams et al 1995) but only 14% reported taking anti-depressant medication. The authors attributed this to reluctance by the women to discuss their feelings at a medical consultation. Corney et al (1992) noted that the women who felt moderately or severely distressed indicated several periods of time when there was increased anxiety. These were the times between referral to a consultant and confirmation of the diagnosis and the time between the diagnosis and the surgery. The year following the surgery was also significant for some women who stated that they had become depressed during this time and one third had sought help from their doctor. Loss of self confidence and self esteem, which are also associated with depression, were also noted by Stellman et al (1984); Andreasson et al (1986); Tamburini et al (1986) and Corney et al (1992). This led to a withdrawal from their previous social contacts.

As noted earlier, the onset of lower lymphoedema may also curtail physical activities and this may also have a psychological impact, as it may impact on how one sees oneself, thus negatively affecting body image and self-esteem (Janda et al 2004).

Body image has been defined as the internal representation of your own outer appearance, your own unique perception of yourself (Thompson et al 2002) and a marked change in the women’s feelings regarding their body image was specifically recorded in the studies by
Moth et al (1983); Stellman et al (1984); Thuesen et al (1992) and Corney et al (1992). Andersen and Hacker (1983) recorded that the women’s perception of their body image was ‘extreme’ and noted that many felt embarrassed and isolated as a result of their operation. Stellman et al (1984) reported that a third of women had poor body image. Half the women in the study by Moth et al (1983) had an altered sense of their body image, describing feelings of ‘not being the same woman’ after their surgery. This was subsequently supported in the studies by Andreasson et al (1986) and Thuesen et al (1992). Corney et al (1992) also reported deterioration in body image in 21% of women in their comparative study. However, it is not clear whether this referred to the women with vulval or cervical cancer. Green et al (2000) also note that women who are depressed at the time of their surgery are more likely to report a clear change in their body image subsequently.

Stellman et al (1984) reported that 4 women were unable to name the area that was removed at surgery. This may have increased the women’s feelings of isolation and embarrassment as they were unable to use the appropriate words to describe the area of their body affected by their diagnosis and treatment. None of the women in the studies by Andersen and Hacker (1983) and Stellman et al (1984) feel that they would have been able to discuss their surgery with anyone except their most intimate friend.

In summary, the review of the psychological effects has shown that women with vulval cancer may experience depression and anxiety following their surgery. It may be related to a change in their body image even though the area where the surgery has taken place is hidden from view. Here, parallels may be drawn with women with breast cancer. Lindop and Cannon (2001) showed that women who had a wide local excision for breast cancer as
opposed to a mastectomy had significantly greater needs for psychological support. This may be associated with the notion that although surgery to the breast is also to an area hidden from view, women may find that surgery involving a wide local excision may make their body more distorted, than if a mastectomy was performed and a matching prosthesis worn subsequently. Lindop and Cannon (2001) also showed that women in the 46-53 year age group experienced a change in body image and loss of femininity following mastectomy more keenly than older women. This age group is similar to the women with vulval cancer reviewed here.

2.4.3 Impact on sexual function

As shown in Table 2, while 9 studies were specifically concerned with pre-diagnosis and post operative sexual functioning (Moth et al 1983; Andreasson et al 1986; Andersen et al 1988; Weijmar Schultz et al 1990; van de Wiel 1990; Willibrord et al 1990; Thuesen et al 1992; Green et al 2000 and Likes et al 2007), a reduction in sexual function was noted in 13 published studies (Andersen and Hacker 1983; Moth et al 1983; Stellman 1984; Andreasson et al 1986; Tamburini et al 1986; Andersen et al 1988; van de Wiel et al 1990; Willibrord et al 1990; Corney et al 1992; Thuesen et al 1992; Green et al 2000; Janda et al 2004; Likes 2007). This appears to be due to the vulval surgery, as although the long term nature of the symptoms of vulval cancer may impact on sexual functioning, there does not seem to be a significant association between the symptoms at presentation and post operative sexual function (Weijmar Schultz et al 1986; Andersen et al 1988; Likes et al 2007). For example, the findings by Andersen et al (1986) showed a significant change in sexual function with a two to three fold increase in dysfunction, with 33/42 women no longer sexually active, compared with 8/42 pre-operatively. Moth et al (1983) noted that
13/15 women described satisfactory pre-operative sexual functioning, but after their surgery 7 women had stopped having sexual intercourse. Corney et al (1992) recorded that 15/28 women who underwent a radical vulvectomy were sexually active pre-operatively but only 5 women were able to resume intercourse subsequently. Tamburini et al (1986) also reported deterioration in sexual behaviour with 11/21 women reporting that they had suspended all sexual activity following their surgery. None of the 9 women in the study by Stellman et al (1984) had sexual intercourse post operatively.

In summary, the majority of studies concluded that there was a correlation between the degree of surgery and the extent of post-operative sexual difficulty, with the greater surgical procedure accounting for the greater sexual difficulty (Andersen and Hacker 1983; Stellman et al 1984; Andersen et al 1986; Likes et al 2007). However Green et al (2000) concluded that since there was no association between sexual dysfunction and the extent of the surgery or type of vulvectomy, all women undergoing vulval surgery are at risk of sexual dysfunction whatever the extent of the surgery.

Other symptoms that impacted on the women’s sexual function were a loss of sensitivity in the genital area with persistent numbness which was noted by Andersen and Hacker (1983); Moth et al (1983) and Andreasson et al (1986). However Willibrord et al (1990) recorded that all 7 women reported that sensitivity returned, especially in the area of the clitoris. Dyspareunia was noted in 9/15 women by Moth et al (1983); 7/25 women by Andreasson et al (1986); and in 6/18 women by Thuesen et al (1992). Green et al (2000) noted that women with pre-operative dyspareunia were sexually active after their surgery, but the exact figure is not reported. It is not known if the dyspareunia was exacerbated by a
precancerous condition such as lichen sclerosis or VIN 3, which may have been relieved by removal of the affected tissue.

A loss of libido was noted by Moth et al (1983); Andreasson et al (1986) and van de Wiel et al (1990). The loss of orgasm was discussed in the studies by Andersen and Hacker (1983) and Moth et al (1983) but the exact number of women is not recorded. Andreasson et al (1986) noted that orgasm was achieved in 6/24 of women, despite extensive surgery.

A reduction in the frequency of intercourse was noted by Andersen and Hacker (1983); Moth et al (1983); Tamburini et al (1986); Andreasson et al (1988); Thuesen et al (1992); Corney et al (1992); and Green et al (2000). Since the study by Corney et al (1992) involved 108 women with a gynaecological cancer, of whom 28 had had a radical vulvectomy, it is unclear if these results referred specifically to the women who had cancer of the vulva. There may be a connection with the age of the respondent, as Likes et al (2007) found that with an increase in age there is an increase in sexual dysfunction and decrease in quality of life. However, the age range of this ‘older’ group is not specified. Other potential factors that may have contributed to a reduction in the frequency of sexual intercourse for some women, for example the effect of menopausal changes, was not considered.

The findings indicated that the impact of surgery for cancer of the vulva on the woman’s subsequent sexual function may be related to the length of time that had elapsed after the surgery. Andersen and Hacker (1983) noted that women who had their surgery less than 3 years earlier had greater disruption regarding sexual function. A suggestion was made by
Likes et al (2007) that there may be improved sexual function as women adapted to their surgery which may support the earlier work by Weijmar Schultz et al (1986) who showed that women were satisfied with their sexual relationship after 2 years. However Likes et al (2007) were unable to show a correlation between the time of the excision, sexual function and quality of life. Andersen et al (1988) also reported that more women became sexually inactive over time although many women stated that they would have preferred to maintain their sexual activity as they considered sexual intercourse to be part of their pre-diagnosis life-style. The women’s preference to remain sexually active was highlighted by Stellman et al (1984) whose results showed that seven of the women were no longer sexually active, and five were dissatisfied with this situation. A longitudinal study was recommended by Andersen et al (1988) to explain further the impact of time on sexual activity.

In contrast to the pattern above, when focussing on the impact of the disease on couples, Weijmar Schultz et al (1986) found that after the surgery 7/10 couples were sexually active with 9 women and 8 men reporting satisfaction with their sexual relationship, although 6 couples reported no or only partial sexual rehabilitation. Weijmar Schultz et al (1986) noted that motivation and sexual affection may be more important in sexual rehabilitation than the effects of the surgery. Pre-operatively 9/10 women achieved orgasm, and post operatively 5/10 women could experience orgasm again. The authors note that extensive surgery such as a radical vulvectomy does not always mean that this is no longer possible. This is supported by Willibrord et al (1990) who reported that all the women who were sexually active prior to their surgery had resumed sexual activities within 12 months. For some of the couples, intercourse took place for the sake of the male partner despite the woman’s own problems. This may be because of a fear of a negative impact on the
relationship and apprehension that the woman may lose him and the support that he provided to her. This is known as the Equity Theory (Walster et al 1978), a factor noted by Weijmar Schultz et al (1986) and van de Wiel et al (1990). This may help to restore the balance of emotional support as one woman said ‘Well I really have to force myself to it (intercourse). I think to myself: come on, you have to do something for someone else now and again’ (van de Wiel et al 1990).

The quality of the sexual relationship between the respondent and her husband/partner was shown to vary over time. Andersen et al (1988) recorded that despite difficulties with sexual desire and excitement, the relationships were satisfactory and this is supported by Corney et al (1992) who noted that there is no significant statistical difference in how the women viewed the quality of their relationships after surgery despite the decrease or absence of sexual activity. These findings indicate that an assessment of a woman’s sexual relationship should not depend totally on whether she is able to achieve intercourse. For example the studies by Andersen and Hacker (1983) included 10 different sexual activities, and Andersen et al (1988) included 24 sexual behaviours including kissing and caressing. These aspects need to be considered to give a more complete picture of the effects of vulval surgery. An earlier study by Drahne et al (1979) noted that following a diagnosis of cancer the need for touching and caressing increased for both a woman and her partner and there was a change in the type of sexual activity desired, but this does not appear to have been addressed in the majority of the published studies.

While the interest of the partner appears to be a factor in the maintenance of sexual activity (Weijmar Schultz et al 1986), feelings of depression and anxiety were noted in the studies
which looked at the impact on the husband/partners of the women (Moth et al 1983). Several women in Stellman et al (1986)’s study felt compelled to protect their husband from the sight of their vulva for fear of arousing feelings of distaste or disgust. Moth et al (1983) noted that 7/8 men reported depression. This may have been related to the physical change in their partner’s body following the surgery, although it may also have been due to a reaction to the diagnosis of cancer itself and the fear of a recurrence, as half of the men interviewed acknowledged their anxieties in this regard. Changes in mood and emotional disturbance in the partner were also noted by Andreasson et al (1986) who reported that almost half of the men had psychological problems after their partner’s surgery. Andersen and Hacker (1983) alludes to the fact that since some of the partners were involved in their partner’s post operative wound care, this may have been instrumental in the ending of sexual activity.

Only one study has reported exclusively on the experiences of the partners. This was a pilot study conducted by van de Wiel et al (1990) and involved 16 men. Here the study sought to assess the impact of their partner’s diagnosis of vulval cancer in relation to their involvement, support, sexuality and relationship. The findings indicated that many men found the experience of supporting their wives/partners to be extremely stressful. This had led to sexual problems which they were unable to discuss with their partner, because of her own emotional disturbance. This is supported by Andreasson et al (1986) who reported that the partner often feels isolated with his problems, and unable to talk about them.

In summary, the findings from the literature have shown that women who have undergone surgery for cancer of the vulva may experience sexual dysfunction, dyspareunia, loss of
libido and a decrease in frequency of intercourse. This did not appear to be related to the extent of the surgery according to Green et al (2000). However Weijmar Schultz et al (1986); van de Wiel et al (1990) and Willibrord et al (1990) reported that in their studies, the majority of couples were able to achieve a satisfactory sexual relationship. The findings from the literature have also shown that post operative consequences affecting physical, psychological and sexual functioning may last some time. This insight indicates that there is a need for further research to explore the consequences of vulval surgery.

It is possible that the women’s adjustment to post-operative functioning may have been affected by the provision of information, an issue considered below.

2.4.4 Information provision

Six of the published studies noted that one of their aims in conducting the research was to assess the quality of the information that these women received, the time it was given and the importance it may have had for the woman and her partner (Andersen and Hacker 1983; Moth et al 1983; Andreasson et al 1986; Weijmar Schultz et al 1986; Andersen et al 1988; Thuesen et al 1992). The focus of the information appears to relate to the implications of vulval surgery, rather than more general information regarding coping with a diagnosis of cancer, the provision of cancer services and supportive agencies. Although both doctors and nurses involved in the care of patients are responsible for the provision of information, the women solely referred to the information provided by the doctors involved in their care.
Andersen and Hacker (1983) and Andersen et al (1988) reported that most women felt that information about the surgery was adequate, and Moth et al (1983) noted that both the women and their partners described the information received as either good or excellent. However, the information about sexuality was either absent, falsely reassuring or insufficient, leading to a sense of embarrassment and isolation (Andersen and Hacker 1983; Moth et al 1983; Andreasson et al 1986; Weijmar Schultz et al 1986 and Andersen et al 1988). One woman recalled ‘One minute’s information with the Chief Physician. There was no choice - no talk’ (Moth et al 1983). The need for pre and post operative counselling was noted by Andreasson et al (1988); Moth et al (1983); Stellman et al (1984); Weijmar Schultz et al (1986); Tamburini et al (1986); Willibrord et al (1990); Corney et al (1992); Green et al (2000) and Likes (2007). Andersen and Hacker (1983) reported that if the women had received a realistic appraisal of likely genital numbness, they could have altered their sexual expectations or activities and Andreasson et al (1986) reported that anticipatory information would have helped the women to adapt post operatively. Two of the respondents reported by Thuesen et al (1992) recalled that they had not resumed sexual activity after their surgery because of a lack of sufficient information and pre and post operative advice.

Since women are at risk of poor sexual function and a decrease in quality of life following vulval excision, Likes et al (2007) also noted the importance of assessing for any pre-existing problems.

The need to provide information to the husband/partner and for him to be included in the discussions regarding the proposed treatment was noted (Stellman et al 1984; Weijmar Schultz et al 1986; Andreasson et al 1986; Andersen et al 1988; van de Wiel et al 1990;
Willibrord et al 1990; Thuesen et al 1992; Janda et al 2004). Andreasson et al (1986) reported that 11 men were not given any anticipatory information about the surgery. Since this study also highlighted that almost half the partners had psychological problems after their partner’s surgery, this may be significant. In contrast to the pattern above, Weijmar Schultz et al (1986) reported that in their retrospective study that while 9/10 men considered it useful for the gynaecologist to discuss sexuality with them prior to the surgery, after discharge from hospital all 10 men would not appreciate a discussion on vulval cancer.

The findings highlighted that there was a paucity of information regarding the impact and likely post operative consequences for a woman after surgery for cancer of the vulva. There was also a lack of verbal information provided by the doctor involved in her care and this may be linked to the relationship the woman had with the health care team.

2.4.5 Relationship with the health care team

Moth et al (1983); Stellman et al (1984); Andreasson et al (1986) and Corney et al (1992) noted that most women undergoing vulvectomy were unable to take the initiative in learning about vulvectomy surgery and this may be related to the relationship they had with the health care team. For example, Moth et al (1983) noted that 7 women could have been helped by undergoing a minor operation to relieve vaginal stenosis causing dyspareunia, but either the doctor did not suggest this or the women felt unable to discuss her sexual function with the doctor. Andreasson et al (1986) and Corney et al (1992) reported that doctors may be shy about discussing sexual aspects of care, and Tamburini et al (1986) suggested that the care of these women may be a stressful experience for the
clinicians involved. Stellman et al (1984) reported reluctance by the women to question the doctor about the surgery, the area of tissue to be removed and post operative sexual functioning. This may contribute to a lack of understanding about the disease which was highlighted by Green et al (2000).

Only two studies reported on the care for these women provided by nurses. Weijmar Schultz et al (1986) discussed the care provided by ward-based nurses while women were in-patients, and Corney et al (1992) referred to a senior nurse with counselling skills providing post operative support for psychological and sexual dysfunction.

In summary, only 6 studies detailed the impact of nursing and medical staff involved in the care of these women. They have highlighted that there may have been difficulties in communication between the women and the medical team, which may have been partly due to the women’s reluctance to discuss her concerns and the doctors’ unwillingness to provide any other component of holistic care other than the physical element. There is also a deficit in the published studies on the impact of nursing care.

2.4.6 Recommendations

The majority of published studies made recommendations to improve the care of this patient group and highlighted the need for further research. The study by Andersen et al (1988) involved a review of the women’s medical notes, and the authors made the additional observation that there was a lack of notations in the women’s medical notes regarding any post operative incidence of complications such as urinary problems, sexual problems or body disturbance. Since the study showed that these consequences had
occurred, it is recommended that the medical staff should ask the women about their physical and sexual function and also document this information.

Several authors recommended a discussion of sexual concerns at all stages of the illness and treatment (Moth et al 1983; Andreasson et al 1986; Corney et al 1992). It is suggested that sexual counselling involves a health care professional who is comfortable talking about these matters, and has good knowledge of the sexual consequences of the surgery. The authors stressed that it should not be assumed that the couple have no concerns if no questions are asked. Andreasson et al (1986) recommended that the health care professional has undergone the relevant training and the couple are offered sexual and emotional guidance pre-operatively and at 3 and 6 monthly intervals post operatively. They also recommended that any concerns or sexual anxieties are discussed at all stages of the illness and treatment and that both male and female therapists see the woman and her partner. It is also recommended that the interview takes place in the gynaecology department where the medical consultant is also available.

As noted earlier, the only study to refer to make recommendation regarding the establishment of an out-patient clinic staffed by a senior nurse with counselling skills was made by Corney et al (1992). However this appeared to be available at the first post operative appointment only and there does not appear to have been any published work to assess any measurable outcomes from this intervention. Andreasson et al (1986); Tamburini et al (1986) and Green et al (2000) stressed the need for a multi-disciplinary team approach to the care of these women by involving colleagues who specialise in psychology or sexology.
Several authors suggest that further research is conducted on a larger group of women (Weijmar Schultz et al 1986) and Likes et al (2007). Likes et al (2007) recommended that further research should measure body image, depression and marital relationship satisfaction, while Weijmar Schultz et al (1990) recommended further studies on sexual functioning. The need for qualitative research was recommended by Andersen et al (1988) as an important and necessary step in gaining an understanding of the sexual and psychological difficulties that may affect this group of women.

2.5 Summary

The literature review has shown that only 14 studies on women with cancer of the vulva have been previously published which investigated sexual functioning, quality of life and information provision. The overall designs were limited by the small number of women involved, and the limitations imposed on research design. Two studies were part of a longitudinal study (van de Wiel 1990; Willibrord et al 1990) but despite extensive searching in the literature, the final results from these studies do not appear to have been published.

Although the published studies have produced limited insight into the impact of this disease, it is clear that a diagnosis of cancer of the vulva and the subsequent treatment do have an effect on physical, psychological and sexual functioning of these women. The wider implications of the disease are less well known since little work has been done to capture the women’s feelings about their experiences. Only one study has included British women (Corney et al 1992) but since this study incorporated women who had cancer of the cervix, the post operative consequences for women with vulval cancer is not clear. It was
also undertaken 16 years ago, before the recent Government initiatives to develop cancer services for rarer cancers.

Although several researchers highlighted their recommendations for further work with this group of women, there is still a lack of awareness of the lived experience of women following their diagnosis and surgery for cancer of the vulva, and there is a need to gain a greater understanding of the post treatment consequences in contemporary health care today. This factor led to the study reported here, explored further in the following chapter which considers the philosophical basis for the study.
CHAPTER 3
METHODOLOGY

3.1 Introduction

A review of the literature has indicated that there is a deficit in knowledge concerning the impact that a diagnosis of cancer of the vulva and subsequent treatment may have on a woman. The previous studies have indicated that this condition may lead to physical, psychological and sexual changes, but what is less clear is what this illness really means to the women themselves. The research question posed in order to address this lack of understanding is:

‘What must it be like to be diagnosed with, and have surgery for a cancer of the vulva?’

The focus of the study is to gain an insight into how this condition is experienced and the effect on each woman, and through these insights the impact on her husband/partner. This chapter describes the research methodology that underpins the study, and provides the background to the processes undertaken to address the research question.

All research studies must use an appropriate methodology to answer the research question (Allen et al 1986). A qualitative approach was chosen and adapted to address this question, as qualitative research is concerned with understanding the meaning that people attach to their experiences within their social world (Ritchie and Lewis 2003). It uses written or oral data to obtain rich information about an experience and its meaning in their life.
The philosophical basis that was used for this qualitative research was phenomenology, since phenomenological enquiries are suited to the study of life experiences (Speziale and Carpenter 2003). Given the focus on the ‘meaning’ of experiences, it was considered the most appropriate method to address the research question.

The philosophy of the phenomenological movement and the work of Husserl, Heidegger and van Manen are discussed below. The processes involved in designing the study, modes of data collection, sampling issues and the ethical principles concerned are also described.

3.2 Phenomenology as a philosophy

Phenomenology may be understood in one of two ways: as a movement in the history of philosophy or as a disciplinary field in philosophy (Moran 2000). Philosophers who are associated with the practice of phenomenology are diverse in their interests and in their development of the phenomenological method. The fundamental issue is that it is a study of conscious experience or in other words, a study of the way we experience things. It has been described by Moran (2000) as an attempt to get to the truth of matters, to describe phenomena in the broadest sense as ‘whatever appears, in the manner in which it appears, that is manifest itself to the consciousness of the experienced’. Merleau-Ponty (1962) states that phenomenology is the study of ‘essences’. The word ‘essence’ is derived from the Latin verb ‘esse’, which means ‘to be’. An essence is therefore something that defines its character and is the most important feature, thus making it what ‘it is’. Accordingly, all phenomenological studies amount to finding definitions of essences, such as the essence of an experience, or its fundamental nature. A phenomenological study involves taking a human science approach by studying people, in the world in which they live. It involves
description, interpretation and self-reflection in order to understand the phenomenon being studied. It is therefore ‘discovery-oriented’. It wants to find out what a certain phenomenon means and how it is experienced (van Manen 1990).

The origins of phenomenology may be traced back to Kant, who described it in 1764 as the study of phenomena or ‘things’, in a scientific context (Cohen 1987). The phenomenological movement began in the early part of the 20th century with the work of Husserl (1859-1938). He portrayed it as a radical new way of progressing philosophy in an attempt to bring philosophy back from abstract metaphysical speculation in order to come into contact with matters themselves, with concrete living experiences (Moran 2000). It has continued to evolve throughout the 20th century with further developments by Heidegger (1889-1976), and more recently van Manen, and has had influences on social psychology, sociology, anthropology and theology.

3.2.1 An Overview of the work of Husserl

Husserl (1859-1938) held the conviction that things existing in thoughts were real, and the terms ‘lived experience’ and ‘life-world’ are derived from the philosophy of phenomenology. Each refers to a person’s own subjective experience of the world in which they are living. Husserl talked of ‘lived experiences’, which is a phrase that has become the catchphrase of the phenomenological movement (Cohen 1987). He believed that the purpose of phenomenology was to deconstruct experiences and render them accessible to scrutiny. Husserl held that to ‘know’ means to ‘see’ reflecting a belief in experience as the definitive means of finding knowledge and understanding of the world. This is achieved by ‘eidetic’ reduction, which shifts the focus from the empirical and factual, to the essential,
necessary features of experience (Moran 2000). Husserl believed that as the mind is directed towards objects, consciousness was ‘to be conscious of something’. This directness he called intentionality, and was based on the assumption that our own conscious awareness was the one thing of which we could be certain and the starting point of knowledge building. Researchers use lived experiences as the basis of recalling how one lived through an event (Kleiman 2004).

Husserl thought that phenomenological practice required a radical shift in viewpoint that is ‘presuppositionlessness’. This is a suspension or bracketing of the everyday natural attitude and all the ‘world-positing’ intentional acts which assumed the existence of the world until the practitioner is led back into the domain of pure transcendental subjectivity (Moran 2000). This is known as phenomenological reduction and can be done in two ways, either by setting aside our assumptions and seeing and hearing something as if for the first time, or by intuiting or grasping by logic and insight (Jones 2001). By deliberately examining his or her own beliefs about the phenomenon and bracketing them, the researcher attempts to acknowledge and identify these problems and apply rigorous techniques to avoid influencing both the collection and interpretation of the data (Jasper 1994). According to Husserl, without this phenomenological reduction, genuine phenomenological insight would be impossible, although most of his students, including his colleague Heidegger, were not convinced of the value of this.
3.2.2 Hermeneutic phenomenology: the work of Heidegger

Heidegger (1889-1976) was interested in ontology, which is how we live in the world, and how we make sense of the world around us. Heidegger rejected the notion that we are separated from the world of objects about which we try to gain knowledge, rather we are inseparable from an already existing world (Moran 2000). He rejected the central idea of phenomenological bracketing, and maintained that researchers must already have background knowledge about the focus of their enquiry. Phenomenology was linked to existentialism and through this, philosophical hermeneutics was developed. Hermeneutics is a method of interpreting and understanding ways in which people live in the world. The investigations that researchers undertake within their world or society may be things that they have previously taken for granted, and there is a sense of wonder, as their significance and importance is explained.

A qualitative researcher following Heidegger’s philosophy may ask ‘What *is* it like to be diagnosed with cancer?’ or ‘What *are* the consequences of radical surgery?’ Both the words ‘*is*’ and ‘*are*’ come from the Latin verb ‘esse’ translated as ‘to be’, and Heidegger refers to this as a study of the meaning of Being, or essences, which was noted earlier in this chapter. He refers to it as going ‘back to the roots’ of the phenomenon being studied (Heidegger 2005). Heidegger explicates this further by focusing on:

- The essence of an entity, or its nature, or what it is that makes it so. It has also been described as what-being.
- The existence of an entity, or that-being. It signifies that the entity is real.
Heidegger describes his philosophy as a reciprocal activity between the researcher and the participants in the study as being within a circle of understanding or hermeneutic circle. This is shown diagrammatically below.

**Figure 2: Hermeneutical Circle of understanding**

The hermeneutical circle of understanding illustrates how the phenomenon has an impact on the participants, and the participants also have an understanding of the phenomenon they experienced. The researcher is also affected by the phenomenon and the participants who experienced it. The third person involved is the reader who is affected by reading and learning about the phenomenon, and the role and writings of the researcher.
This may also be depicted as a series of decreasing circles, as shown below. As the reader learns more, they are moving in the spiral too, towards the essence of the phenomenon as shown in Figure 2.

Figure 3: Hermeneutical Spiral of understanding

Van Manen has continued the work of Heidegger, by developing the hermeneutical phenomenological approach to the investigation of life experiences.

3.2.3 An overview of the work of van Manen

Van Manen (1990) uses the terms human science, phenomenology and hermeneutics interchangeably. He describes phenomenological research as a way of questioning the way we experience the world in which we live, in order to let that ‘which is being talked about be seen’ (van Manen 1990 p122). He describes the four fundamental components that
make up the structure of the lived world in which we live, and uses them as a guide to reflection in the research process. They are:

- Lived Time: this is subjective time, and the past, present and future constitute a person’s temporal being.
- Lived Body: this refers to the fact that we are always bodily in the world, experiencing the world through our physical or bodily presence.
- Lived Relationship: this is the relationship we have with others in the interpersonal space we share with others.
- Lived Space; this is felt space, or the environment in which we live and move.

(Adapted from van Manen 1990)

Lived Time, Lived Body, Lived Relationship and Lived Space can be differentiated but not separated, as they are interdependent. Van Manen (1990) suggests that by reflecting on these four existentials, there is an immense richness of meaning within the phenomenon that is being investigated.

Researchers utilise their writing and language skills to describe, show and interpret the phenomenon while remaining true to the ‘object’ of the enquiry. The writing involved in phenomenological studies also has the effect of ‘bringing into nearness, that which tends to be obscure’ (van Manen 1990 p132). Van Manen uses the term ‘logos’, which has the meaning of conversation, enquiry, and questioning towards the phenomenon. By being as perceptive, insightful and discerning as possible, the researcher aims to disclose the phenomenon in all its fullest richness and greatest possible depth (van Manen 1990). He describes this as determining the aspects or qualities that make a phenomenon ‘what it is
and without which the phenomenon could not be what it is’ (van Manen 1990 p79). This enables the reader of the research to understand the significance of the experience for the participants.

### 3.3 Phenomenology as a research method

The development of phenomenology as a research method has evolved in order to identify the essence of the phenomenon being investigated and to describe it accurately within the context of everyday lived experiences. Different philosophers may involve a variety of procedures, but broadly speaking it involves formulating questions that need to be asked in pursuit of their phenomenological enquiry, in order to enable the answer to be found. The key is to allow the research question to determine what kind of method is appropriate for the research question to provide the most rigorous and accurate interpretation of the phenomenon in question (van Manen 1990). The interpretation of the findings will then lead to an understanding of what an entity is, and a capacity to understand it (Mulhall 1996). The aim is to increase the understanding and meaning of human experiences and practices.

Van Manen (1990) states that phenomenological research does not have to follow a particular method. This view is supported by Speziale and Carpenter (2003) who report that there is no quick step by step method to phenomenological enquiry. However a set of guidelines or a framework is helpful to understand the principles of undertaking of a phenomenological research study such as that offered by Mulhall (1996).
Table 4: Framework of a Phenomenological Research study

<table>
<thead>
<tr>
<th>Step</th>
<th>Description</th>
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<tbody>
<tr>
<td>1.</td>
<td>An enquiry is an enquiry about something</td>
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<tr>
<td>2.</td>
<td>The enquiry asks about something</td>
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<tr>
<td>3.</td>
<td>The object of the enquiry is interrogated</td>
</tr>
<tr>
<td>4.</td>
<td>The researcher reflects about the generated data</td>
</tr>
<tr>
<td>5.</td>
<td>The nature of the topic is interpreted, and clarified</td>
</tr>
<tr>
<td>6.</td>
<td>The findings are written down</td>
</tr>
<tr>
<td>7.</td>
<td>The conclusion is drawn and something is discovered</td>
</tr>
<tr>
<td>8.</td>
<td>Access to the conclusions is enabled</td>
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</tbody>
</table>

Mulhall (1996)

This framework is considered below to set the scene for explanation of the way in which it was incorporated into this study.

1. An enquiry is an enquiry about something

Speziale and Carpenter (2003) note that prior to undertaking a study, phenomenological researchers should ask if there is a need for further clarity about the chosen phenomenon. The enquiry therefore has a direction or purpose. It may be vague at the outset, but it is not a casual question and is based on the pre-existing interest of the researcher. Van Manen (1990) describes the process of research as a caring act, as we seek to know and understand more about the world in which we live and the people we meet day by day.
2. The enquiry asks about something

The researcher asks about a lived experience, or phenomenon. In qualitative research studies, researchers recognise the importance of the subjective component in their quest for knowledge (Speziale and Carpenter 2003). It is impossible for the participants in the study to be completely objective about their experience since it has been part of their everyday reality. Neither is it possible for me, as the researcher, to be objective, or neutral, as I have my own view of the historical, social and cultural aspects of the phenomenon being investigated. This supports the work of Heidegger, as noted earlier. The phenomenon being explored motivates and formulates the research question, and impacts on all the questions posed subsequently. The enquiry is also a theoretical investigation, which attempts to expose the characteristics of the phenomenon in question.

3. The object of the enquiry is interrogated

The method of data collection is the voice of the participants who have experienced the phenomenon, and access may be sought through interviews, focus groups or the use of videos. Denzin (1984) describes a state of ‘emotional inter-subjectivity’, which is required to understand each other’s meanings. It is a process by which we, as researchers, enter the world of the researched and bring their experiences into our own frames of reference through the process of sharing. It is not the same as empathy or sympathy, as both the researcher and the participant understands each other’s position. Qualitative researchers believe that there are multiple realities or perspectives to consider in fully understanding a situation (Cheek 1996; Boyd 2001). Participants in research studies may have experienced the same phenomenon but respond in different ways, depending on their previous
experiences. The overall aim is to give the participants an opportunity to allow their experiences to be heard.

4. The researcher reflects about the generated data

Qualitative research generates a large amount of data. This may be in the form of transcriptions of interviews that are then read and re-read, or audiotapes, which are listened to several times. This involves an element of perception as the participant recollects an experience that is already lived through and the researcher and the participant consider why this particular phenomenon has special significance, and the nature of that significance. Van Manen (1990, p32) describes the process of reflecting as ‘a thoughtful reflective grasping of what it is that renders this or that particular experience its special significance’. This involves considering the importance and the meaning of the words the participants used, as well as thinking about the facial expressions, laughter and silence. In addition, the presuppositions the researcher brings to the research experience are examined and explicating. Many writers refer to researchers becoming immersed in their data, as they become totally involved in the study, and this involvement adds to the richness of data collection and analysis (Singleton et al 1988; Silverman 2000). Koch (1999) describes this as engaging your whole self (as the researcher) in the process, including understanding what is real for you and what is important in your own life.

5. The nature of the phenomenon is interpreted and clarified

Phenomenological research is a search for the meaning of the experience. Heidegger describes this as a progressive abstraction. For example by interviewing patients with the
same medical condition, the researcher has the potential to be able to uncover or discover the essence of their unique experience of this condition.

Researchers may use thematic analysis to develop themes and categories or devise their own process of interpretations, as there are multiple realities or perspectives to consider in fully understanding a situation (Cheek 1996; Boyd 2001). A ‘theme’ has been described by DeSantis and Ugarriza (2000) as an abstract entity that brings meaning identity to a recurrent experience and its variant manifestations. Van Manen (1990, p88) has described the value of themes in phenomenological research as:

- The needfulness or desire to make sense (of the data), and to get at the notion
- The sense we are able to make of something, giving shape to the shapeless
- The openness to something, describing the content of the study
- The process of insightful invention, discovery, and disclosure to unlock a deep meaning.

Themes may be about the nature of the experience. For example, broad categories may emerge as similarities in experiences are identified. These patterns and items of particular significance and interest may then be grouped together (Bell 2005). As more detailed examples become apparent, they may warrant a label of their own, and are identified as a sub-theme. Connections between the themes may then be made. Concepts are developed in order to define and explain the phenomenon and to gain an understanding of what the experience has really meant to the respondents in the study. This involves the use of free imagination (Speziale and Carpenter 2003) or a process of insightful discovery as an act of ‘seeing’ meaning (van Manen 1990).
6. The findings are written down

The findings are reported in a way that remains true to the respondents, by including quotations, and commentaries to add to the richness of the report and to the understanding of the experience and to provide a context in which it occurs (Speziale and Carpenter 2003). It is possible that the researcher may write and re-write his/her findings many times, in order to adequately describe the phenomenon (van Manen 1990). The findings are also reported in a way that is meaningful, and will enlighten the readers with a greater understanding of the respondents’ experiences.

7. The conclusion is drawn and something is discovered

The reader of the research has an insight into the participants’ experience, if it has been adequately described in language that reawakens or shows us the lived quality and significance of the experience in a fuller or deeper manner (van Manen 1990). Although phenomenological research cannot be generalised to a wider group of people and the findings are dependent on the researcher’s own interpretation, it is hoped that by reading about the nature of the experience the reader will display an increasing thoughtfulness and be better prepared to act tactfully in situations in the future (van Manen 1990). The effects for those readers who study the lived experience of respondents in the world of nursing practice is a better understanding and ultimately better outcomes in all relevant domains of nursing (Speziale and Carpenter 2003).
8. Access to the conclusions is enabled

The findings from the study are shared with others through publications or presentations.

The framework offered by Mulhall (1996) was used to inform the design of the study reported below.

3.4 Design of the study

Phenomenological research demands a mode of collecting information that will present the participant’s experiences precisely from their particular perspective i.e. in terms of the significance it has had for them personally (Crotty 1996). Interviewing is a well-established research method that involves an interaction between the researcher and the respondent who has experienced the phenomenon being investigated, and is the most effective way of gathering the data (van Manen 1990). A criticism of conducting interviews is the issue of trustworthiness, since qualitative studies provide readers with little more than brief persuasive data abstracts, which may not provide a true perspective of the people being studied (Bryman 1988). A further weakness is that of reliability. Although the interviews are recorded and may be transcribed verbatim, the issue of the interpretation of the transcriptions by the researcher may be questioned (Silverman 2000). However by conducting interviews, information would be accessed to enable the research question to be answered, and any concerns about trustworthiness and reliability may be addressed by documenting the procedures undertaken at all stages of the study (Kirk and Miller 1986). This process will add to the rigor of the study and help to support inherent validity that may be claimed in qualitative data using qualitative interview data (Clifford 1997 p130).
Interviews may take a variety of forms, such as structured, semi structured and unstructured. An unstructured interview is one in which the researcher asks as few questions as possible, permitting the respondent to talk freely, intervening only to refocus the discussion or probe for additional insights into a key area. This technique enables the respondent to establish the parameters of the discussion, a process which itself reveals what is important to them. It attempts to achieve a holistic understanding of the respondent’s perspective and understanding of events. Indeed, many phenomenological researchers may have just one question to ask their respondents, such as ‘Can you tell me about the time you were diagnosed with cancer?’

However, a more detailed approach utilising a structured interview was needed here. It involved asking the respondent a series of questions in a set order. The structured approach was utilised to ask women who had been diagnosed with cancer of the vulva to tell me their stories about what it is like, what their feelings are, and their understanding of the events following their diagnosis or in other words ‘What was it like for you?’ I wished to start the enquiry from before the time that the diagnosis was made, as I was aware from the review of the literature and my clinical experience that some women may experience symptoms for some time before the diagnosis is made. A perception of how their lives are now was key to this study. In addition insights were sought into the effect of their illness on their husband/partner and their family.

The next step was to develop an interview schedule which was structured to allow questions to be asked and the participants to share their experiences. Andersen and Hacker (1983), Moth et al (1983); Stellman et al (1984); Andreasson et al (1986); Tamburini et al
(1986); Andersen et al (1988); Corney et al (1992); Thuesen et al (1992); Green et al (2000); Janda et al (2004) and Likes et al (2007) highlighted that this group of women may experience physical, psychological and sexual changes from the onset of the symptoms of cancer of the vulva and following their surgery. These issues were considered in the design and the following questions were asked.

Questions relating to the physical impact:

- Symptoms noted before the diagnosis was made
- Changes in micturition, which may have occurred both before the diagnosis was made and post operatively
- Post operative recovery
- Healing of the operation site and if there was a delay in the healing process
- The effects of lymphoedema.

Questions relating to the psychological impact:

- The impact of the diagnosis of cancer
- The effect of the diagnosis on how women think of their body
- The impact of the surgery on how women think of their body
- The emotional effect of a diagnosis of cancer
- The emotional impact of surgery to the vulva
- Any feelings of embarrassment as the vulva is considered a private area
- Fears about the possibility that the cancer may recur.
Questions relating to the effect on sexual functioning:

- The effect on the woman and her partner’s sexual relationship from the onset of her symptoms to the time of the interview

Moth et al (1983); Andreasson et al (1986) and Weijmar Schultz et al (1986) noted that emotional and practical support can be significant for this group of women. I therefore wanted to ask questions relating to the support from their husband/partner, family and friends, and also support derived from other patients. These questions related to:

- The partner’s involvement in the woman’s care
- The effect on her children, family, friends and work colleagues
- The possibility of attending a patient support group.

Other questions relating to the previous studies were concerned with the amount and appropriateness of information that these women received. The questions regarding information were:

- Written and verbal information received
- Discharge advice from the hospital.

Previous studies referred to the relationship with the doctors involved in their care. Moth et al (1983); Stellman et al (1984) and Andreasson et al (1986) noted that there may be reluctance on the part of both the woman and her doctor to discuss the possible consequences of her diagnosis and surgery. This aspect of her care was considered during the interview by discussing the care she received from the health care professionals and
any suggestions that she could make to improve care in the future. The questions related to this included:

- The referral process, describing the way in which the woman was referred by her general practitioner to the gynaecology oncology consultant
- The experience of regular follow up appointments
- The care received from health care professionals
- Any improvements in medical or nursing care provision that may be suggested.

The next questions were related to the nursing care that the woman had received during her stay in hospital. They were asked about any suggestions that could be made to improve service delivery. I was also interested in the care received from nurses in the primary care setting, for example district nurses and allied health professionals, for example physiotherapists. The questions relating to this aspect of care were:

- If nursing support was given at the time of the diagnosis and subsequently and if this had made a difference
- Care from nurses in the primary care setting and from physiotherapists
- Improvements in medical or nursing care that they could suggest.

The remaining questions related to my thoughts as a woman. I was interested to explore if these women were able to resume their previous life style of work and leisure, and if this had had an impact on their family activities and also if their life had changed in any way. The questions asked were:

- About their return to previous life style; work, holidays, leisure
- Concerning any other way their life has changed since their diagnosis.
3.5 Interview schedule

Having thought about the questions I wished to ask the respondents, the next step was to devise the interview schedule. This involved thinking about the most appropriate words to use during the interview. It required clarity and carefully phrasing, using language that was understandable to the respondents (Bell 2005). I also needed to formulate questions that were open-ended and followed a logical sequence (Bell 2005). A degree of flexibility and sensitivity was required in order to develop a dialogue with the respondent and adapt and seek any clarification as the interview progressed. Some space for quiet reflection was also necessary before proceeding to the next question. This enabled an interpretation of what was being said to take place in order to decide about further questioning or probing to eliminate any misunderstanding. Sufficient time was also needed in order to build up a trusting relationship between myself as the researcher and the respondent, and allow sensitive information to be shared (Speziale and Carpenter 2003; Bell 2005). A quiet comfortable environment where privacy and confidentiality may be assured, without interruption, was also needed.

Initially, the questions were very general and the supplementary questions were a series of bullet points. An example is shown below.
From this starting point, I reflected on the type of words to use. I wanted to hear the respondent’s own story of her illness, encouraging her to use her own words as clearly and as thoroughly as possible, articulating her view of the phenomenon experienced. The questions, therefore, needed to be more considerate and crafted in such a way as to encourage the respondents to talk about the nature of their experiences.

All the questions were open-ended, such as ‘Can you think about the time...?’ ‘Did you have any idea about...?’ and ‘Do you mind if we talk about...?’ I also needed to ensure that all the questions were clear and easily understood. A general question at the outset enabled me to have a background of the events leading up to diagnosis and help her settle into the interview situation. Gradually, the interview schedule developed into a script. For example, question one asks: ‘Can you tell me why you went to see your General Practitioner (GP) at the beginning?’ The supplementary questions were: ‘What symptoms did you have to make you go and see him?’ ‘Did you have any thoughts about what might be wrong?’

### Table 5: Interview schedule: Preliminary Sample Question

| When you went into hospital for your operation, what information did you receive? |
| Prompt questions  | Outpatients? |
|                   | Wards? |
|                   | Verbal/Written? |
|                   | Amount of information? |
|                   | Timing at which it was given? |
|                   | Doctor or nurse provided information? |
|                   | Pain? |
|                   | Side effects? |
In all, 33 main questions were prepared, together with supplementary questions. It was divided into sections to cover the different times in a patient’s illness to give the interview a logical sequence.

- Section 1: From the onset of symptoms, to discharge from hospital
- Section 2: Physical effects following the operation
- Section 3: Emotional and sexual effects following the operation
- Section 4: Involvement of the husband/partner and the care she received.

The interview schedule may be found in Appendix 4.

Having prepared the schedule, I discussed it with a colleague with experience in conducting patient interviews. We debated the issues that I wanted to address and discussed the interview design to check on the clarity and structure. Practical ways of developing a rapport with the respondent were shared and she provided positive feedback about the design of the interview. A pilot study was not undertaken as the potential sample size of respondents was quite small and I did not want to limit the number of respondents that would be included in the main study.

A clinical psychologist was contacted and he agreed to see any of the women who needed additional support following the interview. I was also aware that should she become unduly distressed during the course of the interview; I would protect her by curtailing the interview. In addition, the respondent’s general practitioner and hospital consultant were informed of the woman’s participation. In the event, none of the women became distressed.
by taking part in the research and none of them required support from the clinical psychologist.

Although I have been a Clinical Nurse Specialist for a number of years and have a wealth of experience in talking and listening to patients and their families, I ensured that I was familiar with the specific techniques involved with conducting interviews, for example maintaining eye contact and the use of facial expressions (Silverman 2000). I emphasised that the interview was an open one and that the respondent was permitted to think aloud, to be doubtful and pause if necessary. This demanded complete concentration on my part. Although the skills involved in undertaking interviews as a Clinical Nurse Specialist are similar to those required in undertaking a research interview, the key issue to note is that the difference pertains to the role of listening attentively and asking further questions to clarify their comments. I was careful to keep my mind ‘open’ and note what was important to the respondents, rather than making any presumptions on my part. Advice and guidance on coping with any issues that arose during the course of the interviews with the women was not given, as my role was that of a researcher rather than as a Clinical Nurse Specialist. In addition, the time allowed for the interview was unlimited, compared with the time constraints that are often necessary during a Clinical Nurse Specialist’s busy working day.

The interviews were tape-recorded. The recordings were important so that eye contact could be maintained with the respondent and being able to listen to the tapes several times in order to analyse the data. However, a tape recording may cause the respondents to be inhibited in their responses to the questions (Bell 2005).
3.7 Sampling

Having designed the interview schedule, the next phase was to consider the women who had experienced the phenomenon under investigation. Since the sample selection affects the quality of the research, participants need to be appropriate for the study and above all be good informants, who are articulate, reflective and willing to share with the researcher (Morse 1991). However, the exact criteria for the women needed to be addressed. The means of accessing the women and ethical approval for the study was also necessary.

A purposive sample of women aged less than 50 years of age was selected to reflect the increased incidence in the younger age group and the initial concern that prompted me to undertake this study. There is also some benefit in reflecting the age group of women previously studied (Moth et al 1983; Andreasson et al 1986; Andersen et al 1988; Willibrord et al 1990; van de Wiel et al 1990; Thuesen et al 1992 and Likes et al 2007). By choosing the same age group, the findings from this study would add to the existing knowledge about this group. Finally work on women with breast cancer in the 46-53 year old category reported greater needs than older women (Lindop and Cannon 2001; Foot and Sanson-Fisher 1995). This age was defined further by specifying that the women were aged less than 50 at the time of their surgery rather than at the time of the interview.

The women were heterosexual, and with a husband or partner. They also needed to be able to speak English as I did not have the resources to pay for an interpreter.

The time that had elapsed from the time of their surgery was also considered. Women who had their surgery between 6 months and 5 years previously were investigated. This time
frame allowed the women to have recovered from the acute post operative side effects of the surgery and be in the rehabilitation phase following their treatment. Women who were interviewed less than five years after their diagnosis and treatment were more likely to recollect their feelings and experiences, having lived through it (van Manen 1990).

The Cancer Data Manager at the hospital where I am employed was asked to provide a list of all the women who had a diagnosis of cancer of the vulva during the previous five years, who were under 50 years of age and all had their surgery between 6 months and 5 years previously. In addition, I approached two hospital consultants to ask if any of their private patients fulfilled the criteria for the study.

In all, 27 women were identified. Of these, 14 were unable to participate or were ineligible, because they were:

- Receiving chemotherapy treatment for metastatic disease and were unwell at the time I wished to conduct the interview
- Had developed further recurrence in the vulva, necessitating surgery to form a stoma, prior to further vulval surgery and adjuvant radiotherapy. They declined to participate
- Entering terminal phase of their illness and were too poorly to participate.

In addition:

- Some women were lost to follow up and I was unable to contact them
- I decided not to contact one woman as her child had developed cancer
- Bereavement of her husband made one woman ineligible for the study.
I wrote to the remaining 13 women, detailing the purpose of the study and enclosing the patient information leaflet giving a detailed explanation of the study. They were all Caucasian; eleven were English, one was Welsh, and one was Irish. If they were interested in taking part, they were invited to complete the reply slip and return it to me in the enclosed stamped addressed envelope. All 13 women agreed to be interviewed. Once the replies had been received, I telephoned the women and arranged a day and a time to interview them. The interviews were conducted between 22/08/2003 and 22/11/2004. Twelve of the respondents chose to be interviewed in their own home and one preferred to be interviewed in my office, as she was attending an out-patient appointment on the same day. The interviews were audio-taped and labelled with the respondent’s number and the date that the interview took place. The interviews lasted between 1 hour 20 minutes and 3 hours 15 minutes. They were subsequently transcribed by a secretary, and the tapes returned to me and stored in a locked filing cabinet. The transcriptions were between 8,769 and 27,028 words in length. I also made field notes following each interview and maintained a research diary.

Background information about the women who took part in the study, their ages and the length of time since their surgery is provided in chapter 5, ‘The Stories’.

3.7 Ethical issues

Ethical standards must also be considered in any research study to ensure that the study maintains ethical principles and protects human rights (Speziale and Carpenter 2003). The primary ethical principles of the Code of Ethics (Belmont Report 1985) are listed and discussed further below:
• Justification for the study
• Beneficence and non-maleficence
• Respect for dignity
• Confidentiality and anonymity
• Right to privacy. (Belmont report 1985)

Munhall (1988) suggests that the justification for the study from an ethical perspective needs to ask the question ‘Toward what goal and for what end?’ As the review of the published literature noted the paucity in knowledge and understanding about women with cancer of the vulva, this study will add to previously published findings.

There is an impact on the people taking part and the principle of beneficence is ‘above all, to do no harm’. The risk/benefit ratio to the respondent has to be considered and it was important that the respondents fully understood the purpose of the study. For example, there may be potential benefits to the participants in the study, such as being able to discuss their experience of vulval cancer in the knowledge that they may be helping others with a similar problem and these should be weighed against the potential costs. These include the psychological distress from self-disclosure, loss of privacy and loss of time (Polit and Hungler 1997).

Adequate information about the research was required and the respondents needed to be capable of comprehending the information and have the power of free choice, enabling them to consent voluntarily to participate in the research or decline participation (Polit, Beck and Hungler 2001; Bell 2005). An information leaflet was prepared which gave
information about the study (Appendix 5). A contact telephone number was provided for further clarification of the study. The leaflet was posted to the respondents, together with a letter inviting them to participate in the study (Appendix 6). The woman was invited to telephone me if she wished to participate and an appointment was made for the interview to be conducted, at a time and place of her own choosing. This allowed time for the respondent to read the information leaflet carefully at her own pace before deciding whether she wished to take part.

Respect for dignity also means that the respondents can decide voluntarily whether to participate in the study without the risk of incurring any penalties or prejudicial treatment (Polit and Hungler 1997; Bell 2005). They also have the right to terminate their participation at any time, to withdraw retrospectively any consent given and to require that their own data, including recordings, be destroyed (British Psychological Society 1985). Respect for dignity includes gaining the respondent’s informed consent and is part of their human rights. A consent form was prepared (Appendix 7) that provided information about the research study and also me as the researcher and printed on the hospital notepaper where I am employed.

Confidentiality and anonymity for the participants is an important part of the researcher’s responsibility. Potential participants were informed that their involvement in the study necessitated a tape-recorder to record the in-depth interview, and that the information will be kept confidential. The respondents were assured that the information they provided would not be used against them (Polit and Hungler 1997). The tapes would not identify the participant in any way and would be stored in a locked filing cabinet, in accordance with
Data Protection requirements (1998) and the British Psychological Society (1985). The data generated by the study would also be used in such a way that only the researcher is aware of the source (Behi and Nolan 1995). Each respondent in the study had a number and the tapes were labelled with the date of the interview and the number allocated to the respondent, for example ‘Number 13, 22/11/2004’. The confidentiality clause also extended to the secretary who typed the tapes.

The respondents were also informed that their anonymity would be further protected when the findings were written up, by being given another first name. It is particularly important to protect respondents with a rare illness who may otherwise be easily identifiable. However an interesting article by Kite (1999) raises some implications on changing peoples’ names. She remarks that although it is necessary to comply with ethical principles and procedures, with every anonymisation the person is removed from who they are, as her name is taken away and her identity and her place in a set of relationships with others has changed. Nevertheless all the names of the women were changed to protect their identity and the geographical area where they lived was not identified.

The application for ethical approval from the Local Ethics Committee was submitted at the beginning of 2001. The application included the research aims and a plan of the study. The patient information leaflet, letter to the hospital consultant and the GP, copy of the interview schedule and the consent form were included. All the procedures were approved in April 2001 (number 0654) and extended for a further two years in 2004. These may be found in the Appendix 9.
3.8 Summary

This chapter details the philosophical background to the study and describes the phenomenological method of research that underpins my study. The overall research design is outlined, including details of the development of the interview schedule and the rationale for purposive sampling. The following chapter describes the method of analysing the data.
4.1 Introduction

Qualitative research using interviews generates a large volume of data that is unstructured at a macro level, but at a micro level contains detailed accounts of the respondent’s experiences. This knowledge, in the form of texts, not only describes phenomena but also evokes understandings that would otherwise lie beyond reach (van Manen 2006). The researcher has to provide some coherence and structure to the data set, while retaining a hold of the original accounts and observations from which it is made (Ritchie and Spencer 1994). The process utilised to analyse the data was framework analysis. This chapter explores the benefits of framework analysis, then examines in turn the key stages of familiarisation, identifying a thematic framework, indexing, charting and mapping. The key ideas, which developed from the thematic framework, are detailed, thus providing a clear audit trail of the processes involved. The themes identified are shown to share van Manen’s (1990) four existentials of living in the everyday world. The chapter concludes by reflecting on my original research question ‘What must it be like to be diagnosed and treated for cancer of the vulva?’ Listening and re-listening to the audiotapes, reading the spoken words and thinking about the data enabled concepts to be developed that gave understanding to the women’s experiences.

Framework analysis was originally initiated by a qualitative research unit within the Social and Community Planning Research (SCPR) Institute and has proved to be versatile over a wide range of qualitative research studies (Ritchie and Spencer 1994). It has been used in a study which posed a similar research question. Scott et al (2006) explored 17 patients'
initial experiences and reactions to developing symptoms of oral cancer and their relationship with the health care professional involved in their care. Framework analysis has also been used in a study which addressed cancer patients' information needs and information seeking behaviour (Leydon et al 2000) and is therefore an appropriate tool to use in this study.

4.2 Framework Analysis

Framework analysis is not a mechanical process, but relies on the creative and conceptual ability of the researcher to determine the meaning, salience and connections (Ritchie and Spencer 1994). As Koch (1999) notes, the interpretation of the data is dependent on reading the transcribed texts of the interviews, observing and listening to the respondents during the interviews and reflecting on their experiences. The data analysis needs to be flexible, as new ideas and concepts emerge. It also needs to be clearly visible, so that it may be verified by one’s peers and it is apparent to the reader how the findings of the research have been obtained. Framework analysis was developed in order to achieve these aims. It involves a systematic process of sifting, charting and sorting data into key issues and themes and by following a well-defined procedure, it is also possible to reconsider ideas because the analytical process has been documented and is therefore accessible. The benefits of framework analysis are shown in Table 6.
Table 6: The Benefits of Framework Analysis of Qualitative Research

<table>
<thead>
<tr>
<th>Benefit</th>
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<tr>
<td>1. Grounded or generative: it is heavily based in, and driven by, the original accounts and observations of the people it is about.</td>
</tr>
<tr>
<td>2. Dynamic: it is open to change, addition and amendment throughout the analytic process.</td>
</tr>
<tr>
<td>3. Systematic: it allows methodical treatment of all similar units of analysis.</td>
</tr>
<tr>
<td>4. Comprehensive: it allows a full, and not partial or selective, review of the material collected.</td>
</tr>
<tr>
<td>5. Enables easy retrieval: it allows access to, and retrieval of, the original textual material.</td>
</tr>
<tr>
<td>6. Allows between- and within-case analysis: it enables comparisons between, and associations within, cases to be made.</td>
</tr>
<tr>
<td>7. Accessible to others: the analytic process, and the interpretations derived from it, can be viewed and judged by people other than the primary analyst.</td>
</tr>
</tbody>
</table>

Ritchie and Spencer 1994

The five key stages of framework analysis are:

- Familiarisation
- Identifying a thematic framework
- Indexing
- Charting
• Mapping and interpretation. (Ritchie and Spencer 1994)

These key stages are explored further below.

4.2.1 Familiarisation

Familiarisation involves gaining an overview of all the material gathered in the interviews. This involved listening to the audiotapes, reading and re-reading the transcribed texts, studying field notes and becoming immersed in the data, as described in chapter 3. This process enabled me to gain an overview of the diversity and richness of the data.

4.2.2 Identifying a thematic framework

The next step was to identify a thematic framework. To do this, I reviewed all the transcripts of the interviews and wrote down a list of recurring themes and issues that appeared to be important to the women themselves. Some of the themes were informed from the research questions and introduced during the interview schedule, described in chapter 3. DeSantis and Ugarriza (2000) note that themes bring meaning identity to a recurrent experience and its various manifestations. They also give a sense of control and order to the research. The themes are then related to each other and allow associations to be made between the women’s experiences. The list of key themes identified at the outset is indicated below:

• Symptom mapping
• Referral process
• Diagnosis
• Surgery
• Psychological/emotional consequences
• Alteration in body image
• Sexual function and identity
• Sport, holiday and leisure
• Access to information and resources
• Comparisons with other cancers
• Effect on husband/partner, wider family, friends, children
• Relationship with health care professionals
• Experiences of follow up appointments
• Personality/use of humour as a defence
• Fears and anxieties
• Attitudinal changes
• After care: physical, emotional, psychological, spiritual components
• Suggestions for future health care.

To support the development of an audit trail in the thematic framework, the text was marked by numbering the lines of the interviews so that they could readily be identified, interview by interview. For example, 1.3.47 referred to respondent number 1, page 3 and line 47. The framework was then devised according to the principles suggested by Ritchie and Spencer (1994). A column was drawn on the left hand side of each page and the names of the respondents were written in this column in the same order. Horizontal lines were drawn to separate the comments of one respondent from the next. This enabled the whole data for each respondent in the study to be reviewed easily, giving structure and consistency to the analysis and supporting the process of Indexing.
4.2.3 Indexing

Each interview was read carefully line by line and as a new experience or insight was identified, it was written down by hand and referenced to the page and line number of each respondent. For example, the framework in Table 7 illustrates the respondents’ answers to my question about the presentation of their symptoms.

All the new experiences emerging from the data warranted a separate piece of paper and a fresh chart was made. This allowed diversity of experience and circumstance for each respondent to be documented. It also involved logical and intuitive thinking, as judgements were made about the meaning, the relevance and importance of the issues and implicit connections between ideas (Ritchie and Spencer 1994). For example, theme number 1 was ‘Symptom mapping’. In relation to this, several sub themes had already been identified from studying the findings from the previous studies and were introduced during the interview. They were labelled as 1.1, 1.2, 1.3, 1.4:

1.1 Presentation- the type of symptoms
1.2 Past medical history
1.3 Psychological effect of the symptoms
1.4 Effect of the symptoms on sexual function
### Table 7: Indexing Framework

<table>
<thead>
<tr>
<th>1.0 Symptom mapping</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.1 Presentation: types of symptoms</td>
</tr>
</tbody>
</table>
| Sarah | I had noticed a little tiny spot on the vulva 1.25. No bigger than a mole 1.21. Very tiny 2.25  
| Eve | It was itchy and I thought it was thrush all the time 7.160. I just kept asking for thrush cream  
| Donna | It was really itching and burning. It hurt when I did a wee 2.35.  
| Anne | It hurt, I was having problems sitting and to be crude and horrible, I got a mirror and it looked almost like a bit of liver growing 6.180. I had a look as I was sore 7.232. Itching was driving me mad 51.1770. I never used to be able to sleep properly 59.1980  
| Laura | I’d got an ulcer, some sort of abscess thing and I didn’t know what it was, so I went to see what it was. And I’d been having loads of thrush 2.37-9. Sleeping was really, really difficult, I just couldn’t get comfortable 3.73.  
| Josie | Itching since aged 19 1.16-18. It used to drive me nuts, I’d get constant scratching. And I would scratch that much it would bleed and then it would very sore 1.33-9.  
| Stella | I was sore an awful lot, I kept itching 1.16. It started as if I’d got like a lump. It was right on the edge of me (sic) vulva and it was itching a lot. Within a week, it had grown to ½”, sore, itching 2.45-7 Every time I went back they give (sic) me something else, they kept telling me it was thrush, I said “I’ve had thrush before, it’s not like this.” 27.894.  
| Irene | I had like a mole sort of thing on the side of my privates 1.19. It was just getting a bit sore and started to catch 1.28. I lost a stone and a half in 3 months 3.76-85  
| Denise | Itching, skin really sore 4.122-9. She (GP) was giving me different creams and stuff and eventually she told me to go to the GU (Genito-urinary) clinic 1.28-34.  
| Ria | Constant itching, very sore. Said it was thrush 1.22-32 Painful to pass urine 3.967-8. I’m still having irritation 10.322. Wakes me up at night 10.335, 343-6, 354-6  
| Kay | I found a lump 1.11-14. This cyst was getting bigger; as big as a golf ball 2.47-54. I was really tired 46.1523-4  
| Leigh | I thought it was a wart 1.11. It felt just like a small wart 1.19. It was very itchy 1.32.  
| Julie | I had a lump. And I had a lot of trouble. First it was a cyst 1.11-17. I was in a tremendous amount of pain, I couldn’t go for a wee properly 1.26-8  

As the data analysis progressed, further sub themes were developed and labelled separately. For example, several sub themes reflected the manner in which the women
were referred for specialist care. This included the attitude of the GP which was included in the symptom mapping as the some of the women noted that he/she had not diagnosed their condition straightaway, which had resulted in a delay in care. A further sub theme that became apparent during the data analysis was the impact of the symptoms on the clothes that the women wore and the implications of this. The sub themes were added to theme number 1 ‘Symptom mapping’. They were subsequently labelled, as shown:

1.5 The attitude of the GP.
1.6 Delay in being diagnosed
1.7 Attendance at the Genito-urinary (GU) clinic
1.8 Consultation with a skin specialist
1.9 Effect of the symptoms on the clothes the respondents wore

Some comments by the respondents were identified in several sub themes. For example,

*Um I was sore an awful lot, I kept itching, and I kept going to see him (GP) and for four or five years I had gone to Hospital X and then (sic) and they kept telling me there was nothing wrong with me, they just kept fobbing me off with creams and stuff* (Stella 1.16-19)

The phrase ‘*Um I was sore an awful lot, I kept itching*’ was identified in theme 1, symptom mapping, sub theme 1.1, presentation of symptoms. The phrase ‘*I kept going to see him*’, referred to the fact that the woman had made a number of visits to see the GP, which is theme 1 symptom mapping, sub theme 1.5, the attitude of the GP. The next phrase ‘*for four or five years I had gone to Hospital X*’ was included in the theme 1 symptom mapping, sub theme 1.6, delay in being diagnosed which referring to the length of time that she had
attend her local hospital before a diagnosis was made. However, the whole sentence was also included in theme 1 symptom mapping, sub theme 1.3, the psychological impact of the symptoms as Stella was articulating how frustrated she felt with enduring her symptoms over many years, without having the appropriate treatment. This sentence and this associated meaning is also included with the relationship with health care professionals (10.1), as it indicates the doctor’s lack of experience of a rare condition and also his/her attitude towards the respondent as she felt ‘fobbed off’. Ritchie and Spencer (1994) note that since single passages may contain a number of different themes, each of which needs to be referenced, multiple indexing can highlight patterns of association within the data. Although this is subject to the individual interpretation of the researcher, by annotating the data the process is made visible and accessible to others, so they can see for themselves how the data is being sifted and organised.

As the analysis developed, some themes were sub-divided. For example, one theme, number 8, was to include the attitude of the husband/partner, family, and friends. However this was soon sub-divided into more specific sub themes as data emerged that was specifically related to the different groups. Sub theme 8.1 referred to the effect on her husband/partner, 8.2 was associated with the effect on the children, 8.3 referred to the impact on friends, and 8.4 referred to the woman’s work colleagues.

Framework analysis allowed for this flexibility and also for different themes to emerge. For example some themes were related to physical concerns, such as post-operative wound healing, Theme 5, after care, 5.1 Physical aspects, 5.1.1 wound healing.
The stitches never held. They all broke so I had this massive hole (Eve 8. 180)

The psychological changes noted by the respondents included an alteration sense of body image. These were both positive and negative,

*I don’t look any different* (Sarah 42.948-9)

*It ain't* (sic) *going to be back to normal ever again* (Donna 29.714-5)

In this way, I was able to retain an overview of all the themes as they were written down clearly and labelled. It was also clear to see at a glance how many respondents had a particular experience. For example, the framework analysis enabled me to identify in theme 1 symptom mapping, sub theme 1.7, attendance at a Genito-urinary clinic that 4 women had attended, as their accounts were indexed together on the same chart, as noted:

*She told me to go to the GU clinic* (Denise 1.33-34)

*I even ended up in the GU clinic* (Donna 2.42-3)

*They (GP) advised me to go the GU clinic* (Leigh 1.12-4)

*Then I actually ended up at the clinic, they thought it was some sexually transmitted disease* (Julie 1.12-7)

I was able to identify that only one respondent had been seen by a skin specialist, as only one set of comments recorded in theme 1, Symptom mapping, sub theme 1.8 referred to this.

**4.2.4 Charting**

The charting process involves building up a picture of the data as a whole, by considering the range of attitudes and experience for each theme (Ritchie and Spencer 1994). This was
done theme by theme across all the respondents. It involved ‘lifting’ sentences and phrases from their original context and rearranging them into the appropriate theme or themes. It was essential to keep all the respondents in the same order for each theme and sub-theme so that the comparisons could be made more easily. A separate word document was then created to record direct quotations from all the respondents in each theme and sub theme and accurately referenced so that the source could be traced more easily.

In all, 11 main themes were identified, which incorporated 67 sub themes as shown in Table 8.
Table 8: Thematic Framework

<table>
<thead>
<tr>
<th>1.0 Symptom mapping</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>1.1 Presentation</td>
<td></td>
</tr>
<tr>
<td>1.2 Past medical history</td>
<td></td>
</tr>
<tr>
<td>1.3 Psychological aspects</td>
<td></td>
</tr>
<tr>
<td>1.4 Sexual function</td>
<td></td>
</tr>
<tr>
<td>1.5 Attitude of GP</td>
<td></td>
</tr>
<tr>
<td>1.6 Delay in referral/treatment</td>
<td></td>
</tr>
<tr>
<td>1.7 Genito-urinary clinic</td>
<td></td>
</tr>
<tr>
<td>1.8 Skin specialists</td>
<td></td>
</tr>
<tr>
<td>1.9 Clothes</td>
<td></td>
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</tbody>
</table>

<table>
<thead>
<tr>
<th>2. Referral process</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>3.0 Diagnosis</td>
<td></td>
</tr>
<tr>
<td>3.1 Practicalities</td>
<td></td>
</tr>
<tr>
<td>3.2 Appointment with gynaecology oncology consultant</td>
<td></td>
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<tr>
<td>3.3 MRI scan</td>
<td></td>
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<tr>
<td>3.4 Psychological effects</td>
<td></td>
</tr>
<tr>
<td>3.4.1 Fatalistic</td>
<td></td>
</tr>
<tr>
<td>3.4.2 Denial</td>
<td></td>
</tr>
<tr>
<td>3.4.3 Stigma</td>
<td></td>
</tr>
<tr>
<td>3.5 Age</td>
<td></td>
</tr>
<tr>
<td>3.6 Smoking habit</td>
<td></td>
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<tr>
<td>3.7 Employment</td>
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</tbody>
</table>

<table>
<thead>
<tr>
<th>4.0 Surgery</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>4.1 Issues around admission</td>
<td></td>
</tr>
<tr>
<td>4.2 Travelling to cancer centre</td>
<td></td>
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<tr>
<td>4.3 Multiple operations</td>
<td></td>
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<tr>
<td>4.4 Psychological effects</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>5.0 After care</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>5.1 Physical aspects</td>
<td></td>
</tr>
<tr>
<td>5.1.1 Wound healing</td>
<td></td>
</tr>
<tr>
<td>5.1.2 Lymphoedema</td>
<td></td>
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<tr>
<td>5.1.3 Housework</td>
<td></td>
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<tr>
<td>5.1.4 Sport/Holiday/Leisure</td>
<td></td>
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<tr>
<td>5.1.5 Work</td>
<td></td>
</tr>
<tr>
<td>5.2 Psychological aspects</td>
<td></td>
</tr>
<tr>
<td>5.2.1 Meeting other women with the same condition</td>
<td></td>
</tr>
<tr>
<td>5.2.2 Experiences of follow up appointments for patient</td>
<td></td>
</tr>
<tr>
<td>5.2.3 Experiences of follow up appointments for husband/partner</td>
<td></td>
</tr>
<tr>
<td>5.2.4 Fears and anxieties</td>
<td></td>
</tr>
</tbody>
</table>
5.2.4.1 Fears of recurrence
5.2.4.2 Fears of infection
5.2.4.3 Fears of another cancer
5.2.4.4 Fears of being discharged
5.3 Comparisons with other cancers

6.0 Body image
6.1 Positive aspects of changes in body image
6.2 Negative aspects of changes in body image
6.3 Embarrassment
6.4 Knowing your own body
6.5 Body let down
6.6 Checking for recurrences
6.7 Clothes
6.8 Impact of questions

7.0 Sexual function and identity
7.1 Post operative impact on sexual function
7.2 Impact on/attitude of partner/husband
7.3 Advice and input from health care professionals

8.0 Effect on husband/partner, children wider family, friends and work colleagues
8.1 Partner/Husband
8.2 Children
8.3 Family
8.4 Friends
8.5 Work Colleagues

9.0 Access to information
9.1 Positive aspects
9.2 Negative aspects

10.0 Relationship with health care professionals
10.1 GP
10.2 Consultant gynaecologist
10.3 Skin specialist
10.4 Consultant gynaecology oncologist
10.5 Consultant clinical oncologist
10.6 Nurse/CNS/practice nurse
10.7 District nurse
10.8 Physiotherapist

11.0 Resolution
11.1 Use of humour as a defence
11.2 Improvements in care
11.3 Impact of taking part in research
Some of the original main themes were subsequently incorporated as sub themes. For example, ‘impact of the follow up appointment’ was initially a theme by itself but became sub theme 5.8 as a part of the main theme 5 ‘After care’ and framework analysis allowed for this flexibility.

The broadly general psychological/emotional impact, which was originally planned as a general theme, became more specific as:

1.3 Psychological effects - Symptom mapping
3.4 Psychological effects - Diagnosis
4.4 Psychological effects - Surgery
5.2 Psychological effects - After care

One sub theme was further divided. Theme 5, ‘After care’ includes the sub theme 5.2 Psychological aspects, and sub theme 5.2.4 Fear and anxieties. This is subsequently divided into specific fears as shown in Table 8.

5.2.4.1 Fears of recurrence
5.2.4.2 Fears of infection
5.2.4.3 Fears of another cancer
5.2.4.4 Fears of being discharged

In the charting process, some sub themes were rearranged within the main theme to give a more structured approach. It was more logical within the context of the study to discuss
physical issues first, followed by psychological and sexual effects. For example, theme 1 ‘Symptom mapping’ had 9 sub themes, which are shown in column 1 of Table 9, and which were subsequently developed, as shown in column 2.

Table 9: Initial and regrouped sub themes within Theme 1

| Symptom Mapping |
|-----------------|-----------------|
| **Initial sub themes within Theme 1** | **Regrouped sub themes within Theme 1** |
| 1.1 Presentation- the type of symptoms | 1.1 Presentation- the type of symptoms |
| 1.2 Past medical history | 1.2 Past medical history |
| 1.3 Psychological effect of the symptoms | 1.3 Attendance at the GU clinic |
| 1.4 Effect of the symptoms on sexual function | 1.4 Consultation with a skin specialist |
| 1.5 The attitude of the GP. | 1.5 Effect of the symptoms on the clothes the respondents wore |
| 1.6 Delay in being diagnosed | 1.6 Psychological effect of the symptoms |
| 1.7 Attendance at the GU clinic | 1.7 The attitude of the GP |
| 1.8 Consultation with a skin specialist | 1.8 Delay in being diagnosed |
| 1.9 Effect of the symptoms on the clothes the respondents wore | 1.9 Impact of the symptoms on sexual function |

This was reflected in the other main themes.
4.2.5 Mapping

When all the data had been sifted and charted according to the core themes and subthemes, I began to pull together the key characteristics of the data and to interpret the data as a whole (Ritchie and Spencer 1994). This involved reading and reflecting on the transcripts of the interviews, reviewing all the charts and research notes. It concerned comparing and contrasting the women’s experiences, searching for patterns and connections within the structure as a whole. I then spent some time thinking about what the experience of having a cancer of the vulva really meant to the respondents taking part and how this could be expressed in a meaningful way to the readers of the study. This illustrates the reflexive nature of the data analysis as I, as the researcher, acted as the instrument in the capture and analysis of the data (Andrews 1996). This involved the development of concepts.

4.3 Development of concepts

A concept is developed by using words or phrases to build up a description that depicts a phenomenon or a particular experience and is used to describe the meaning of the phenomenon or the ‘essence’. The word ‘essence’, as already noted page 52, is derived from the Latin word ‘esse’ which means ‘to be’. An essence is, therefore, something that makes the phenomenon ‘what it is, without which it could not be what it is’ (van Manen 1990 p177). The origins of phenomenology may be traced back to Kant (Cohen 1987), see chapter 3. He described the use of concepts to describe a general representation or impression of an occurrence or phenomenon. The development of a concept involves a process of:

• Comparison: noting how one woman’s experience relates to another’s
• Reflection: thinking about different experiences several times

• Abstraction: understanding the meaning the women have given to their experiences.

As noted in chapter 3, Heidegger has described the development of concepts as a progressive abstraction. It also involves the use of free imagination (Speziale and Carpenter 2003). I then tried to think of the appropriate words or phrases to articulate these experiences in order to share this understanding, and the following four concepts emerged:

One concept arose out of the women’s feelings of:

I had tried the products on the market you can find to stop itching (Leigh 2.37)

I must have tried everything in the book (Stella 27.896)

I couldn’t tell you how many operations I’ve had but its loads (Anne 3.97)

He said there was (sic) some cancerous cells there. What that means again I don’t know (Ria 8.244-5)

I took myself off down the library: it didn’t give me much information (Josie 23. 758-60)

It was 4 years from the time of my first symptoms (Donna 2.42)

The word to define this concept needed to incorporate the women’s feelings of ‘looking for help’, ‘repeated visits to the doctor’, ‘seeking advice’, ‘being on the look out for any remedies that may alleviate their symptoms’. The word that appeared to epitomise all these feelings is the word ‘Searching’. The concept of Searching describes the manner in which the women searched to control their symptoms by their own efforts and by undergoing
surgery, the search to understand the truth about their condition and the search for help to access information. The tempo in which the search was undertaken is also noted.

Another concept involved the women’s sense of isolation due to the geographical distance between the woman’s home and the hospital,

*I didn’t get many visitors* *(Kay 11.370-2)*

A sense of separation was noted as the women described their loss of sexual function following the onset of their symptoms of vulval cancer and subsequent treatment, and their inability to enjoy the sexual relationship they had previously,

*You can’t do it (have sexual intercourse). When you have all the operations you don’t have a sex life at all. Still now you can’t* *(Eve 27.654, 658-60)*

The women also felt that there was a lack of knowledge about this condition and a perceived lack of understanding,

*My friends had never heard of it* *(Kay 57.1309)*

*I tend not to talk about it if I can help it* *(Denise 30.985-1002)*

The word chosen to describe the meaning that the women gave to these sentiments was ‘Aloneness’, as it appeared to summarise the women’s sense of loneliness.
A further concept arose from the women’s sense that they felt different after their diagnosis and treatment. This included both physical and psychological changes and also impacted on their feelings regarding their body image. It had both positive and negative aspects and led to a sense of powerlessness and uncertainty. ‘Everything’ appeared to be different for the women after their diagnosis of cancer,

_No one talked about how our lives might be different post-operatively (Josie 45.499)_

_I look at life differently (now) (Sarah 37.847)_

_The doctors said it (the cancer) would definitely come back but it’s just, just (sic) a matter of time (Irene 19.630)_

The diagnosis of cancer of the vulva also impacted on the woman’s family and changed her subsequent lifestyle,

_I went and told my daughter; everyone she’s known with cancer has died (Josie 15.497-9)_

_He (my son) became very aggressive at school (Ria 49.1632)_

_I decided I wanted a baby. That was a big change (Sarah 37.833-842)_

The phrase that appeared to sum up these experiences was ‘All Change’. This concept also included the women’s perspective of the future with a fear of recurrence. Suggestions for service development are also examined.

An additional concept was concerned with the relationship between the women and the health care professionals involved in their care during the journey from diagnosis to
rehabilitation within the context of the health care system. As cancer of the vulva is a rare condition, there was a lack of empirical knowledge, and a range of care and advice. The word that I used to describe the concept relating to the relationship between the women and the health care professionals in her care was ‘Professional Connectivity’. The use of the word ‘Connectivity’ also implies there may be a ‘Dis-connectivity’ with an opposite meaning. Connectivity and Dis-connectivity are illustrated as two opposing factors regarding the women’s dependency on the doctors involved in their care and also a loss of faith in the medical profession.

The analysis of the data noted a lack of communication between doctors in the community and the hospital setting and this is highlighted, together with a lack of communication with the women themselves, in the form of verbal and written information. The issue of time is also included as the women perceived that insufficient time was allocated to them during their consultations.

As noted earlier (Kirk and Miller 1986 p62), there is a need in qualitative research to ensure that the data is reliable as I have included only brief quotations from the women to support my interpretation of the data. However the inclusion of these specific quotations was a means of illustrating the issues raised by the women, in their own words (Clifford 1997). Thus the data can be said to be valid as it was the women’s own voices that were heard and the richness of their stories and the uniqueness of their experiences acknowledged (Cohen and Crabtree 2008). I developed the themes by being fully immersed in the data and by bringing my own nursing experience and empathy to the process of analysis. To address the need to ensure reliability and trustworthiness, I
documented the process carefully and checked and double checked my findings. External auditing was conducted by my supervisors, researchers who were not involved in the research process, who examined both the process and the product of the research study. I also discussed my interpretation with nursing colleagues as a means of challenging the conclusions reached. This helped to evaluate whether the findings interpretations and conclusions are supported by the data (Cohen and Crabtree 2008; Mays and Pope 1995). The reader may also discern for themselves the patterns identified and verify the data, its analysis and interpretation. This is illustrated by the Hermeneutical circle of understanding, (page 53), which depicts the understanding of the phenomenon explored as being shared between the women, myself as the researcher and the readers of the study (Sandelowski and Barroso 2002). However, it is recognised that responsibility for the interpretation lies with me: other phenomenological researchers with access to the same data may have interpreted the data differently.

The next step involved the integration of the themes and concepts within the phenomenological framework.

### 4.4 Integration of themes and concepts within the phenomenological framework

Analysis of the data identified eleven main themes, as shown in Table 8, which depicted the time from the onset of their symptoms into the rehabilitation phase. The four concepts which emerged, Searching, Aloneness, All Change and Professional Connectivity, described the meaning the women gave to these experiences. I then returned to the phenomenological basis for the study to ensure that the themes and concepts ‘fitted’ within
the principles of van Manen’s (1990) phenomenological research philosophy. Van Manen (1990) identified four components of living in the world, in everyday situations. These are Lived Time, Lived Body, Lived Relationships and Lived Space. I then sought to integrate the themes and concepts that emerged from the study into the four components of living in the world. This showed that:

Lived Time refers to the period of time before the diagnosis was made, the period of time that the diagnosis of cancer was made and the period of time following the surgery

Lived Body incorporates the physical, psychological and sexual issues concerning the effect of the onset of symptoms, surgery and subsequent recovery on the respondents.

Lived Relationship details the relationship between the respondent and her husband/partner and family, her wider network of friends and work colleagues, and the health care professionals in the hospital and community who were involved in her care.

Lived Space epitomises the environmental factors involved in the respondents care, in various hospitals, in the primary care setting and at home.

In the light of this interpretation, I then re-read the transcripts of all the interviews to ensure that the main themes emerging from the study mirrored these. I also met with my supervisor regularly to discuss the interpretation of the data.
Table 10 shows that some of the themes (symptom mapping, referral process, diagnosis, surgery, after care, access to information, relationship with health care professionals and resolution) are concerned with all four components of living in everyday situations, while others (alteration to body image, sexual function, attitude of husband/partner, family and friends, and resolution) reflect three of the components. Table 10 illustrates that while the four components of everyday living can be differentiated; they cannot be separated as they are interdependent (van Manen 1990).

**Table 10: Association between the themes of everyday living and the themes from the data**

<table>
<thead>
<tr>
<th>Main Themes</th>
<th>Lived Time</th>
<th>Lived Space</th>
<th>Lived Body</th>
<th>Lived Relationship</th>
</tr>
</thead>
<tbody>
<tr>
<td>Symptom mapping</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Referral process</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Diagnosis</td>
<td>Yes</td>
<td>Yes</td>
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<tr>
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</tr>
<tr>
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<tr>
<td>Sexual function</td>
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<td></td>
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</tr>
<tr>
<td>Attitude of husband/wider family/friends</td>
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<td></td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Access to information</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Relationship with health care professionals</td>
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<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Resolution</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
</tr>
</tbody>
</table>
The concepts of Searching, Aloneness, All Change and Professional Connectivity were also shown to be connected with all the components of everyday living, as noted by van Manen (1990) and shown in Table 11.

<table>
<thead>
<tr>
<th>Concepts</th>
<th>Lived Time</th>
<th>Lived Space</th>
<th>Lived Body</th>
<th>Lived Relationship</th>
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<td>All Change</td>
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<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Professional Connectivity</td>
<td>Yes</td>
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</tbody>
</table>

The key themes and the four concepts were then shown to correlate within van Manen’s (1990) phenomenological framework, as depicted in Table 12.

4.4 Summary

This chapter has provided an explanation of the method of analysing the data, identifying the themes and developing the concepts. The following chapter provides vignettes of the women involved and is entitled ‘The Stories’. It provides background information about the women, enabling the reader to have knowledge of them and their family and work situation. The findings from the data will then be discussed in chapters 6-9 utilising the concepts of ‘Searching’, ‘Aloneness’ ‘All Change’ and ‘Professional Connectivity’.
Table 12: Relationship between the Key Themes, the four concepts and the four components of everyday living (van Manen1990)

<table>
<thead>
<tr>
<th>Main themes</th>
<th>Concepts</th>
<th>Components of Every day Living</th>
</tr>
</thead>
<tbody>
<tr>
<td>Symptom mapping</td>
<td>Searching Aloneness</td>
<td>Lived Time</td>
</tr>
<tr>
<td>Referral process</td>
<td>All Change</td>
<td>Lived Space</td>
</tr>
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<td>Diagnosis</td>
<td>Professional</td>
<td>Lived Body</td>
</tr>
<tr>
<td>Surgery</td>
<td>Connectivity</td>
<td>Lived Relationship</td>
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<tr>
<td>After care</td>
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<td></td>
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<tr>
<td>Alteration in body image</td>
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<tr>
<td>Sexual function</td>
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<tr>
<td>Attitude of husband/wider</td>
<td></td>
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<tr>
<td>Family/friends</td>
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<td>Access to information</td>
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<td></td>
</tr>
<tr>
<td>Relationship with Health care</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Professionals</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Resolution</td>
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</tr>
</tbody>
</table>
CHAPTER 5
THE STORIES

5.1 Introduction

This chapter contains information about the 13 women who took part in the study. I have called them ‘stories’, as they provide details about their background, for example their families and their work, while maintaining their anonymity and preserving confidentiality. It aims to acquaint the reader with the respondents and to enable them to ‘get to know’ the women as people, rather than as patients with an illness.

The women had presented with cancer of the vulva in a variety of ways. Some had pre-invasive disease for a number of years, while others developed primary tumours of the vulva without a previous vulval abnormality. The number of operations and also the extent of surgery varied. The journey from the onset of symptoms to their diagnosis was not limited to a particular time frame. Some women were diagnosed relatively quickly, while others were not diagnosed for many years.

The overview of the presentation of symptoms demonstrates that each woman’s experience was unique to them. The intent is to enable the reader to become familiar with the women prior to discussing the findings from the data analysis.
5.2 The Stories

Sarah

Sarah and her partner Alan have been together for 7 years. A career woman, forty three year old Sarah was efficient and highly organised. As a bank manager, she enjoyed her job, although it involved working long hours and travelling to various branches within a 25 mile radius. Private health insurance was one of the privileges that went with her career. A few months prior to her diagnosis, Sarah had noticed a small cyst on her vulva and was seen by her GP. As there was no change to the cyst following a course of antibiotics, and as she had recently received the results of her routine cervical smear test which showed that she had abnormal cells known as cervical intraepithelial neoplasia, her GP referred her to a consultant gynaecologist. An appointment at a local private hospital enabled Sarah to see him a few days later.

The gynaecologist appeared to be more concerned about the recent cervical smear than the abnormality on her vulva. Given the reassurance that it was probably a ‘cyst or something’, Sarah underwent a wide local excision of the abnormal vulval tissue under a general anaesthetic.

Sarah was called back to see the consultant several days after it was removed and was shocked by her diagnosis of cancer. She was not expecting to be told and had attended on her own, as her partner was playing tennis that evening. A referral to a consultant gynaecology oncologist was made, and she underwent a further wide local excision of the area, and the removal of the lymph nodes in the groin of her left leg. Following this
surgery, Sarah has required several further vulval biopsies, which showed that there was no further evidence of cancer.

The diagnosis of cancer caused Sarah to re-evaluate her priorities in life. She resigned from her job and decided to have a baby. At the time of the interview her daughter was aged 16 months. Less financially secure now, Sarah is disappointed that she is unable to obtain life insurance because of her diagnosis of cancer.

**Eve**

Irish by birth, thirty three year old Eve lives with her partner of 7 years and two sons, aged 15 and 8. Eve felt that as regards her health, she had had ‘one thing after another’ as she has had two cancers: cancer of the cervix in 1998 and then two years later cancer of the vulva. She underwent a Wertheim’s hysterectomy, and post operative radiotherapy to treat the cervical cancer, and then developed pre-invasive VIN which necessitated two operations to remove the affected area of vulval tissue. The pre-invasive VIN then developed into invasive cancer in 2000, and she underwent a wide local excision. Since the surgery for cancer, she has required three further operations for VIN.

Prior to her diagnosis of VIN, Eve lived in a flat which was situated over a row of shops which included an off licence and a fish and chip shop. According to Eve, the stairway of the flats was always dirty so Eve and her partner moved to a semi-detached house which they refitted from top to bottom. Here she spends her days washing and cleaning, and changes all the bed linen daily. She feels that this helps to reduce her risk of repeated VIN
infections. Neither did she allow anyone to visit the home if they had any kind of cold or
infection.

After Eve’s operation for invasive cancer, her wound broke down and she had to visit the
hospital daily for dressings. It took several months to heal up and it has left her with a thin
area of skin which is very sensitive in cold weather. Eve is unable to plan holidays or
outings, as she is always going into hospital. It is just something she accepts since other
members of her family also have cancer.

**Donna**

Thirty four year old Donna lived with her husband, and two sons aged 10 and 12. A warm
and bubbly personality, Donna and Mick had been married for 10 years. Her work at a call
centre involved working long hours doing various day and night shifts. At home, she was
very practical and energetic; be it landscaping the garden, re-laying the patio or going to
the gym. Devoted to the two boys, Donna and Mick did everything together as a family,
whether it was visiting friends or attending rock concerts.

For four years Donna had suffered from vulval itching and had seen several different
consultants at two different hospitals as well as at the Genito-urinary clinic. On one
occasion the consultant informed her that there was nothing wrong with her and it was ‘all
in her mind’. Nevertheless Donna decided to ask for a second opinion. She was then very
shocked to be told that she had a cancer of the vulva. Donna had a radical vulvectomy and
bilateral groin node dissection, but since a large amount of tissue was removed her wound
took several months to heal. A month long stay in hospital was spent getting to know all
the other patients (or inmates, as she called them), to such an extent that women who had already been discharged came back to visit her.

Post operatively, Donna’s sexual relationship with Mick was badly affected since she had such extensive surgery. Donna thought that she may not have needed such extensive surgery if she had been diagnosed earlier. When she had recovered, she changed her career, and moved to another job with more sociable hours. Describing herself as being much more relaxed now, Donna is ‘laid back’ about her targets to achieve at work and confided that she is no longer so house-proud. Donna’s most recent cervical smear showed a borderline abnormality, which has caused her some anxiety and uncertainties about another cancer.

Anne

Forty five year old Anne lived with her husband of 20 years and their two sons aged 5 and 8. The bread winner in the family, Anne has a high powered job and has worked for the same company for over 25 years, travelling a great deal across the UK. Her husband is a ‘house-husband’ and works part-time to fit in with the children’s schooling and to take them to various after school activities.

From the age of 29, Anne had had a history of lichen sclerosis. She was treated in the private sector, as she had private health insurance with her job, and had undergone numerous operations to remove pre-invasive disease before developing vulval cancer. In fact she had had so many operations she was unable to remember how many, or even the year that she was diagnosed with cancer. Anne recalled that even after she had undergone a
vulvectomy, she was oblivious to her diagnosis or the extent of her surgery for some time afterwards. Having put it to the back of her mind, she presumed that having cancer was something that would never happen to her.

Following her surgery Anne developed mild lymphoedema in one leg. She attributed this to a lack of nursing care as post operatively the nurses had left the redivac drainage bottle closed, instead of leaving it on free drainage. The lymphoedema upset her a good deal as she was very conscious of one leg being slightly bigger than the other, and regretted that she was no longer able to wear certain styles of trousers. Nevertheless she was determined to get back to normal and even took up cycling, which she had been unable to do before. Since her surgery, Anne was relieved that the symptoms of itching, which she had had for the previous 15 years had now resolved and she has not required any further surgery.

Laura

The youngest of all the respondents, Laura was aged 27 and lived with her husband of 3½ years. Childless, Laura and her husband had been living abroad when she developed symptoms of thrush. Although she had been seeing her GP for about 12 months, she was still experiencing the same symptoms, so when they returned to this country, her GP referred her to a gynaecologist and the diagnosis of cancer was made.

Laura underwent a radical vulvectomy and bilateral lymph node dissection. It was stage 2 disease (see Appendix 2). The surgery took place in a hospital which was about 40 miles from her home, but only about one mile from her parents. Consequently Laura’s parents took over a lot of her care when she was an in-patient and she was subsequently discharged
to her parents’ home. Although they both worked full time, her parents reduced their hours and took it in turns to stay with Laura in the initial post operative stage and her mother assisted with her personal care. Several holidays were taken to aid Laura’s recovery. Following her surgery, Laura worked as a volunteer in a local charity shop while she looked for a part time job.

Laura was quite fatalistic about her diagnosis of cancer. She recalled that her surgery had to be done so there was no point in letting it bother her, but the fact that she was childless had a big impact on her and she wished that she had had her children before her diagnosis was made. Following her surgery she was unable to have sexual intercourse due to vaginal stenosis, and was unwilling to undergo further surgery to correct this.

Josie

Fifty year old Josie lived with her husband Bill. They had been together for 7 years; it was their second marriage. Working as a health care assistant in the community, Josie enjoyed meeting new people in their own homes. Bill and Josie were very fond of the countryside: their garden was a haven for wild birds and they spent their holidays enjoying coastal walks. From the time that she was 19, Josie had had lichen sclerosis and had tried numerous remedies to try to control the itching. Advice was sought from doctors in Chinese medicine, homeopathic medicine and skin specialists to no avail. Her symptoms of itching were her ‘cross to bear’.

Eventually a referral to a consultant gynaecology oncologist was initiated, and diagnosis of cancer of the vulva was made. She underwent a radical vulvectomy and bilateral groin
node dissection, and subsequently developed a wound infection which required re-
admission to hospital. Josie was very open about her disease and surgery. By talking about
her symptoms of vulval cancer, she thought that it may encourage other women to seek
advice if they had similar problems. A lot of women she encountered were ignorant about
their anatomy and unsure where exactly the vulva was. She described her surgery as “the
best thing that had ever happened” to her as her symptoms of severe itching had now
resolved.

**Stella**

Fifty year old Stella had been with her partner Don for 16-18 years, and she had three
grown up children and several grandchildren who were a real joy to her. Working in a
cycle shop, Stella wore leather jacket and trousers to ride her own motor bike to work
daily. For more than 4 years Stella had been attending her local hospital with symptoms of
vulval itching, and she was frustrated that nothing seemed to relieve it. Despite “knowing
her own body”, Stella felt that she was being fobbed off with various creams to try. A
tumour subsequently developed on her vulva and she was referred to the cancer centre
where she underwent an anterior hemi-vulvectomy and bilateral groin node dissection.
Post-operatively Stella was shocked about the amount of tissue that had been removed, and
this had an effect on her in many ways. Physically she had a problem with micturition, as
when she passed urine, the urine tended to come out at an angle, and wet her leg instead of
going down into the toilet. There was a psychological effect on her body image as she felt
“different” from other women. The subsequent impact on her sexual function affected both
Stella and Don, and she remarked that if she had not been so strong willed or had such a
strong relationship she would not have been able to cope with her sexual dysfunction.
Since her surgery, Stella had developed other abnormal areas on the vulva. She had undergone biopsies of these areas to check that they were not a recurrence of her original tumour. Fortunately there was no further evidence of cancer.

The diagnosis of cancer caused Stella to alter her outlook on life. She feels that she is able to cope with other people’s illnesses better now and is aware that there is always someone else worse off than her. Although she was told to have four months to convalesce, as soon as she could ride her motor bike again, she returned to work. Determined to live life to the full following her diagnosis, she and Don have enjoyed several holidays to America and South East Asia.

**Irene**

Fifty one year old Irene had been married to Terry for fifteen years: it was her second marriage. Irene has complex medical problems; she is diabetic, and has heart disease, osteoporosis and arthritis. Unable to walk far, Irene also uses a stair lift to go upstairs. Despite being restricted in her activities, Irene enjoys seeing her friends and she remarked that her family and friends describe her as being ‘the life and soul of the party’

Irene had previously had cancer of the cervix so when she developed a vulval growth and lost 3 stone in weight, she was not surprised by the urgency with which her GP referred her to her local hospital for a vulval biopsy. However she was not told her diagnosis directly. Instead the consultant gynaecologist telephoned her at home to notify her of her referral to the cancer centre and that as regards her diagnosis, the remark ‘I think you have your own ideas’ was made. Irene underwent a vulvectomy and due to the size of the tumour she
underwent further surgery two months later to remove the lymph nodes in the groin of her right leg. The lymph nodes were not affected by cancer, and adjuvant therapy was not required. Subsequently her wound broke down, but Irene was adamant that she did not want to be readmitted to the ward. She preferred to stay in her own home, and was cared for by the district nurses daily until the area healed.

Irene was determined to maintain a positive attitude but was fatalistic about her illness since she was told that the cancer would definitely recur at some point. She tried to shield Terry from knowing too much about her prognosis and resolved to set an example to her friends and family regarding the way she copes with her ailments.

**Denise**

Denise is fifty three and has been married to Jim for 30 years. They have 3 children; sons who were aged 19 and 27, and a daughter aged 14. Jim and Denise had complementary roles within the household: he enjoyed decorating and servicing the cars, while Denise did all the cooking and household chores. She also worked in an office part time. Close to all her children, she loved shopping with her daughter and was well acquainted with current trends in pop and rock music.

Denise had been seeing her GP for nine months with vulval itching, before being told she had herpes and referred to a Genito-urinary clinic. This had an impact on her marriage. She was worried that if she was found to have a sexually transmitted disease, Jim must have been unfaithful to her and caught herpes from another woman. Denise knew that she could
She underwent a vulval biopsy and was subsequently referred to a cancer unit for a further biopsy. Before she was given the results, she was referred to a cancer centre for further surgery. Denise was devastated by her diagnosis and the process by which her referral for treatment was made. Following her biopsy, she had to wait a further four weeks for the area to heal before undergoing further surgery which as she remarked is “a hell of a long time when you think you’re dying”. A radical vulvectomy was performed, but Denise developed a recurrence two years later, and had a wide local excision of the recurrent disease.

Since her diagnosis Denise feels very different about herself and definitely not “the same person” as she was before. She expressed her view as “you don’t feel like you’re a normal person, you feel strange”. Neither did she resume her sexual relationship with Jim, but felt that she might have done so if only a health care professional had discussed this with them as a couple. It was now too late, she felt, to try to resume their sexual relationship and she grieved for this loss after 30 years of marriage. Counselling was also required as Denise felt that her GP had not cared for her very well. Denise’s daughter was particularly affected by her mother’s diagnosis and surgery and was convinced that her Mum was going to die. Determined to keep positive and carry on as normal, Denise describes herself as ‘being on a mission’ to stay as healthy as she can.
Ria

Born and living in Wales, Ria is aged 30 and lives with her husband of 3 ½ years and their two sons, aged 3 and 9. Close to her family in a tight knit community, Ria lives next door to her parents and adjacent to her brother and his family. Ria’s parents are unwell, her father has lung cancer and her mother also has medical problems. With a cheerful and vivacious personality, Ria described how everyone always turned to her in any family crisis and to solve any of their problems. A housewife at present, Ria hoped to do an adult education course when her younger son went to school.

Having had VIN for 3 years Ria required three operations two years previously and one operation the preceding year before undergoing a wide local excision for invasive cancer. Post operatively her stitches became infected and she developed a breakdown of her wound, which was managed by her GP and district nurses. A lack of information and knowledge about VIN and cancer of the vulva have troubled Ria a good deal. She felt quite isolated, because she was so young to be requiring treatment and because she was unable to find out any specific information about her own illness from the doctors involved in her care. Uncertainties about her prognosis also worried her. Neither did she receive much support from her own family or friends as they did not understand and Ria was always perceived as someone who was strong and able to cope.

Her sexual relationship has also been affected by the symptoms of VIN and the amount of tissue that was removed at the time of her surgery, and she is concerned about the impact this is having on her marriage.
Ria had tried to shield her older son, Duncan, from knowing too much about her illness and he became more aggressive after his mother’s illness. Ria and her husband were asked to attend a meeting at the school to discuss his behaviour, and Duncan subsequently confided to the school doctor that he was afraid his Mum was going to die. After this, the school doctor advised Ria to be more open about her illness with him. This was difficult for Ria, as she felt that she did not understand about her illness herself.

**Kay**

Married for 16 years, forty one year old Kay had two children; a daughter aged 12 and a son 16. Kay’s husband suffered for depression following a redundancy and had been unable to work for some time. Working as a teaching assistant in the same school that her children attended, Kay loved her job and thought that all the members of staff were a great team to work with.

Kay had cancer of the Bartholin’s gland and had the most advanced disease of all the women. Her GP had presumed that she had an infection for several months although she was not examined, and he treated her with antibiotics. A neighbour suggested that Kay went back to the GP for further help as her condition was not improving, and she was subsequently referred her to the local hospital where her diagnosis was made. This happened on the day of her 40th birthday and Kay ruefully remembered the impact of her birthday cards announcing that ‘life begins at 40’.

Kay felt that if she had had an illness which was more common such as breast cancer she would have been treated more quickly. Due to the complexity of her condition Kay was
referred for a radical vulvectomy and bilateral groin node dissection at a cancer centre 100 miles away from her home. This had an impact on Kay as the family do not have a car and were not able to visit her in hospital very often. In addition, Kay had not been away from her daughter before and this had an emotional impact on them both.

Following her surgery, Kay required a course of post operative radiotherapy for 5 weeks at a hospital closer to her home. Despite the side effects of radiotherapy which are tiredness, soreness, cystitis and diarrhoea, Kay managed to go to work each morning at the school where her colleagues supported her as much as possible. Lifts by car from a friend to the radiotherapy treatment centre helped to reduce her feelings of tiredness.

Kay has now developed lymphoedema of both legs, abdomen and pelvis, and her life style has changed considerably since her operation. She is unable to wear the clothes or shoes that she used to, as her legs and body are a different shape now owing to the swelling caused by the lymphoedema. Her hobby of making her own clothes is now no longer possible; she is unable to make clothes that will fit her, now that her shape has changed. Neither does she does have the sensation in her legs to operate her old sewing machine. Walking is tiring for Kay now, and it exacerbates the discomfort from the lymphoedema.

Her sexual relationship has changed following surgery as she has a loss of feeling and sensation due to the amount of vulval tissue that was removed and her subsequent lymphoedema and she wishes that she and her husband could have been prepared for this eventuality more. Her prognosis was of great concern to her as there is no guarantee that her cancer will not return and her younger child was only 12.
**Leigh**

Forty four year old Leigh lived with her son, aged 10. Although she was divorced four years previously, she and her ex-husband were the ‘best of friends’. He accompanied her to her hospital appointments, visited daily and helped to care for her and their son post-operatively. Working for social services in the community, Leigh had a wide circle of friends. An avid supporter of her son’s football team, Leigh cheered them on at every opportunity.

Leigh had developed symptoms of vulval irritation which did not respond to the cream that her GP had given her or anything she bought herself at the pharmacy, and so she was referred to a Genito-urinary clinic, where she had a biopsy taken. A delay in the referral process meant that the results of the biopsy confirming cancer were not given to her. Two months later Leigh received an appointment for the cancer centre which was located over 100 miles from home. At the time she presumed that this hospital provided general care for women with gynaecological disorders, and was unaware that she had been referred there because she had cancer. Leigh and her ex-husband travelled there totally unaware that she was going to be told her diagnosis and would require an operation. Shocked on hearing this news, Leigh subsequently gained a great deal of support from her friends and family.

Leigh underwent a radical vulvectomy and bilateral groin node dissection, and was fortunate to receive lots of visitors while she was an in-patient including her son who was allowed to miss the last lesson at school. A good recovery following her surgery ensued and Leigh returned to her previous job. As the cancer had gone, Leigh was able to put her
diagnosis and surgery behind her and get on with her life. Her interview took place at the cancer centre prior to a follow up appointment.

**Julie**

Forty three year old Julie had been married for 16 years, and as the mother of 6 children she was a full time housewife. The three oldest lived away from home, and the three younger ones were aged 16, 15 and 11. Her husband worked part-time.

Julie had been in and out of her local hospital for over 12 months with a vulval swelling which was treated with antibiotics, and she was then referred to a Genito-urinary clinic. This referral caused her some distress because of the stigma associated with this clinic, and she was worried about what people would think as she had always been faithful to her husband. Following a biopsy she was not told her diagnosis for a further 4 months. It came as a total shock to her especially as the doctor ‘just blurted it out’.

Since Julie’s local cancer centre had a long waiting list, she agreed to a referral to another one further away. She underwent an anterior hemi-vulvectomy, and then returned to the hospital a few weeks later for an ipsilateral groin node dissection. Her hospitalisation had a huge impact on the family as they did not have their own transport and the train journeys from their home to the hospital took up to 2 hours each way. This affected the children’s education as they missed their afternoon lessons in order to travel and they were tired the following day. Julie’s Mum was able to help with the household chores.
Since her surgery, Julie developed severe lymphoedema in one leg affecting her micturition, mobility, sleeping and sexual relationship. The lymphoedema has also had an impact on the clothes that she wears, as she has to rely on baggy trousers or loose long skirts to hide the swelling and to ensure she feels comfortable. Her feet are different sizes too, and every day activities relating to the care of her family have also been curtailed. ‘Everything feels different now’ was her comment in trying to describe the change in her sexual relationship and she has a loss of libido. Instead of having intercourse every day, she and her husband have intercourse approximately once a month. At the time of the interview Julie was waiting for an appointment with a lymphoedema CNS.

Fears of recurrence cause Julie anxiety and her children have been nagging her to stop smoking. She is hoping to get some nicotine patches to help her to stop smoking when she feels a bit stronger.

5.3 Overview

As the stories have noted, all of the women are married or with a partner, except Leigh who was divorced. The length of the marriages varied between 3.5 and 30 years and this is shown in Table 13. Eight of the women had children, ranging from 3 to 19 years and this is also included. Three of the other women, Josie, Stella and Irene, had adult children who were no longer living at home. The remaining two women were Laura and Sarah. Laura was childless while Sarah had a little girl after her surgery. The time frame between the surgery and the time of the interview is also shown in Table 13.
The overview of the respondents has shown that the women come from a variety of backgrounds, with a range of careers and social support. This diversity is reflected in the impact that the diagnosis of vulval cancer, subsequent treatment and recovery has had on these women, their husband/partner, children, wider family, friends and work colleagues. There was also a range of symptoms that first alerted the women that they needed to seek medical attention. The care of the women within the context of the National Health Service is described in chapter 9, Professional Connectivity. I was the Clinical Nurse Specialist involved in the care of 4 of the women in this study, Donna, Irene, Kay and Leigh.
Table 13: The number of years the women had been with their husband/partner and the number and ages of children

<table>
<thead>
<tr>
<th>Name</th>
<th>Age</th>
<th>Marital status</th>
<th>Years with partner</th>
<th>Children</th>
<th>Time since surgery</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sarah</td>
<td>43</td>
<td>M</td>
<td>7 years</td>
<td>Daughter, 16 mths</td>
<td>3 years 3 months</td>
</tr>
<tr>
<td>Eve</td>
<td>33</td>
<td>P</td>
<td>7 years</td>
<td>Two sons, 8 and 15</td>
<td>2 years 11 months</td>
</tr>
<tr>
<td>Donna</td>
<td>34</td>
<td>M</td>
<td>10 years</td>
<td>Two sons, 10 and 12</td>
<td>3 years</td>
</tr>
<tr>
<td>Anne</td>
<td>45</td>
<td>M</td>
<td>20 years</td>
<td>Two sons, 8 and 5</td>
<td>1 year 7 months</td>
</tr>
<tr>
<td>Laura</td>
<td>27</td>
<td>M</td>
<td>3.5 years</td>
<td></td>
<td>12 months</td>
</tr>
<tr>
<td>Josie</td>
<td>50</td>
<td>M</td>
<td>7 years</td>
<td></td>
<td>3 years</td>
</tr>
<tr>
<td>Stella</td>
<td>51</td>
<td>P</td>
<td>17 years</td>
<td></td>
<td>5 years</td>
</tr>
<tr>
<td>Irene</td>
<td>51</td>
<td>M</td>
<td>15 years</td>
<td></td>
<td>1 year 6 months</td>
</tr>
<tr>
<td>Denise</td>
<td>53</td>
<td>M</td>
<td>30 years</td>
<td>Son aged 19, Daughter aged 9</td>
<td>5 years</td>
</tr>
<tr>
<td>Ria</td>
<td>30</td>
<td>M</td>
<td>3.5 years</td>
<td>Two sons, 3 and 9</td>
<td>8 months</td>
</tr>
<tr>
<td>Kay</td>
<td>41</td>
<td>M</td>
<td>16 years</td>
<td>Son aged 16, Daughter aged 12</td>
<td>12 months</td>
</tr>
<tr>
<td>Leigh</td>
<td>44</td>
<td>D</td>
<td>N/A</td>
<td>Son aged 10</td>
<td>6 months</td>
</tr>
<tr>
<td>Julie</td>
<td>43</td>
<td>M</td>
<td>16 years</td>
<td>Sons aged 15 and 16, Daughter aged 11</td>
<td>7 months</td>
</tr>
</tbody>
</table>

Key

M  Married
D  Divorced
P  Partner

5.4 Symptoms experienced
As already noted in the chapter 1, there are approximately 1000 new cases of cancer of the vulva each year in the UK. It is a relatively rare condition, accounting for between 3-5% of gynaecological malignancies. Cancer of the vulva may present in a variety of ways. The most common symptom is an abnormal area or lump, or with vulval itching (Moore-Higgs 2000) and 9 of the respondents presented in this way. The other 4 women had a history of pre-invasive vulval disease, which had been diagnosed many years previously. Two women had lichen sclerosis for between 16-30 years, and 2 women had VIN which had been diagnosed 3-8 years previously. While both conditions remain relatively rare compared with other precancerous conditions, the incident of VIN has doubled over the last two decades and has tripled for women under the age of 50 (Joura et al 2000). The women’s’ accounts of their symptoms are summarised below.

*When I was about 19 and I just kept getting itching down in the vaginal area. My G.P. had diagnosed lichen sclerosis (Josie 6.191).*

*That was many years ago: it was probably in 1989. He thought it was this lichen sclerosis, yeah (Anne 5.141).*

*They found out that I had the VIN so I went for some more tests and they took biopsies. That was 8 years today (Eve 3.72).*

*And he (Consultant Gynaecologist) went on to explain that it’s vulval intraepithelial neoplasia. It started when I was pregnant. My little one will be 3 in October (Ria 3.74-94).*

The other 9 respondents, who had not had a previous history of pre-invasive disease, had developed an abnormality in the vulval area. This was described in a variety of ways, as a wart, ulcer or as a mole,

*I thought it was a wart. It felt just like a small wart (Leigh 1.11, 1.19)*

*I’d got an ulcer, some sort of abscess thing (Laura 2.37)*

*I had um like a mole sort of thing on the side of um my privates (sic) (Irene 1.19)*
Stehman and Look (2006) confirmed that most patients have a visible lesion which may be raised, flat, ulcerated, exophytic, or plaque-like.

The size of the lump varied considerably. They started as very small areas that gradually increased in size,

I’d noticed a little tiny spot, um, on the vulva. I mean it was no bigger than that sort of mole. It was very tiny (Sarah 1.25, 2.25).

It got to be a little growth (Laura 2.65).

I’d got like a lump. Only a little tiny one, and it was right on the edge of me (sic) vulva and it was itching, and it was itching a lot. And if you touched it or anything it started to bleed. Within a week, it had grown to ½” long (Stella 1.32-5, 2.45-7).

I mean I would say it was about the size of a golf ball towards the end that um you know (sic) it was towards the end (Kay 2.47-54).

The women then took different referral pathways in their journey towards the diagnosis and treatment for their cancer.

5.4 Summary

This chapter ‘sets the scene’ and helps the reader to put the women into the context of their illness, the onset of their symptoms and subsequent recovery. The concepts of Searching, Aloneness, All Change and Professional connectivity are discussed in chapters 6-9.
CHAPTER 6
SEARCHING

6.1 Introduction

This chapter focuses on the concept of Searching, which was introduced in chapter 4, on page 94 as experienced by the women in this study. The sense of searching was characterised by a search for control. This was related to the physical component including, for example, searching to control the distress of the presenting symptoms by wearing certain clothes or by undergoing surgery to remove precancerous tissue. This had a practical application in ameliorating the impact of their symptoms on their everyday activities. The psychological component in the search for control was related to the effect of the cancer diagnosis on their emotions and the sense of being ‘out of control’. This was illustrated by their search for information.

O’Connor et al (1990) defined searching as asking questions aimed at giving the experience purpose and placing it in the context of total life pattern, by reworking and redefining past meanings while at the same time looking for meaning in the current life situation. This is related to the women’s own perception of their symptoms, and their journey towards a definitive diagnosis and treatment. This may be described as their situational meaning, as noted in work by Thompson and Janigian (1988) and Fife (1994), and is part of the coping process. There is also an existential meaning for the women at the time of their diagnosis of cancer, as they adjust to the implications of a potentially life threatening illness on them, their family and their future. Many authors studying the impact of a cancer diagnosis have referred to the question of ‘Why me?’ posed by respondents (Greer 1991; Kaye 1996; Faulkner 1998; Koch et al 2001). Benner and Wrubel (1989)
have also noted the link between coping, the meaning of illness and the context of the illness experience. In previous studies on women with vulval cancer, several women referred to the search for a possible cause for their cancer, noting that they had not had any previous gynaecological problems (Janda et al 2004). Green et al (2000) also reported that the women referred to a search for meaning and a lack of understanding about their condition.

The concept of searching was seen in the context of time, or the passage of time, rather than a linear time scale. For the respondents, it is seen as subjective time as the past experiences live on into the present and also the future. Heidegger (1889-1976) described how philosophical studies may be seen in ‘the light of time’. A search may be concluded fairly quickly, or the process may continue for many years. It may also be modified over time as women experienced more distressing symptoms and their search for help became more urgent. Several women had symptoms up to 20 years before their diagnosis of cancer was confirmed and the searching continued during this period of time.

The process of searching is also linked to resolution, which is the outcome of the process of assimilation, whereby a person makes sense of the phenomenon they have experienced, accommodation where they are able to accept their experience and resolution which acknowledges that their relationship with the world has undergone a permanent change (Horowitz 1986).

The concept of Searching may be summarised by the Searching to Control, Searching for Meaning, and Searching: the time element. This is shown diagrammatically below.
In summary, the concept of ‘Searching’ incorporates the desire to manage the physical symptoms of vulval cancer and the quest for informational and emotional support. The sense of searching was also manifest in the referral process for the appropriate treatment. The psychological component included the search for meaning to understand the implications of their condition, both in the present and for the future.

6.2 Searching to control the symptoms

The search to control the physical symptoms of cancer of the vulva is discussed initially. It involved the women taking their own initiative in their search for practical ways to relieve
the distress of their symptoms and undergoing surgery to remove the precancerous vulval tissue.

The most distressing symptom for the majority of the respondents was itching, which occurred at night as well as during the day,

_It was really itching and burning (Donna 2.35)_

_It used to drive me nuts, I'd get constant scratching, um as much as you tried not to, you couldn’t help it (Josie 1.33)_

_I never used to be able to sleep properly (Anne 59.1980)_

This has also been noted by Buscema, Stern and Woodruff (1980) and Stehman and Look (2006) who reported that 80% of women present with itching, which may have been present for a number of years. It was the most severe symptom noted by Janda et al (2004). The women tried to control their symptoms of itching by searching for relief in various ways.

**Bathing the area**

Stella used to bathe her vulval area particularly during the night,

_And nine times out of ten I’d go to the bathroom to put something cold on it to, 'cos (sic) it was, it was like a burning feeling, it was always red, really hot, it was just like itching and the more I scratched it the more it, the worse it was, [laughs] it was awful (Stella 2.66-72)_

**Numbing the vulval area**

Julie used a gel to try to numb her vulva, although this led to urinary incontinence,
I was in a tremendous amount of pain, I couldn’t go for a wee properly, I was using gel to numb the area all the time. I couldn’t go to the toilet properly, I was using “Instillagel” (sic) which was deadening that area so I was wetting myself a lot because I couldn’t feel meself (sic) when I wanted to go to the toilet and I was having, get, fetch me (sic) from the chemist by the box load (Julie 1.27-8, 13.409-413)

Julie had been prescribed ‘Instillagel’ by her GP. This is a lubricant which contains 2% lignocaine. It is used as a local anaesthetic and acts by causing a reversible block to conduction along the nerve fibres. It is prescribed for local application to the vulva or perineum if there is severe irritation (British National Formulary 2005)

**Drinking less**

Some of the women found that passing urine exacerbated their symptoms of itching,

*And trying to go to toilet was, you know, near enough impossible ‘cos (sic) it used to sting really badly, it was horrible (Laura 3.86)*

*I knew as soon as I’d go to the toilet to have a wee, it (the itching) would start again, it would start it off (Josie 2.37-8)*

They sought to control this by drinking less,

*I tried not to drink too much at some points. Then when I wanted to go toilet I’m thinking I don’t really want to go. Thinking I can do without this (Laura 3.95)*

*That’s why I, even now, I sort of hold myself off before I go to the toilet because I used to then (Josie 1.33-9)*

By reducing the amount of their fluid intake, the women hoped that they would pass urine less frequently, and reduce the amount of vulval irritation. However, the lack of fluids caused the urine to become more concentrated and this had a negative impact on the vulval irritation.
Wearing certain clothes

The symptoms also had an impact in other areas of the lives of these women, for example, the clothes that they wore. The women were careful to wear clothes that would not exacerbate the symptoms of itching,

_I couldn’t wear jeans or anything like that. If I got hot it would start the itching off_ (Eve 7.169)

_I couldn’t wear pants, couldn’t wear trousers, and couldn’t wear anything. I just went round with long skirts on and not wear anything underneath. I bought this long vest; it came to my knees. I never used to wear no tights (sic) (Josie 3.84-6, 9.296, 10.312-4)_

_The only thing I was comfortable in was cotton and nine times out of ten it was better if there was nothing there at all, but that’s not feasible is it, [laughs] to go to work, but um yeah, it was much easier if I didn’t wear anything at all. I haven’t worn tights or jeans for years (Stella 3.76-83)_

This is related to the women’s perception of their body image (see chapter 2) which has been defined as the internal representation of our own outer appearance (Thompson, Heinberg et al 2002). It involves the social aspect where the opinions of others can be extremely important (Price 1990a, 1990b). The symptoms of vulval cancer appear to have had a negative effect on body image, as these women were not able to wear the clothes they wished to. This is discussed in depth in chapter 8, All Change.

Medication

In addition some women tried to resolve their symptoms by searching for products in the local pharmacy. Leigh had purchased medication from her pharmacy, as she had presumed she had Thrush,
I’d been given ‘Diflucan’ and um sort of things like that, I had tried the products on the market you can find to stop itching and things like that, so I had tried to apply various stuff to stop the itching, so, (sic) but nothing worked (Leigh 2.36-9)

Thrush or candidiasis is the second most common vaginal infection after bacterial vaginosis (Irving et al 1998). Typical symptoms include vulval and vaginal itching or soreness as well as an increase in vaginal discharge. The treatment for Thrush is ‘Diflucan’ which may be purchased from a pharmacy. It is usually administered in the form of a pessary, which is inserted high into the vagina. Single-dose preparations are usually effective. Nyirjesy et al (1997) noted that 73% of women with symptoms of vaginitis self-medicated for 2 or more years with over-the-counter remedies, spending $2 to $1000 per year on such treatments.

Josie and Stella had tried complementary therapies,

I decided to try um homeopathy. So I went to see, see Dr A. and I mean she’s a proper doctor, but she specialised in homeopathy as well. So I went to see her privately and she was trying different things (Josie 5.144-6)

I remember somebody going on the Internet for me and finding out about (sic) when it first started itching and he come up with some Tea Tree oil, Tea Tree cream or something, or Tea Tree balm I think it was called and that eased it for a bit (Stella 52.1735-8)

It has been shown that women with chronic vaginal symptoms are increasingly rejecting antimicrobial therapies in favour of alternative remedies (Nyirjesy et al 1997). This study reported that 42% of women used alternative medicines, such as yogurt and Tea Tree oil (Melaleuca alternifolia). However, to date the evidence for complementary and alternative medicine therapies for vaginitis is largely composed of inconclusive, poorly controlled
studies and in vitro evaluations and in the case of Tea Tree oil may also cause a bad allergic rash (van Kessel et al 2003).

Josie also sought advice from skin specialists and a doctor, who was qualified in Chinese medicine,

> With visits in between to the skin, skin (sic) specialists who um again just did the same thing; just gave me different steroid creams, a bit stronger and stronger creams, but nothing helped. Somebody gave me um a name of a doctor who worked at X University and also did clinics (in Chinese medication) on the side privately (Josie 1.25-7, 3.92-5)

### 6.2.1 Searching to control by surgery

The second means of controlling the symptoms of itching was to undergo surgery to remove the precancerous tissue, the cause of the symptoms of irritation. Four of the women, Anne, Josie, Eve and Ria, were diagnosed with the precancerous conditions of lichen sclerosis and VIN 3. They were referred to a consultant gynaecologist or consultant gynaecology oncologist who removed the area of vulval tissue that was causing the irritation. This surgery involved wide local excisions of the vulva for this group of women,

> I had absolutely loads of operations over the years I think it was last year that I had this done (radical vulvectomoy), but the year before I had two operations, the year before that I had two operations so (sic) (Anne 2.58, 3.101-4)

> He’s had to do a few operations…and then he’s done that one (for invasive cancer) and I’ve had another few since then (Eve 7.169-70)

Since the surgery had not controlled the development of precancerous changes, further surgery was needed on more than one occasion over the course of many years. Anne and Ria were unable to remember how many operations they had had,
Um yeah so I couldn’t tell, you’d have to see the consultant gynaecology oncologist to actually ask how many operations I’ve had but its loads (Anne 3.97)

Was it three or four I had? ‘Cos (sic) I can’t remember, I’m not sure if I had three or four done in B, and then I’ve had like a biopsy and well he said he was going to take a small area of skin…. and then I went in, in the November and I had another area removed (Ria 9.292-80)

The search to control emotions is also linked to a search for information. It is interesting to note that this applies to women with breast cancer (Galloway et al 1997; Rees and Bath 2000) as well as patients with other types of cancer (Leydon et al 2003).

6.2.2 Searching to control emotions: informational needs

The provision of patient information is considered to be an important element in helping people to cope with a diagnosis of cancer (Cassileth 1980; Fallowfield, Ford et al 1995) and research has shown that the vast majority of cancer patients want to be informed about their illness (Meredith, Symonds et al 1996). It is also one of the key recommendations of the NHS Cancer Plan and the New NHS: Providing a Patient-centred Service (Department of Health 2004a) states that all patients should have access to good information throughout the course of their illness.

The search for information for women, who knew they had a precancerous condition or were diagnosed with cancer of the vulva, was generally perceived as a negative experience. Eve was unable to find any information about VIN,

There’s not much information about it like. I got some books but none of them mentioned it. There was everything else but that (Eve 32.789-96)
At the time that the women had received their diagnosis but before they were admitted to hospital for treatment, some women were unable to find out any information,

*I took myself off down the library the one day and had a look through the books down there. [chuckles] But as I said it didn't really give me much information anyway* (Josie 23. 758-60)

*There was no kind of information about vulval cancer. No, it’s whether there’s no information or you don’t know where to look* (Stella 53.1781-3)

Sarah had searched for information on the internet, but had subsequently regretted it. Anne had also looked on the internet but was discouraged from doing so by her consultant,

*The one thing, which I did do, which in hindsight, I wouldn't have done, er... as soon as I knew what I'd got, I tried to read up everything I could possibly find about vulval cancer and it frightened me to death. But some of the things that we found on the internet and we read, I wished I had not. Because I found that more frightening than anything really. There are things that you are better not knowing (sic)* (Sarah 43.890-4, 43.989-991)

*I did go on the internet and have a look at things on the internet. There was a lot, I know there was a lot more from America on there than this country. I didn’t find it scary, I can remember telling the consultant gynaecology oncologist and he was saying oh that he hated the Net because you can just read all these different things on it and that but um no it didn’t bother me* (Anne 15.468-79)

The search for information has been noted in previous studies by Janda et al (2004); Green et al (2000); and Weijmar Schultz (1986). Carlsson and Strang (1996) studied 173 women who were newly diagnosed with gynaecological cancer, and those who had been treated up to 5 years previously. The findings indicated that information about cancer and how the disease and treatment would affect them in their daily lives was of primary importance. This was reinforced in findings by Ekwall et al (2003) who found that women with gynaecological cancer stressed the necessity for information concerning how the disease and treatment could influence their quality of every day life. In a study of ovarian cancer
patients (Jefferies 2002), 34% of women had not received any written information and 31% indicated that it had answered only a few of their questions.

Dirksen (2000), Lindop and Cannon (2001) and Landmark (2002) in their studies on women with breast cancer highlighted the women’s search for information about the disease process, treatment and investigative tests, noting a sense of a ‘lack of control’. Rees and Bath (2000) noted that women with breast cancer have distinct needs for information throughout their disease trajectory. The information enabled the women to understand more about the practicalities of attending for hospital consultations, and it facilitated a reduction in stress by assisting them to control their emotions. It also helped to reduce uncertainty (Dirksen 2000; Lindop and Cannon 2001; Landmark 2002). This has also been noted by Koch et al (2001) in a study on women with chronic illnesses.

Here, several women compared the ready availability of information regarding breast cancer with the lack of information about vulval cancer. This is probably due to the fact that VIN and cancer of the vulva are very uncommon, whereas the incidence of breast cancer in the UK is 43,700 per year. Anne referred to this, and expressed a sense of isolation due to the lack of information,

_There’s lots of information um on breast cancer and support but there’s nothing on this, you’re sort of on your own really (Anne 25.826-8)_

Comparisons with information about cancers affecting men were also made,

_When you go to the doctor’s surgery or even into the hospital it’s always breast cancer. If you have breast cancer there is more information about that (Eve 32.790)_
I mean you have all this about breasts, you have, I mean even men with the testicles, men have all about that, but still nothing to do with women for this bit (Denise 45.1515-20)

The need to search for information once a diagnosis of cancer of the vulva has been made implies that the health care professionals involved in the women’s care had not provided the appropriate or sufficient verbal or written information. This is reflected in the efforts that the women took to obtain further information. It is known that patients vary in how much information they want and this may change during their illness. They may also receive varying levels of information throughout the disease trajectory (Leydon et al 2000; Ekwall et al 2003).

Within this ‘search for information’ there was a sense that the women were articulating a need to raise awareness of vulval cancer through publicity for women in general and increased availability of relevant information. This is reflected in other aspects of this study as will be seen in chapters 7, 8 and 9.

6.3 Searching for meaning

The concept of searching also incorporates searching for meaning which Richer and Ezer (2000) suggest is an important element in the experience of patients with cancer. The concept of meaning has been defined from two main perspectives: situational meaning which is related to how individuals perceive specific events and existential meaning as it is related to the individual’s perception of her place in the world (Richer and Ezer 2000). These will be discussed below.
6.3.1 Situational meaning

Several women described how they searched to understand the reason for their symptoms and a definitive diagnosis. This was also noted by Frankl (1984) who described suffering as a trigger for a search for meaning to make sense of their lives. It has been shown in studies on women with chronic illnesses that it is important to know that an illness has a name as a diagnosis means that there is a possibility of treatment and cure and that there may be an existing body of knowledge about it (Kralik et al 2001).

6.3.2 Definitive diagnosis

Prior to a definitive diagnosis of cancer, the women were thought to have a fairly common infection of the vagina or the Bartholin’s gland. Other women were thought to have benign cysts. Seven of the women reported that they had presumed that their condition was caused by an infection, such as thrush, and had visited their GP to ask for a prescription,

*I thought it was thrush all the time (Eve 7.160)*

*I thought it was thrush (Leigh 2.47-8)*

As noted earlier in this chapter, thrush or candidiasis is the second most common vaginal infection, and it is estimated that up to 75 per cent of women will experience an episode of candidiasis and, of these, 50 per cent will have at least one further episode (Irving et al 1998). The symptoms of vulval itching or soreness corresponded with the symptoms experienced by these women. A course of treatment for thrush was seen as a way of treating the infection.

Other women had presented to their GP with a vulva swelling.
I had a lump. And I had a lot of trouble, I was in and out of hospital for months up here in X, they didn’t know what was wrong, couldn’t find nothing (sic) wrong (Julie 1.11-13, 26)

It was just like a pea size lump on me vulva, on the right hand side. And I actually thought it was one of those pimple things, like a Bartholin’s cyst. I thought it was one of them...He said um “Your lymph glands swell up because of the infection.” (Kay 1. 12-24)

The cause of the swelling was thought to be an infection of the Bartholin's gland. These glands produce a small amount of fluid that lubricates the vaginal lips. A swelling and infection is caused if a flap of skin grows over the opening of one of the glands and the fluid remains inside the gland, causing pain.

Searching for a diagnosis, 11 women had gone to see their GP on several occasions,

I had loads of different creams, you wouldn’t believe how many tubes of cream I’ve had over the last six, seven years, I must have tried everything in the book, and the books were thick and I must have tried every one. Every time I went back they give (sic) me something else (Stella 27.894)

They were just giving me different creams and whatever for thrush (Anne 60.1997-2006)

This may illustrate the women’s dependence on the doctor, as the majority of women appeared to return to the same doctor for further appointments. However the women felt that they were not being listened to,

They (the doctors) kept saying ‘We don’t know what it is’. I was messed about for months. It was like banging my head against a wall (Julie 3.83-4, 33.1095-9)

It does make you feel like that, as if you’re going sort of a bit you know funny because people don’t believe you, it makes you feel as if you’re not being believed and I say you feel there’s something wrong and people keep saying there’s not (Stella 8.244-7)
An interesting facet noted by Stella and Josie was in relation to the gender of the health care professional. This concerns the health care professional’s own experience of a similar condition or their personal knowledge. Stella excused the male doctor’s lack of empathy for her symptoms of itching by stating,

*And it’s very difficult to talk to a (male) doctor or whoever if they don’t understand what you’re saying ...It’s hard to describe to a, to somebody whose, especially a man who’s not got the bit anyway there to itch anyway (sic)* (Stella 27.908-9)

Josie also remarked,

*Like I said to the skin specialist you know I’d say to anybody, “You see how long you can go without scratching. You know if you have something that’s really irritating you.”* (Josie 47.1558-1560)

These comments highlight a lack of understanding and empathy, an issue further considered in chapter 9. Donna felt that she was being laughed at,

*I said I felt something was wrong but he (consultant gynaecologist) said it was all in my mind, and there was nothing wrong with me. He just laughed at me* (Donna 1.19-22)

Some women had been reassured by their GP and hospital consultants that their symptoms were probably due to a benign, non-cancerous, condition. Sarah, Julie and Kay remarked,

*He (the GP) said ‘I don’t think it is anything, it might be a cyst or something, He said ‘You’ve got nothing to worry about, it is just a wart or a cyst’* (Sarah 3.47, 4.81)

*Because I’d had a cyst previously and I’d had that removed, surgically removed. I suppose that’s why my GP kept saying “It’s another cyst.”* (Julie 55.1838-9)

*But my GP said it was a cyst, he give (sic) me some antibiotics and sent me away* (Kay 1.16-18)
Subsequently, some of the women felt ill-prepared for their eventual diagnosis of cancer. It is known that receiving a diagnosis of cancer can be shocking and overwhelming (Corner and Bailey 2001) but this may have been exacerbated because they had previously been told that they had a benign condition,

*I was expecting something minor as the doctor at the other hospital said it was all in my mind. I felt angry, really angry* (Donna 2.49-50, 3.66-68)

*Um he (consultant gynaecologist) did a biopsy and the next thing I knew I’d had, I had a phone call from the secretary asking me to go there (to the cancer centre). But nothing was said at the time that he (sic), it could have been what it was* (Denise 2.37-9)

Four women, Eve, Anne, Josie and Ria, were diagnosed with precancerous conditions prior to their diagnosis of vulva cancer. They searched for the meaning of their condition and were unaware that it may develop into invasive cancer of the vulva.

### 6.3.3 Significance of precancerous conditions

There are two precancerous conditions associated with the development of cancer of the vulva, see chapter 2. The chances of a woman with lichen sclerosis developing vulval cancer is between 4-15%, and even with treatment, up to 7% of women with VIN 3 are at risk of the disease progressing to cancer (Joura 2002). Josie had lichen sclerosis and remarked,

*But nobody had ever told me, my own doctor had never told me but till the Chinese doctor told me, he was a Western doctor as well as a, you know, a (specialist in Chinese medicine) doctor, um that lichen sclerosis can be precancerous. “Cos he was the one that told me “You must get this looked at every year,” but nobody else had ever told me that, not my own doctor, not the skin specialists, nobody had ever told me that before* (Josie 6.200-3)
Eve and Ria had a history of the precancerous condition VIN 3. They recalled,

> After that they found out that I had the VIN so I went for some more tests and they took biopsies. They done (sic) more surgery and then they had to do the vulva (Eve 3.64-66)

> And he (GP) said to me that um it (VIN) was a serious condition, but not to worry about it: it can take a long time for it ever to develop if it ever does. In a lot of women apparently it doesn’t develop into cancer, it stays at a precancerous level and sometimes it even goes away (Ria 4.104-8)

Ria subsequently felt confused by the histology reports following the removal of vulval tissue, as to whether she had invasive cancer or VIN 3, the precancerous condition.

> And I did say to him, “Well what does that mean? Does that mean I’ve got cancer or does that mean I’ve got VIN 3?” And he said “Well you’re marginal.” And I thought oh right, what does that mean? When you, I first saw him he thought that I was just as likely to get breast cancer as I was to ever have cancer here [laughs] and now he was telling me I’ve got cancerous cells in two of the biopsies, one was superficial invasion and one was cancerous cells, doesn’t tell me anything (Ria 8.242-53)

Eve was also unaware of the natural history of VIN 3. She hoped that her operations would prevent the VIN from developing any further, but this did not seem to be happening in her case,

> It seemed that the more they were taking it away, the quicker it was coming back. He (consultant gynaecology oncologist) said that some patients only had one operation and then it had gone but I’ve had loads (Eve 12.278-9, 35.848-90)

Likes et al (2007) reported that there is 8-19% incidence of cancer after excision in women initially diagnosed with VIN. It may also develop in women who have previously had surgery for VIN, independently from the extent of the removed tissue or technique used, including total vulvectomy (Preti et al 2005). Modesitt et al (1998) reported that invasive disease is often seen in association with pre-invasive disease in younger women.
6.3.4 Existential meaning

The search for meaning is also linked to the way in which people view themselves in relation to their set of philosophical beliefs and assumptions about how the world operates or their world view, and this is referred to as existential meaning (Thompson and Janigian 1995). A diagnosis of cancer may precipitate strong emotional reactions as it is associated with contagion, suffering, pain and death (Sontag 1991). Although it is part of our culture, it continues to be feared more than any other disease and whilst cancer is part of the everyday lives of thousands of people, it does not seem to be ‘everyday’ at all, but remains a frightening disease (Corner and Bailey 2001). Herzlich and Pierret (1987) discuss the notion that while cancer is an illness of an individual, it can only be seen in relation to society as a whole. Although cancer affects 1:3 of the population, a frequent response to a diagnosis of cancer is ‘Why me?’ (Kubler-Ross 1969). This sentiment was expressed by several of the women in this study. For example, Laura associated a diagnosis of cancer with older people. She was aged 27, and remarked,

Sometimes, in the, in the early days I used to think why me? It’s OAPs (old aged pensioners) who have cancer (Laura 43.1436, 44.1485)

Sarah also remarked,

No, I mean you do go through your ups and downs, you do get a bit (down) from time to time, and I think why does this happen? (Sarah 60.1368-70)

Herzlich and Pierret (1987) emphasise that some people see themselves as predisposed to cancer, because of their family history. Members of Stella’s family also had cancer and she remarked,
Sometimes I think why me, why do I have to have it all? I think it’s just unfortunate that two or three of us in our family that have got it. Why me? (Stella 40.1340-3)

Anne did not have anyone in her family with the disease and thought it would never happen to her,

I didn’t know um I suppose what to do with myself and oh why me and so yeah because I, coming home I was crying. You um, I suppose you tend to think it would never happen to me and there’s, there’s no cancer in my family (Anne 23.746, 39.1319)

Anne felt that this still applied to her, even after she was diagnosed with lichen sclerosis. She felt reassured by her regular check ups that her precancerous condition would not progress to invasive cancer,

I’m the type of person that just convinced myself that nothing’s gonna happen, nothing’s wrong. And even when it was precancerous I was just thinking people get precancerous cells and things like that. And I was just thinking oh you know whip it away and it’ll be all right. The assurances at that time was you know “We’ve caught it early, it won’t sort of progress,” and then I was on regular check-ups and whatever (Anne 5.157-60, 2.53-54)

Denise felt that she herself was responsible for her diagnosis. She said,

I keep thinking it’s my fault that me (sic) body’s done this, you know, my fault. ‘Cos there’s so many things gone wrong (sic). I never catch colds, I don’t have coughs and colds, I don’t have the easy stuff, I seem to get the major things and I think well why? (Denise 32.1078-82, 32.1066-8)

While Denise did not wish anyone else to have a diagnosis of cancer, her sense of anger was reflected in her question,

What I feel angry about is why’s it happened to me and why doesn’t it happen to, not that I would want it to happen to other people, but I feel like why has all this happened to me? (Denise 32.1074-8)
However Ria felt unable to ask ‘Why me?’ as she would not want anyone else to have the same condition,

_Even my worst enemy in the world I wouldn't wish it on. So I can’t say “why me?” Why does it happen to anybody else? (Ria 36.1871-2)_

The women’s sense of searching from the time that they first realised that they had a problem has also given rise to the notion that there was a sense of pace throughout their searching activities.

### 6.4 Searching: the time element

Josie had had symptoms of itching for 30 years and recalled that although she had tried numerous sources of help for her symptoms, at times she was resigned to her condition and the searching aspect was conducted at a slower rate. She noted,

_With visits in between to the skin, skin specialists who um again just did the same thing... but nothing helped as I say it would do it for a time, but in the end even they stopped working so half the time I didn’t bother going back, I just used to put up with it as such (Josie 1.25-29)_

Conversely, Anne and Laura described a sense of urgency in their searching for relief as they were unable to cope with their symptoms any longer. Laura had been living abroad, and saw a gynaecologist as soon as she returned to the UK,

_I just thought it was um, I don’t know it was just driving me mad, I just, the itching was just really, really driving me mad (Anne 2.43-44)_

_When I came back to England I went to see a gynaecologist. I had to have tablets and creams (for thrush) but nothing seemed to work and it seemed to keep coming back (Laura 6.178, 2.43-49)
The sense of pace and timing is also reflected in the way that the women were referred to the gynaecology oncology consultant. Nine of the women encountered a delay between the time that they first noticed the symptoms and the time that they were referred to a cancer centre. The NHS Cancer Plan (2000) has stipulated that anyone who is suspected of having cancer should be seen within 2 weeks of seeing their GP, but the women had experienced their symptoms for between several months and several years before they were referred to a consultant gynaecology oncologist. Leydon and Coleman (2000) also noted a delay in diagnosis in a study of 17 cancer patients.

*It was about 9 months before I was eventually diagnosed* (Denise 4.104-7)

*It was 4 years from the time of my first symptoms (before I was diagnosed)* (Donna 2.42)

As noted earlier in this chapter, many respondents described how they had been seen by the GP on several occasions over a period of time,

*The doctor was giving me thrush cream (my own doctor here) and then when she said that it couldn’t be thrush all that length of time. I went to her and so she had a look and said that it didn’t look right* (Eve 7.160-2)

*Because I was pregnant and I was constantly itching just constantly itching, I felt very, very sore. And I went to him and no examination took place, I was given because I was pregnant it was an automatic assumption I had thrush, so I had the Canisten. Went home, put that on religiously, no improvement so I went back and it was probably three or four months of just going back and forward to the doctor getting no response whatsoever; and nobody examined me* (Ria 1.22-28)

*My GP said it was a cyst, he give (sic) me some antibiotics and sent me away. He said “Well, if it hasn’t gone in a couple of weeks, then come back to me.” So of course it hadn’t gone and by then it was quite a bit bigger, and my lymph glands were swollen on the right hand side. I went back again, he give me (sic) some more antibiotics* (Kay 1.13-22)
This finding supports an earlier study by Coleman and Santoso (2000) who noted that unfamiliarity with the disease and reluctance on the part of the doctor to perform an examination can add to a delay. Addressing this, other women had appointments at their local district general hospital,

*I was having investigations over 12 months: it was a long time. They kept saying ‘We don’t know what it is’. I was messed about for months (Julie 1.26, 3.83-4)*

*For 4-5 years I had gone to Hospital X (Stella 1.17-19)*

However Donna had referred herself for a second opinion,

*So I went to see the GP and he sent me to A. and then to B. He thought I would just need a bit of laser treatment. So I had the laser treatment and he said it won’t come back but it did, and I had more laser treatment. It was a nuisance, not feeling right. It was a real pain and it was a drag to have to keep going to the hospital. The GP sent me to an Obstetrician at A. I knew it wasn’t right so I asked for a second opinion, and so I went to X (Donna 1.21-4)*

The NHS Cancer Plan (2000) stipulates that the Health Service should treat patients with cancer within 62 days of their first referral, or 31 days of being told their diagnosis. However 2 respondents experienced a further delay in between having the biopsies taken and being told that they had a diagnosis of vulval cancer,

*I saw a doctor who said I needed a biopsy straight away so they admitted me in to X in the November and then it was the March when I went back and they said it was a cancerous lump (Julie 1.14-18)*

*I had the biopsy in August: my appointment was in the October (Leigh 4.108-9)*

The process of searching is also linked to resolution, whereby a person makes sense of the phenomenon they have experienced, and accommodation where they are able to accept their experience and resolutions. Here several women have been able to ‘move on’ after
their diagnosis and treatment and have resumed their previous activities. For others, the concept of searching is an on-going process as they continue to experience persistent symptoms or after-effects from surgery and thus their search for resolution continues. Aspects of this are considered in chapter 8, All Change.

6.5. Summary

This chapter has described the concept of Searching, which emerged from the analysis of the data. It has been shown to have both physical and psychological components, leading to an over-riding sense of futility as the women looked for ways of managing their symptoms, while seeking medical advice and appropriate treatment. There is a sense that the process of searching took place over a passage of time, from the initial presentation of symptoms to diagnosis and treatment.

The impact of searching was an isolating experience as for some women the search took place over a number of months and years. The perception of isolation is reflected in the concept of Aloneness and is considered in the following chapter.
CHAPTER 7
ALONENESS

7.1 Introduction

This chapter discusses the concept of ‘Aloneness’ which is characterised by a want of nearness, normality, awareness and openness. Aloneness for want of nearness is patterned in the way that the women had to be treated in a cancer centre according to the Government directives (Department of Health 1999). Van Manen (1990, p102) states that ‘we know the space in which we find ourselves affects the way we feel’. Some of the women were cared for in a hospital many miles from home and this created a sense of aloneness with the associated difficulty in travelling for family and friends. Most women stayed in hospital longer than other in-patients adding to their sense of isolation. Aloneness for want of normality is related to the symptoms of constant itching which were exacerbated by sexual intercourse and this led to a withdrawal of intimacy with their husband/partner. Since cancer of the vulva is a rare condition, the women felt a sense of aloneness for want of awareness, as the health care professionals involved in their care and family and friends showed a lack of knowledge about their disease. This applied to the women with precancerous conditions as well as those who had primary tumours of the vulva. Although there appears to be evidence in the literature about feelings of isolation that develop once a diagnosis of cancer has been made (Spiegel 1997), there is less evidence describing how the search for treatment, and coping with distressing symptoms have an impact prior to a histological confirmation of cancer.

Aloneness for want of openness is linked to a lack of shared experiences. Unlike women with more common cancers, such as breast cancer, these women were unable to find solace
within a shared experience with other women with the same diagnosis. The personal nature of the site of the disease made women reluctant to discuss it with their family and friends because of feelings of embarrassment. There was also a sense of isolation exacerbated for some by the referral pathways via genito-urinary clinics and the stigma associated with this.

The concept of Aloneness for want of nearness, normality, awareness and openness is shown in the following diagram and will be discussed in turn.

**Figure 5: The Concept of Aloneness**
7.2 Aloneness: for want of nearness

Aloneness for want of nearness refers to the geographical location of the hospital where the women received their in-patient treatment. Kay, Leigh, Ria and Julie were referred to a hospital which was over 100 miles from home. Although there was a cancer centre in closer proximity to their homes, they were referred both because of the complexity of their condition and due to a long waiting list. Julie remarked that she would have travelled ‘anywhere’ for her treatment,

_And then I went back to see the doctor up here and they said it was cancer, they’d got a big waiting list up here then things moved pretty quick once I saw the consultant gynaecology oncologist in X. I said ‘No I’ll go anywhere as long as I can get rid of it’ you know (Travelling) really didn’t come into it- I’d have gone anywhere (Julie 3.101-3, 4.102-3, 5.144-8)_

Ria was also seen in the private sector initially as she had asked her GP to refer her to another consultant for a second opinion. She was willing to travel from Wales to see him,

_My mum and dad weren’t happy for me to wait to see this Dr C (on the NHS), so my mum and dad paid for me to go and see him in a private clinic privately (Ria 4.129-131)_

The distance in travelling also had an impact on how much the friends and family were able to visit the women while they were in-patients. Leigh was still able to see her visitors as they had their own transport, whereas Kay did not have many visitors as they relied on public transport, and she felt isolated and alone,

_I still got visitors…its 100 miles (Leigh 7.223, 230) I didn’t get many visitors. It was after I had had the surgery I was quite down. I remember one day I didn’t have any visitors and I just burst into tears (Kay 11.370-2)_
Aloneness for want of nearness has a geographical implication as already discussed, but this is also linked to the nearness associated with a sexual relationship and the isolation that may develop subsequently if this nearness is no longer part of their previous experience. The impact on sexual function is one of the key issues that emerged from the findings, and this is discussed in Aloneness: for want of normality.

7.3 Aloneness: for want of normality

Several previous studies have used a validated tool to assess sexual functioning, for example the Derogatis Sexual Functioning Inventory (Derogatis and Melisaratos 1979) was utilised by Andersen et al (1988) and Stellman et al (1984), whilst others developed tools specifically for the purpose of their study (van de Wiel et al 1990; Willibrord et al 1990). I did not use a specific tool to measure sexual functioning but relied on the women’s own subjective accounts of pre and post operative functioning as did Andersen et al (1986) and Andersen et al (1988).

Eleven women described their sexual relationship as ‘normal’ before the development of their symptoms of vulval cancer. They had been married or with their partner for between 3½ and 30 years, with an average length of partnership of 12.5 years. The other two women, Irene and Leigh, were not sexually active as Irene had co-morbidity problems and Leigh was divorced and did not have a sexual partner. The physical symptoms that have already been described in chapters 5 and 6 affected their sexual function from the onset of their symptoms and led to reduced sexual intimacy with their husband/partner. Several women noted,

_As I started to notice my symptoms, like the itching, I said ‘No, let’s not bother’_
(with sexual intercourse) (Donna 28.683-6)

We couldn’t do a lot of sex (before the operation) because obviously I was really sore, but things were fine. I became more sore (sic) and then things got more difficult (Laura 47.1565)

Ria has on-going symptoms from VIN 3 which has affected her sexual function,

It’s got to a point now, like particularly over the last month, that I am that uncomfortable I don’t want sex. I just don’t want it because it hurts me and I like my sex a lot... I’ve only been married for three and a half years, at the moment it’s quite important to me (Ria 10.322-6)

Josie also recalled that since her symptoms became worse after intercourse, she would rather not have intercourse. It increased her sense of isolation,

It used to irritate it; (sic) sex used to irritate it and like the sperm would be there afterwards. So I just got to the way of thinking oh it ain’t (sic) worth it, you know. Sex has never been of much importance to me, because of all the problems I’ve had (Josie 43.1434-43)

Previous studies also noted the onset of the symptoms of vulva cancer was associated with a reduction in sexual intimacy (Andreasson et al 1986; Andersen et al 1988; Willibrord et al 1990; Corney et al 1992; Green et al 2000; Likes et al 2007). However Willibrord et al (1990) noted that there was no difference between the sexual functioning of the age-matched non patient control group and the patient group before treatment despite the physical symptoms of itching, dyspareunia and vaginal discharge. Likes et al (2007) also found that there was no significant association between sexual function and vulvar symptoms prior to surgery.

The surgery to remove the vulval cancer has had an impact on the sexual function for 9/13 women in the study, to a greater or lesser extent. This is shown in the Table 14.
Table 14: Ability of women to achieve sexual intercourse

<table>
<thead>
<tr>
<th>Name of Respondent</th>
<th>Unable to achieve sexual intercourse following surgery</th>
<th>Occasional sexual intercourse</th>
<th>Perseverance needed to achieve sexual intercourse</th>
<th>Satisfactory return to previous sexual relationship</th>
<th>Not sexually active</th>
</tr>
</thead>
<tbody>
<tr>
<td>Laura</td>
<td>X</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Josie</td>
<td>X</td>
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<td></td>
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<tr>
<td>Denise</td>
<td>X</td>
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<tr>
<td>Eve</td>
<td></td>
<td>X</td>
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</tr>
<tr>
<td>Ria</td>
<td></td>
<td>X</td>
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<tr>
<td>Julie</td>
<td></td>
<td>X</td>
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</tr>
<tr>
<td>Donna</td>
<td></td>
<td></td>
<td></td>
<td>X</td>
<td></td>
</tr>
<tr>
<td>Stella</td>
<td></td>
<td></td>
<td></td>
<td>X</td>
<td></td>
</tr>
<tr>
<td>Kay</td>
<td></td>
<td></td>
<td></td>
<td>X</td>
<td></td>
</tr>
<tr>
<td>Sarah</td>
<td></td>
<td></td>
<td></td>
<td>X</td>
<td></td>
</tr>
<tr>
<td>Anne</td>
<td></td>
<td></td>
<td></td>
<td>X</td>
<td></td>
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<tr>
<td>Irene</td>
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<td>X</td>
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<tr>
<td>Leigh</td>
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<td>X</td>
</tr>
</tbody>
</table>

Three of the 13 women, Laura, Josie and Denise, were unable to have sexual intercourse after their surgery, either for a physical reason or due to a psychological effect such as loss of libido. They had all undergone a radical vulvectomy. This number is fewer than might have been expected on the basis of previous findings. Moth et al (1983) noted that 7/15 were unable to have intercourse, and Andreasson et al (1986) noted that 8/15 were unable to achieve sexual intercourse following their vulvectomy. Tamburini et al (1986) reported a slightly higher figure of 60% of women (n=11) who were not sexually active. Andersen and Hacker (1983) also noted that the women reported a marked reduction in sexual
activity but do not indicate the number involved. In contrast, Weijmar Schultz et al (1986) conducted a study on 10 women two years following their surgery and reported that 70% were able to achieve sexual intercourse. All of these women had undergone a radical or partial vulvectomy (Weijmar Schultz et al 1986).

At the time of the interviews 3 women, Eve, Julie and Ria, are able to have intercourse occasionally, approximately every 2-4 weeks. Two of these women, Eve and Ria, had a history of VIN 3 and had undergone several operations prior to the removal of invasive cancer. Studies by Andersen et al (1988), Green et al (2000) and Likes et al (2007) have shown that sexual function decreases as the excision size increases, and therefore the number of operations that the women undergo may also influence sexual function post operatively by compounding this effect.

Three women, Donna, Stella and Kay, were able to resume sexual intercourse at the time of the interview, but they and their husband/partner have had to persevere to achieve this. Regarding the other four women in the study, Anne and Sarah, were able to resume their sexual relationship fairly easily while Irene and Leigh were not sexually active as noted earlier.

The physical and psychological determinant factors involved in resuming sexual function were noted by Weijmar Schultz et al (1990). The physical impairments from surgery include vaginal stenosis, irritation of the mucosa and inadequate lubrication. There may also be alterations in genital sensitivity. These are discussed in turn.
**Physical changes associated with altered sexual function**

Four women, Laura, Eve, Ria, and Julie, are either unable to have intercourse, or to do so only occasionally, for a physical reason. Laura, who was aged 27 at the time of her interview, is unable to have sexual intercourse because she developed vaginal stenosis and adhesions in her vagina post-operatively. She now requires further surgery to remedy this, 

*We haven’t done anything (have intercourse) because basically the area they operated on has scarred over. There’s no, there’s no point when I can’t get the small dilators in there’s no point in... (sic) And I’d tried the dilator they gave me, but the next size I can’t use because it’s... (sic) the consultant gynaecology oncologist said it’s scarred over too much that, for it to be used, you’d need another operation which at the moment fills me with a whole load of dread, nothing that I really want to do at the minute (Laura 47.1567-8, 48.1619-20, 47.1572-9)*

This has made Laura feel frustrated,

*It’s very frustrating I’m a little bit cross, because I think if it had been, if I’d had them (the dilators) sooner I wouldn’t be in the position I’m in now (Laura 48.1609, 49.1646).*

A narrowing of the vaginal introitus was noted in 10/25 women by Andreasson et al (1986), 9/15 women by Moth et al (1983) and 2/18 by Thuesen et al (1992). This could have been remedied by a minor operation to widen the introitus and remove the scar tissue. Some women declined as Laura did, because of a fear of further surgery while others were reluctant to discuss this with the doctor involved in their care as noted in chapter 2, page 43.

Julie had had one half of her vulva removed, and she remarked that this makes her feel ‘lop-sided’,
It feels different to me. Like with only having the one lip on the one side it just feels every, everything’s that way, everything’s pushing towards that side (Julie 43. 1435-1440)

Donna also recalled that although the vulva area had healed up following her wound infection, she was worried that the area may come apart again. Her vagina was now much nearer to her anus and everything was physically different,

Everything’s back to normal, but everything is closer than it was before. It’s not just not being told, you don’t know how it’s going to feel or what it’s like inside. It could have pulled it all apart (Donna 29. 719-722)

**Loss of sexual sensation**

Some women experienced a loss of sexual sensation which has impacted on their relationship. Kay required radiotherapy following her surgery and described the loss of sensation in the pelvic and vulval area due to fibrosis and lymphoedema,

When my husband gets into the vagina, that’s all right because my vagina’s still there, but they had to remove half of all the tissue on that side, so it’s missing completely. Sometimes I do, and sometimes I don’t, feel anything. But I think it’s as hard as a brick (Kay 44.1465-9)

Josie had also suffered from a loss of sensation, following her radical vulvectomy,

The sensations are different because you haven’t got any, I suppose, outside stimulation, there’s numbness round there as well, like round my legs (Josie 66.2198, 2211)

A loss of sexual sensation was noted by Andersen and Hacker (1983) and Andreasson et al (1986) who reported that up to 70% of women may be affected. In particular, Andersen and Hacker (1983) reported that some women were unsure if penile penetration had taken place. Negative sensations during sexual intercourse were also reported by Weijmar
Schultz (1995) who described them as an ‘alienation from the genital area’. In contrast, Willibrord et al (1990) recorded that all the women in their study (n =7) mentioned that there may be genital numbness in the first 12 months after surgery, but sensitivity returns especially in the area of the clitoris.

**Psychological changes associated with sexual function**

Sexual function has been shown to be affected by physical changes. There is also a psychological component to sexual function since it is an integral component of the relationship between the woman and her husband/partner.

Psychological impairment following vulva surgery has been noted by Andersen and Hacker (1983); Moth et al (1983); Stellman et al (1984); Andreasson et al (1986); Tamburini et al (1986); Andersen et al (1988); Thuesen et al (1992); Green et al (2000) Janda et al (2004). Anderson and Wolf (1986) noted the impact of psychological changes on sexual function in patients with physical illnesses. These may include:

- Threat to self esteem, such as mood disturbances, disturbances of sexual identity and alterations to body image
- Threat to personal control over body functions
- Threat to intimacy
- Threat to generativity, including impairment of fertility and fear of transmitting the disease or dying before their child has grown up (Anderson and Wolf 1986)

These will be considered further below.
Threat to self-esteem

Several women stated that their sexual relationship had ended following their surgery. Denise, who had been married for 30 years, indicated that her sex life had now ceased because she felt ‘different’ now, both physically and emotionally,

So it sort of, but it had slowed down, our sex life, but we still, we still had a sex life, but um there’s been nothing since the last op, well since the first operation. Well I feel different... I felt different and I’m afraid that’s, it’ll be a no-no I think now... can’t say we can have any sex life anyway (Denise 35.1169-1177)

It’s physical, and also I think it’s emotional as well, think it’s both, it’s both, it’s not just the one, think it’s the whole impact it has on you. And it does, it has a big impact, so (Denise 36.1194-99)

Irene also noted that although she was not sexually active, she would not have resumed following the surgery as she is different anatomically now,

It’s just like I don’t wanna know (about having sex), that’s it. It probably would have finished me if it was though. Because you’re missing the one bit like you know (Irene 32.1077-82)

Loss of libido

Loss of libido was reported by 9 women. This varied from a short term consequence for Donna and Stella, whose libido gradually returned over a period of several months, to a long term consequence which still affected some of the women after a number of years.

For example, Eve who had her surgery 2 years and 11 months previously said,

It’s not as bad as it was but you just can’t do it (have intercourse) like every single day of the week, you’ve got no chance of doing it. I just don’t really bother (Eve 28.669-70, 681)
Julie and Kay also described a loss of libido following their surgery because of the
discomfort they are in.

*Because it feels different to me now. Sometimes I’m just that tired or in pain I can’t
get comfortable and, just, the desire’s there still sometimes but not so much (Julie
44.1457-1471)*

*I’ve not been interested because it’s been so um, uncomfortable (Kay 43.1422)*

This has had the effect of increasing their feelings of aloneness as they were now only able
to have intercourse occasionally. Loss of libido was reported in 9/13 women by Moth et al
(1983) and 13/19 women by Andreasson et al (1986). Van de Wiel (1990) also noted that
3/6 women had a moderate reduction in libido, 12 months after their surgery. Weijmar
Schultz (1986) also reported this without providing further details. In comparison,
Andersen et al (1988) reported that the women in their study did not lose their desire for
sexual activity. This may be related to other differences, for example the ages of the
women involved.

**Threat to personal control over bodily functions**

Ria and Donna described the impact that sexual intercourse had on bodily functions. Ria
experiences a sensation that she needs to pass urine,

*Every time we have sex ...now its got to a point that I get this sensation because if
I’ve got pain there I need a wee as well (Ria 61., 2049-51)*

Ria stated that even if she empties her bladder immediately prior to intercourse, she
develops the sensation that she is about to pass urine and she and her husband have to stop
their activity so she can go to the toilet. This had an impact on the length of time that they
were able to enjoy intercourse and also on the quality as Ria was unable to achieve an orgasm,

*I need a wee (to pass urine) so I can’t relax to have an orgasm either (Ria 61.2040-41)*

Donna had had much of her perineal tissue removed and there was now very little space between her vagina and her anus. She was frightened that the physical changes might result in her having anal intercourse,

*There is only a little space between my fanny and my bum, so we call it a ‘fum’. It took a long time (to resume sexual relationship). I did my utmost to avoid it; I thought what if Mick slips? It’s the thought of having anal intercourse. I don’t like it, I’ve never done it, and I never want to. It took a long time to get back to having sex again (Donna 28.696-70)*

Donna’s fears had delayed the resumption of intercourse. Post operatively her wound had taken a long time to heal and she was also frightened that the perineal tissue would break down again.

*Even though it had healed, I didn’t want to, not after that operation. I didn’t want to try in case it all fell apart (Donna 28.687-692)*

**Threat to intimacy**

Nine of the women described a loss of intimacy following the surgery. This was described as a loss of touching after the operation, for example,

*You know, and obviously in the, sort of, weeks afterwards, you know, we, he didn't touch me. You know it took a while to get back to having sex again (Sarah 47.1068-70)*
And everything that I couldn’t let him touch with, well he wouldn’t ever have done anyway, because he would have died before he’d wanted to hurt me... (Josie 46. 1532-6, 1540-42, 1546)

It was all, it was different. I mean I’ve, I’m quite, quite strong willed, so I got over the shock, my partner, it took him a while to get over it, um it does cause, it didn’t, it doesn’t cause problems now, it did at first because he couldn’t touch it, he couldn’t do anything. It stops quite a lot of your sex life. It changes that (Stella 5.160-3)

**Grieving for previous sexual function**

Several of the women were grieving for their previous sex life. Eve, Ria and Julie made comparisons between their sexual activity previously and at the time of the interview,

You can’t do it (sexual intercourse). When you have all the operations you don’t have a sex life at all, even when the stitches come out it’s still sore, you can’t do nothing (sic) until it starts to heal up a lot more. Still now you can’t (Eve 27.654, 27.658-60)

Excellent we had a fantastic sex life, having sex three or four times a day and it probably carried on like that until I had my third operation. We have sex probably about once a fortnight for ten minutes (now) [laughs] (Ria (57.1896-9, 62.2077)

We had a good active sex life, but not now. It (intercourse) is once a month, if we’re lucky at the moment. It used to be every night. [laughs]. Hmm. So it is a big difference (Julie 43. 1426-33, 44.1455-67)

Several women would have preferred to remain sexually active but instead they had become resigned to the end of their sexual life. For example Denise remarked,

I’m afraid that’s, it’ll be a no-no I think now. So I think it’s finished, which I think is a little sad, I probably do (miss it) a bit. Well not, not a load, I’m not sort of twenty five and rampant like, you know, but, yeah I do. Yeah I do a bit. I do, it’s a bit sad isn’t it, well we’ve been together a long time, so it’s not like you’re sort of in the first blush of romance, but you know, it was always sort of there like, you know (Denise 35.1151-4, 36.1201-5)

This finding was also noted by Andersen and Hacker (1983). Stellman et al (1984) reported that 0/9 women were unable to have intercourse after their surgery and 5 women were dissatisfied with this. Kay was concerned that her sexual function may not improve in
the future. She had developed lymphoedema which resulted in swelling and loss of sensation,

We used to have a good sex life in that way. Um that, that does frustrate me a bit because I think well it might always be like this. Um, because the top half of me is very swollen and round the tops of my legs with the lymphoedema um I can’t feel anything (Kay 43.1429-31)

There may also be an association between the size of the excision of vulva tissue and the woman’s ability to achieve sexual intercourse function post-operatively. Table 15 was drawn to illustrate this pattern.
Table 15: Pattern to show the ability to have intercourse and the extent of the surgery

<table>
<thead>
<tr>
<th>Name of Respondent</th>
<th>Unable to achieve sexual intercourse following surgery</th>
<th>Occasional sexual intercourse</th>
<th>Perseverance needed to achieve sexual intercourse</th>
<th>Satisfactory return to previous sexual relationship</th>
<th>Extent of surgery</th>
</tr>
</thead>
<tbody>
<tr>
<td>Laura</td>
<td>X</td>
<td></td>
<td></td>
<td></td>
<td>RV, BGND</td>
</tr>
<tr>
<td>Josie</td>
<td>X</td>
<td></td>
<td></td>
<td></td>
<td>RV</td>
</tr>
<tr>
<td>Denise</td>
<td>X</td>
<td></td>
<td></td>
<td></td>
<td>RV</td>
</tr>
<tr>
<td>Eve</td>
<td>X</td>
<td></td>
<td></td>
<td></td>
<td>WLE</td>
</tr>
<tr>
<td>Ria</td>
<td>X</td>
<td></td>
<td></td>
<td></td>
<td>WLE</td>
</tr>
<tr>
<td>Julie</td>
<td>X</td>
<td></td>
<td></td>
<td></td>
<td>AHV, IGND</td>
</tr>
<tr>
<td>Donna</td>
<td>X</td>
<td></td>
<td></td>
<td></td>
<td>RV, BGND</td>
</tr>
<tr>
<td>Stella</td>
<td>X</td>
<td></td>
<td></td>
<td></td>
<td>AHV</td>
</tr>
<tr>
<td>Kay</td>
<td>X</td>
<td></td>
<td></td>
<td></td>
<td>RV, BGND</td>
</tr>
<tr>
<td>Sarah</td>
<td>X</td>
<td></td>
<td></td>
<td></td>
<td>WLE, IGND</td>
</tr>
<tr>
<td>Anne</td>
<td>X</td>
<td></td>
<td></td>
<td></td>
<td>RV, BGND</td>
</tr>
</tbody>
</table>

**Key**

- **RV** Radical vulvectomy, to remove the labia majora and minora, the clitoris and 2 cm area of surrounding healthy tissue
- **WLE** Wide local excision of the vulva, to remove the abnormal tissue and 2 cm area of surrounding healthy tissue
- **AHV** Anterior hemi-vulvectomy to remove the anterior area of the vulva
- **BGND** Bilateral groin node dissection, to remove the lymph nodes in both groins
- **IGND** Ipsilateral groin node dissection, to remove the lymph nodes in one groin only
This data appears to show that the extent of the surgery is not related to the post operative sexual function of these women. As noted in chapter 2, there are inconsistencies in the literature to determine whether the size of the excision has a role in sexual function outcomes. Andersen and Hacker (1983), Andersen et al (1986), Andreasson et al 1992, and Likes et al (2007) report that sexual dysfunction increases with the size of the excision, while Green et al (2000) note that all women undergoing vulva surgery are at risk of sexual dysfunction, irrespective of the size of the excision.

The effect of altered sexual function on the husband/partner

Most of the women reported that although their husband/partner was supportive, the impact on their changed sexual function had also affected them. For example, Stella recalled that the strength of her relationship with her partner had been vital,

> You wouldn’t get through it if you’d got a partner who didn’t or was upset by it because it’s hard enough to cope with the difference in yourself without somebody else having to cope with it as well. And I think it is difficult. We’re getting there. That’s the worst thing for us, that our sex life is different. It’s not so bad now because we’re getting over it and things are getting better um but at first it was just well, if we weren’t as strong as we are we wouldn’t be together (Stella 26.871-83, 41.1374, 42.1409)

Josie recalled,

> I suppose it was strange after the operation, more on (my husband’s) point of view apart from mine, he, he still thinks he’s gonna (sic) hurt me, although I keep telling him he can’t, it doesn’t hurt, it won’t hurt. He’s still got it in his head that it might (Josie 43.1444-6)

Pleasing the partner

In the study by van de Wiel et al (1990), the concept of ‘pleasing the partner’ was discussed. This concept is based on the Equity theory (Walster et al 1986) and is based on
the premise that a woman who had received a lot of emotional support from her partner during and after her treatment will try to restore the balance by resuming intercourse, in spite of her own feelings. Similar findings were reported by Weijmar Schultz et al (1986).

This was shown by several of the women. Kay and Donna stated,

*We’ve been sort of, well I’d say um, my husband has been fed up because I’ve not been interested because it’s been so um, uncomfortable, Well I would say we have sex on a daily basis (now) (Kay 42.1422-3, 45.1510)*

*But I kept saying ‘No’. Eventually (my husband) asked the consultant gynaecology oncologist at one of my check ups when we could. He moans that he doesn’t get enough (sex), but he has always had a higher sex drive than me. We probably do it as often as we did before, sometimes more often. It was a hurdle doing it the first time (Donna, 29.712-6)*

**Partner pleasing his wife/partner**

The opposite sentiment from ‘pleasing the partner’ to ‘the partner pleasing his wife/partner’ was expressed by 4 women. Denise and Josie recalled that their husbands were afraid of hurting them when they resumed intercourse,

*I think he was frightened of hurting me. I think he was very apprehensive as well, you know it’s (intercourse) just sort of stopped (Denise 35.1179, 35. 1776)*

*But I suppose I’m lucky he understands. He’s not pushing or pressuring or looking elsewhere. Because I suppose it could happen. I’m lucky in that respect. He understands and he, he’s patient and what have you (Julie 43. 1445-51)*

Ria is only able to have intercourse fortnightly now, and was concerned how this would impact on her marriage as she had only been married for 3½ years.

*You know it isn’t a one-way street; it isn’t my feelings and my feelings alone. And he’s bound to be still getting sexually aroused and if he’s not getting it here will he ever be tempted so I worry about that aspect of the relationship because like we’re not, we haven’t been married that long, when sex should still be quite an important role in our relationship its become a painful thing so its something that you avoid (Ria 63.2094-99)*
Ria’s husband though was supportive,

_\textit{I’ve been very fortunate and always had a good sex life with my husband and a very open sex life so that I am lucky in the fact that if I am in discomfort or I’m in pain I can tell him and he’ll stop} (Ria 57.1920-22)

**Persevering to resume previous sexual function**

Two women, Donna and Stella, have had to persevere to regain their sexual function following their surgery. Initially Donna tried to avoid intercourse because of her altered anatomy. As discussed earlier, she has lost much of her perineal tissue, and her vagina is now very close to her anus,

_\textit{But I kept saying ‘No’ … I was bothered that it might hurt. Everything’s back to normal, but everything is closer than it was before I didn’t want to try in case it all fell apart. It took a long time to get back to having sex again} (Donna 28.692-6)

Donna’s husband tried to reassure her,

_\textit{He said ‘It doesn’t matter what it looks like, everything will be okay’} (Donna 34.726)

Stella also remarked on her altered anatomy,

_\textit{Everything seems to be you know, the internal organs, have moved over a little bit because everything I do, when we have sex its at an angle we can’t, you know its sort of that way now} (Stella 25.844)

**Threat to generativity**

The examples noted in the research by Anderson and Wolf (1986) concerning the threat to generativity describe the direct impairment of fertility by interference with sexual functioning and indirect impairment of fear of dying before their children have grown up. The subject of fertility was important to two women. In a positive way, Sarah, who was able to resume her sexual relationship, decided to have a baby,
It made, it changed me, in that I decided I wanted a baby. You know, that was quite a big change. I don't think that would have happened. I don't know, it may have done, you don't know do you, but, erm ...but I sort of asked, you know, had a check up everything, and I said, "You know, if I wanted a baby, you know, it hasn't affected anything has it?" (Sarah 37.834-9)

In a negative way Laura, who is now unable to have intercourse because of the development of vaginal stenosis, wished that her diagnosis had occurred after she had had her children, as the thought of having them now frightened her,

"It wouldn’t have been so bad if I’d already had my children or I was a bit older. It wouldn't, it wouldn’t have been so bad. Well at the moment the thought of having children, it fills me with, its horror, but I might change my mind in a few (sic) ...It’s not something I’d consider at the moment (Laura 50.1680-90)

The indirect impairment of the thought of dying before her children had grown up concerned Ria, although she appeared light-hearted about it,

"I said “I can tell you what, I want to see you (older son) have children, you’re not gonna (sic) stop me.” And I said “If you’re asking me, if you’re asking me if I’m going to be a Nan, and so you’re worrying about nothing darling.” (Ria 49.1625-9)

In summary, the findings have shown that resumption of sexual activity was dependent on both physical and psychological post operative changes with 9/13 women experiencing sexual dysfunction to a greater or lesser extent as shown in Table 15.

The resumption of sexual function may also be associated with the length of time following their surgery. Table 16 was drawn up to identify the women who had experienced sexual dysfunction, in relation to the time since their surgery. As noted earlier, Laura, Josie and Denise are unable to have sexual intercourse while Eve, Ria and Julie are
able to have sexual intercourse occasionally, approximately once every 2-4 weeks. Three women, Stella, Kay and Donna have persevered to restore their previous sexual activity.

The findings indicate that the length of time following surgery does not have an impact on whether the women have been able to resume sexual intercourse. Six women have been able to have intercourse occasionally or regularly while Laura, Josie and Denise have not been able to achieve intercourse for physical or psychological reasons as discussed earlier. The reasons did not appear to have resolved by the passage of time. This is in contrast to the findings of Andersen and Hacker (1983) who found that women (n=15) who had had their surgery less than 3 years earlier had significantly greater sexual dysfunction than those who had had their surgery more than 3 years previously.

Table 16: Association between sexual function and the passage of time

<table>
<thead>
<tr>
<th>Name</th>
<th>Age</th>
<th>Sexual Function</th>
<th>Time since surgery</th>
</tr>
</thead>
<tbody>
<tr>
<td>Laura</td>
<td>27</td>
<td>Unable to have sexual intercourse</td>
<td>1 year</td>
</tr>
<tr>
<td>Josie</td>
<td>50</td>
<td>Unable to have sexual intercourse</td>
<td>3 years</td>
</tr>
<tr>
<td>Denise</td>
<td>53</td>
<td>Unable to have sexual intercourse</td>
<td>5 years</td>
</tr>
<tr>
<td>Ria</td>
<td>30</td>
<td>Able to have sexual intercourse</td>
<td>8 months</td>
</tr>
<tr>
<td></td>
<td></td>
<td>occasionally</td>
<td></td>
</tr>
<tr>
<td>Eve</td>
<td>33</td>
<td>Able to have sexual intercourse</td>
<td>2 yrs, 11 months</td>
</tr>
<tr>
<td></td>
<td></td>
<td>occasionally</td>
<td></td>
</tr>
<tr>
<td>Julie</td>
<td>43</td>
<td>Able to have sexual intercourse</td>
<td>7 months</td>
</tr>
<tr>
<td></td>
<td></td>
<td>occasionally</td>
<td></td>
</tr>
<tr>
<td>Donna</td>
<td>34</td>
<td>Persevered to restore previous sexual activity</td>
<td>3 years</td>
</tr>
<tr>
<td>Stella</td>
<td>51</td>
<td>Persevered to restore previous sexual activity</td>
<td>5 years</td>
</tr>
<tr>
<td>Kay</td>
<td>41</td>
<td>Persevered to restore previous sexual activity</td>
<td>1 year</td>
</tr>
</tbody>
</table>
The feelings of aloneness and isolation felt by the women also appear to be a consequence of a lack of awareness among the medical profession and among their family and friends. There was also a lack of anticipatory information regarding the impact of the diagnosis and subsequent surgery. This is discussed as Aloneness; for want of awareness.

7.4 Aloneness: for want of awareness

Several women encountered a lack of knowledge regarding their diagnosis. This links to the role of health care professionals, and is discussed fully in chapter 9, Professional Connectivity. The women’s family and friends also showed a lack of knowledge about the precancerous and invasive cancer of the vulva due to its rarity. For example Eve, Ria, Josie and Anne had precancerous conditions. They found it difficult to explain their condition to their families. Eve said,

*If you were to start talking about it nobody would know what it is. Probably they wouldn’t even know that it existed. When I told my mom and that, she just said what? We had to tell them and all the rest of the family, they didn’t know what it was. When I was telling my friends they hadn’t got a clue. I think some of them still don’t know* (Eve 39.958-62)

There was a subsequent lack of understanding for Eve and her condition when she remarked,

*They (my friends) didn’t understand and it’s like they didn’t like to bring the subject up. They like come away from it. I don’t think they knew what to say. I think it was harder for them because they didn’t understand it* (Eve 39.967-9)

Sarah, Denise and Ria had also experienced a lack of knowledge and understanding among their friends,

*My friends had never heard of it* (Sarah 57.1309)
People, people say at work to me, you know, they say things like um, they know it’s sort of like that part of me body, so they’ll say well “but is it cervical cancer?” And I’ll say “Well no, it’s a form of skin cancer,” then they think it’s the same kind of skin cancer that you get from being in the sun and I’ll say “Well no, you know.” (Denise 30.986-9)

My best friend she’s out in Thailand she phoned me. She goes “How did you get on?” and I said “I’ve got a precancerous condition”. And she said “What are they going to do give you a hysterectomy?” and I went “What?” I said “It’s nowhere near there.” And I remember a lot of people when I told them: “What are they gonna do (sic), are they gonna (sic) give you a hysterectomy then?” And I think well why would they give me a hysterectomy, there’s nothing wrong with my womb, it’s my vulva (Ria 79.2555-9)

The lack of knowledge about female anatomy was also remarked upon by Josie and Julie, who said,

Most people have never heard of it. And uh I only actually said yesterday to a lady I went to, I don’t go to her often and the subject of illness came up, like women talk you know but she said “What were you in hospital for?” and I said “I’ve had a vulvectomy.” And “What’s that?” And if you say to people you’ve had cancer of the vulva they all think of a hysterectomy, they don’t really know, most people, or a lot of people what the vulva is (Josie 48.1610-6)

Yeah, we’ve had that sort of reaction cancer of the vulva, “What’s the vulva?” you know and you’re surprised how many women don’t know what it is (Julie 51.1704-9)

Irene’s friends showed their lack of knowledge by remarking,

A lot of women said they didn’t know they could get cancer down there (Irene 41.1357-8)

Laura felt that she had to give repeated explanations about her condition, which also increased her feelings of being alone with her condition,

It’s difficult explaining to people when, when they don’t understand or when they haven’t heard of things. It’s something many people haven’t heard of. And you have to explain it again and again (Laura 45.1493, 45.1525)
A comparison with breast cancer was also made by Denise, as her friends understand that condition. She admitted that she does not like to talk about her disease,

\[\text{You feel a bit sort of, not very good talking about it, you know, it, it's not, it's not like somebody saying oh you've had breast cancer and everybody understands, you know, or it's not that type of cancer, you don't, you know, you can't sort of talk about it like you could do if it was perhaps breast cancer. So that I tend not to talk about it, if I can help it (Denise 30.999-1003)}\]

Kay also made a comparison with women with breast cancer as she had experienced a delay in treatment, and she equated this with the rarity of the condition, compared with the incidence of breast cancer,

\[\text{We know it's rare and everything, whereas with the breast, breast cancer is common so if you do go about a lump in your breast you do get seen straight away, don't you? Kay (55.1848-1850)}\]

Emotional support for women with breast cancer by their close family members has been shown to be most important (Lugton 1997, Coward 1998) and this was confirmed by Landmark and Wahl (2002) and Dirksen (2000) who noted that women who were given emotional support from their family and friends felt supported, loved, cared for and respected. However this support may be lacking for women with a cancer of the vulva because of the lack of awareness about the disease.

The women experienced a lack of awareness as there appeared to be little anticipatory information about the consequences of their surgery as discussed in chapter 6, page. 132. None of the women recalled that they had been given any verbal or written information to indicate that their sexual function may change after their surgery or have an opportunity to discuss post operative sexual function,
No-one talked about sexual intercourse. It's not just not being told, you don’t know how it's going to feel or what it’s like inside (Donna 29.700-3, 30.719-22)

No-one talked about how our lives might be different (Josie 45.1499)

He didn’t um, (the consultant gynaecology oncologist) did mention that things would, may be different but nobody enlightened us to how, I think that was just trial and error nobody enlightened us; it was a big issue (Stella 42.1404, 43.1421-30)

Although it has been noted that dialogue about sexual matters at each follow up visit is essential, and sexual counselling is effective in reducing long term morbidity (Capone et al 1980), the women also felt that they could not begin a discussion about it at their follow up appointments,

I always felt he was a very busy man; I wouldn’t have tried to have talked to him, if you know what I’m trying to say (Josie 66.2223-4)

Denise specifically stated that if information about resuming intercourse had been available to her and her husband, it may have made a difference to them. Denise stated,

You’re always apprehensive about it, but even, it might have made a difference if somebody had approached it, or talked to us about it. Perhaps if somebody’d sat and talked to me afterwards about it, or talked to me and me husband about it, it might have been different (Denise 39.1313-4)

A lack of verbal and written information was also noted by Andersen and Hacker (1983); Moth et al (1983); Stellman et al (1984); Andreasson et al (1986); Weijmar Schultz et al (1986) Tamburini et al (1986) Andersen et al (1988); Willibrord et al (1990); Corney et al (1992); Janda et al (2004) and Likes (2007). In particular Green et al (2000) reported that two thirds of the women who were studied (n = 41) felt that they would have benefited from more pre-operative information about what to expect in terms of their sexual function following surgery. Auchinloss (1989) has also noted that although a patient may be more
worried about the illness and the risk of dying at the time of the diagnosis, worry about the impact of the treatment on their sex life soon follows.

Ekwall et al (2003) reported that healthcare staff did not always address the issue of sexual functioning in gynaecological cancer patients, and that their needs had been ignored. This may be due to a lack of education of the health professionals with regard to these issues as well as their discomfort when discussing intimate topics (Moth et al 1983; Stellman et al 1984; Andreasson et al (1986); and Corney et al 1992). A lack of support from health care professionals was also referred to by Green et al (2000) and Likes et al (2007) who noted that this may have prevented a return to normal sexual activity for some patients. However Weijmar Schultz et al (1986) reported that 6/10 women interviewed were able to discuss sexuality with the consultant gynaecologist or GP.

The lack of understanding is also linked in a sense to the concept that some women were unable to talk about their illness because it affected a ‘private’ part of the body. This may be described as a lack of openness.

7.5 Aloneness: for want of openness

Several women are unable to share their diagnosis with their friends. Julie remarked,

*Very close friends I’ve been able to tell them in, in quite detail of what I’ve had done but other friends it’s just “I’ve had cancer and I’ve had an operation and I’m all right now,” sort of thing (Julie 51.1711-4)*

Denise also found it difficult to talk to her family about her operation,
But it’s not, it’s not the easiest thing to tell people about, I find it quite difficult to talk about it to people who, who don’t sort of understand me (Denise 30.992-4)

Denise intimated that the lack of openness may be related to her age (53) as there was a lack of openness when she was growing up in the 1950s. She made a comparison with women with breast cancer,

This kind of thing isn’t talked about. I think it’s because you feel its part of your body that you don’t normally talk about, you know, boobs are a big thing, you know, but this part of your body isn’t and it’s a part that’s not normally talked about. And I mean I’m sort of from an era from when you didn’t talk about it, And, and because you just feel like you don’t want to talk about it, it’s too private, you know, you don’t, you don’t wanna (sic) sort of (Denise 29.951-958).

Andersen and Hacker (1983) also noted none of the women would have felt comfortable explaining the procedure to anyone but the most intimate friend, thus increasing their sense of isolation.

Many of the women found it hard to tell their families, and this may have given rise to a lack of emotional support. It appeared to be due partly to the diagnosis as other family members had also had cancer,

I don’t even say that much, my family don’t, I don’t talk to my family about it, you know that’s, just the type of operation I’ve had and things like that, they just, they know I’ve had an operation and that’s it. They (the family) were all very upset (Denise 10.317-22, 24.964-7)

He (my husband) was more shocked than what I was. I suppose, me dad had bowel cancer thirty years ago, so cancer is in our family anyway, uncles have had it and she (my mum), she’s obviously very worried. For, then I went and told my daughter, and she was very upset, more so than me mother, she just dissolved in floods of tears, ‘cos everybody’s she’s known who had cancer has died. So she was very, very upset and um told my son, he was well quite shocked really. I told my son, he was shocked (Josie 14.473, 15.497-9, 15.499-502)
Donna felt her sense of aloneness as she had seen the consultant on her own, and regretted that her husband had not attended with her,

*Mick (my husband) went spare (on diagnosis) I wish he had come in with me, for the first appointment definitely). It would have been helpful to have someone there to hear what you’ve not heard. I mean, they’re emotionally involved in a way, I mean; it affects them, as much as it affects you, (Donna 2.30, 3.54, 3.74)*

Julie found it difficult to tell her teenage sons because of the site of the cancer, and its personal nature,

*It’s a personal place en’t it just to tell everybody en’t it (sic). That was the difficult part of telling the boys as well (Julie 51.1711-9)*

The location of the disease was not the only issue to cause concern, as seen in the next section.

### 7.5.1 Stigma

Feelings of aloneness were also exacerbated by the significance of attending a Genito-urinary (GU) clinic as part of the process to achieve a diagnosis. The women described their feelings of stigma associated with this. Four women, Denise, Leigh, Julie and Donna, were referred by their GP to a Genito-urinary (GU) clinic, as they presented with symptoms of vulval itching. Factors associated with the increased anxiety of attending a Genito-urinary clinic have shown to be related to possible sexually transmitted diseases, stigma, embarrassment and shame (Arkell et al 2006), and these contributed to the women’s feelings of isolation, or aloneness. Stigma has been defined as ‘a fear and mistrust from the undiagnosed that devalues the individual and lowers self esteem’ (Goffman 1965). It is linked to the ‘theory of mind’ (Gilbert 2001b) which enables us to
understand what might be in the minds of others: that is we, our lives and our bodies are judged and evaluated by other people. Stigma is associated with things that others see as bad, weak, inadequate or disgusting which could result in rejection or losing attractiveness in the eyes of others (Gilbert 1998b). Sexually transmitted diseases can be seen as a means of dividing people into ‘clean’ and ‘dirty’ and the negative attitude towards people who attend Genito-urinary clinics remain evident (White and Mortensen 2003).

The women associated the attendance at a Genito-urinary clinic with the acquisition of a sexually transmitted infection, and by inference, the number of sexual partners they may have had. This had an impact on themselves, their husband/partner and the health care professionals involved in their care, summarised as the:

- Feelings of stigmatisation that the women felt themselves by attending the clinic
- Concerns that their husband/partner had passed a sexually transmitted disease to them
- Effect that this uncertainty had on their relationship with their husband/partner
- Attitude of health care professionals involved in their care.

These aspects are described further below.

**Feelings of stigmatisation**

Denise and Leigh recalled,

That was when she (GP) said “I think you’ve got herpes” and she sent me off with this cream and I was horrified to be honest, it was really, really horrible She (GP) told me to go to the GU clinic, which I wasn’t very happy about (Denise 2.61-63, 1.28-34)
They advised me to go to the GU clinic in X so I attended there actually. He examined me and actually had me in to take some biopsies (Leigh 1.12-4)

Both Ria and Denise were concerned that the referral to the Genito-urinary clinic indicated that their GP thought that their symptoms were caused by a sexually transmitted infection. They felt ashamed as they were aware that they could not have acquired an infection like this themselves.

**The concern that their husband/partner had passed a sexually transmitted disease to them.**

Since they were faithful to their husbands, the women were fearful that their husband had committed adultery and become infected by committing adultery with someone who had a sexually transmitted disease.

*Then I actually ended up at the clinic, they thought it was some sexually transmitted disease I was not very happy: I’m married; I only sleep with my husband (Julie 1.12-7, 2.61-5)*

*I was still sort of giving my husband the benefit of the doubt really... as it had never been confirmed (Denise 7. 225, 229)*

This had an effect on their relationship with their husband/partner.

**The uncertainty had had an effect on their relationship with their husband/partner**

Ria and Denise recalled,

*Has my husband been somewhere? (Ria 2.37-8)*

*But after thirty years, you don’t just; I mean we’ve been through a lot together anyway, you know, so you don’t just walk out on a marriage, but I would have done, if I’d have thought he’d been sleeping around. Because that was the one thing that I probably wouldn’t have, you know, been able to cope with (Denise 7.223-9)*
The attitude of health care professional involved in their care

Although Denise recalled that the staff in the clinic ‘were quite good actually’ (2.46), Julie was concerned about what the staff thought of her as a person,

*It’s not, it’s what you think en’t it (sic), it’s one of them things (sic) you think “God, what do they think I am?”* (Julie 2.61-5)

However, in hindsight, Julie recognised that if she had not been referred to the Genito-urinary clinic, her treatment may have been delayed further,

*You know I, how,(sic) so I suppose in a way it’s a good job there’s that sort of clinic, even though it was nothing to do with any, anything like that it was a good place to be sent to get referred I suppose* (Julie 55.1833-6)

Although there is some research on patients with a sexually transmitted disease who attend Genito-urinary clinics, there does not appear to be any research on those who attend a clinic who do not have this diagnosis. Similarly there is evidence in the literature to suggest that many people may experience a diagnosis of cancer as a stigmatisation in itself (Lazare 1986), but the attendance at the Genito-urinary clinic took place before the diagnosis of cancer had been made.

7.5.2 A sense of embarrassment

Since the vulva is an intimate part of the body, it was surmised that this may lead to feelings of embarrassment. Only one woman, Eve, reported that initially she was too embarrassed to go to the GP. She recalled,

*I was too embarrassed. When it all started I didn’t go* (Eve 14.342)
Fear of attending the GP was noted in the study of 17 newly diagnosed cancer patients by Leydon et al (2003) but this was attributed to fear rather than embarrassment.

Most of the women reported a heightened sense of embarrassment in the initial stages when they were being examined by the doctors, giving rise to a sense of aloneness. This was because the disease was in a private area of the body. Over time, they gradually became used to the experience, as Eve and Donna recalled,

\[ I \text{ got used to them. At first it was embarrassing and what have you, but now you get used to all different doctors and just think nothing of it. I had students and everything. I got used to them. Now I am not bothered about seeing them, they're alright (Eve 14.344, 14.325, 14.344) } \]

\[ \text{It doesn’t bother me anymore- it did a bit in the first place- How many people? There was a big group of people. Shortly afterwards (the operation) it is a bit scary, (Donna 16.392, 17.401) } \]

This may have been related to the attitude of the health care professionals involved in their care, as Denise noted,

\[ I’\text{ve had so many people look at me. I don’t, I find it, embarrassing’s the wrong word, I don’t know what the word is actually. It’s, I don’t like what, what’s happening, but I do know it’s a necessity, and, and I do find with the staff I’ve come across at (the cancer centre) have been quite sympathetic towards the way you feel, you know, they, they understand I think to a certain extent (Denise 18.574-9) } \]

Anne noted that an older woman or a single person may have been more embarrassed,

\[ \text{It would be different if I was single, I would be more embarrassed. An older person would be more embarrassed, (Anne 47.1560, 51.1703) } \]

In contrast, Stella is unable to get over her feelings of embarrassment with both female and male doctors,
It’s not the sort of area where you want everybody looking. I know when you’ve had a baby you lose all your dignity and everything but it is um and because of where it is and what they’d done. When you see just the one (Doctor), that’s fine. But when you start getting three or four or four or five it gets embarrassing because you feel like a guinea pig which you are anyway most of the time when you have something done. Because they need to, if it wasn’t for things like this they wouldn’t find out anything would they you know and they need I suppose to look at things to see how things are. But it is embarrassing, very embarrassing sometimes. Even female doctors, it’s not the sort of area where you want everybody looking and because of where it is and what they’d done they wanted people to see it so they could see what they’d done which, you don’t like it but sometimes you think they’ve got to do it but it does get a bit embarrassing, it really does (Stella 22. 716-23, 22.733-8)

Janda et al (2004) also reported that 2 women described the embarrassment of seeing the consultant gynaecology oncologist as ‘emotionally challenging’.

Support from other patients with cancer can diminish a patient’s feelings of loneliness and isolation (Carlsson and Strang 1996) and this is discussed now within the context of a lack of shared experience.

7.5.3 A lack of shared experience

Only 3 women, Leigh, Kay and Julie, have met another patient with the same diagnosis, due to the rarity of the illness. This had happened while they were in hospital,

I started talking to the lady opposite and she had the same). This lady was, she was good to talk to (Kay 10.305-22, 10.232-8)

I was fortunate because there was a lady who came in (with the same condition) (Leigh 34.1145-53)

Julie also met a woman who had the same operation, but remarked on the woman’s age, which also reflected her feeling of aloneness,
I know there was a woman in when I was in that had this same operation but she was a lot older than me (Julie 34.1118-9)

Janda et al (2004) also noted that the women had a sense of ‘being the only one’ with the disease.

It has been shown in studies involving women with breast cancer that they gain a great deal of support from being with people who have the same diagnosis (Dirksen 2000). Auchincloss (1985) noted that gynaecological cancer patients have difficulties in forming peer support groups, although a more recent study by Ekwall et al (2003) noted the beneficial contacts with other patients as ‘only those who had been through the same thing could truly understand what they had been through’. Five women, Sarah, Eve, Josie, Denise and Kay, indicated that they would definitely have liked to have met someone else with the condition and three others indicated that they might have been interested. Sarah and Eve remarked,

Yes, I would actually (have liked to meet someone), yeah. Yeah, I would have liked to. I don't know at what stage, I'm sure what stage I would have like to have spoke (sic) to somebody. I think it possibly would have helped just to have known what to expect (Sarah 54.1235-7)

I would have liked to meet other women to see how they dealt with it (Eve 32.784)

However, support groups are not helpful for all patients as Irene noted,

I think that’s what women should do, get on with life (Irene 17.574)

The lack of a shared experience with other patients is also linked to the age of the women. Several women associated a diagnosis of cancer with older people,
They are usually older people than me, it’s very seldom you see younger people even. I’m usually the only one in there; they’re usually a lot older than me. It’s never young kids in there, always older (Eve 38.922-5)

I was 34, reasonably young. In the ward everyone else was older. Everyone with my condition was older (Donna 5.123, 30.732, 30.734)

You think “Why me at my age?” you know (Julie 51.1695)

As noted earlier in chapter 6 Searching: existential meaning, page 141, Laura recalled her sense of isolation because of her age,

I suppose I felt more isolated, I did feel a bit like I was the only one um to have this. But it was an odd thing that I’d got it at my age. It’s OAPs who have cancer (Laura 44.1485, 62.2090-5)

The age of the women was also remarked upon by the consultant gynaecology oncologists, who were caring for them,

Um, because even the consultant gynaecology oncologist was saying “Oh its usually older women that get this,” um and then he just mentioned as I say that there was one other person that he was treating about my age with um, who was very, very similar (Anne 25.833-5)

Yeah he did say I think the consultant gynaecology oncologist said I was probably one of the youngest that had actually got it, had it when it first come up (Stella 10.315-21)

All the women were aged less than 50 years at the time of their diagnosis, and this may have implications in the amount of psychological and emotional support that they needed at the time. Lindop and Cannon (2001) noted that women with breast cancer who were in the 46-53 year age group had higher psychological and emotional needs than those over 54 years. This has also been applied to people with a range of different cancers (Foot and
Sanson-Fisher 1995; Wang et al 1999). It may be because older women display more of a stoic acceptance to their diagnosis, which is a known coping strategy (Greer 1991).

### 7.6 Summary

This chapter has explored the concept of Aloneness, an experience that evolves for want of nearness, normality, awareness and openness. It has shown that the women’s feelings of isolation started to develop from the onset of the symptoms and endured throughout the disease trajectory. It is apparent that they have experienced a change in their own lives and those of their families. This contrast with their previous life has affected them physically, psychologically and sexually.

The concept of change, which has had both a positive and negative impact, is developed further in the following chapter, ‘All Change’
CHAPTER 8
ALL CHANGE

8.1 Introduction

This chapter focuses on the concept of ‘All Change’. All Change expresses the sentiment that following a diagnosis or surgery, everything has changed; life is not the same as it was before. Although surgery for cancer of the vulva results in controlling the disease in 85-90% of cases (Stehman and Look 2006), the women felt ‘different’ as a result of their diagnosis and subsequent treatment. Their body image has changed. This has both positive and negative aspects, as past experiences live on into the present and the future. It is also linked to the process of assimilation, whereby a person makes sense of the phenomenon they have experienced and accommodation, when they are able to accept their experience (Horowitz 1986). The positive aspects are related to the new challenges the women have faced since their diagnosis, while the negative effects relate to the consequences, for example of delayed wound healing. Issues related to lack of choice regarding the surgical treatment, and the uncertainty caused fears of a recurrence of the cancer or a new primary tumour. The diagnosis of cancer also has an impact on a patient’s family and friends and this is explored.

The concept ‘All Change’ is illustrated in Figure 6.
8.2 All Change: a difference

The idea of ‘All change: A difference’ refers to the change that the women perceived has taken place regarding the way that they view themselves, or their sense of body image. Body image refers to the internal picture of the body and its functions (Newell 1991) and is the sum of the conscious and unconscious attitudes the individual has towards his or her own body (Salter 1997). It evolves over time, and is adjusted regularly as people mature and age. The way someone feels about their body image may be described as having three components,

- Body reality, which represents the body as it is
- Body ideal which is how the person wants it to be
• Body presentation, which represents the efforts the person takes to find a compromise between body reality and body ideal (Price 1990a).

An altered body image has been described as a state of personal distress. It indicates that the body no longer supports self-esteem as it is dysfunctional, and this limits social engagement with others. Altered body image exists when coping strategies (individual and social) to deal with changes in body reality, ideal or presentation, are overwhelmed by injury, disease, disability or social stigma (Price 1995). Although issues of body image are important to cancer patients, there has been an implicit tendency to equate body image with a person’s perception of his/her appearance. It follows therefore that one’s body image would be affected more if an organ that inherently makes one obviously feminine or masculine were affected by an illness. This has been confirmed by Foltz (1987) who found that women with a gynaecological cancer had a higher risk of developing a negative self-image than women who had other types of cancer. An altered sense of body image was also noted by a number of authors (Andersen and Hacker 1983; Moth et al 1983; Stellman et al 1984; Thuesen et al 1992 and Corney et al 1992).

All the women in this study had experienced a physical, psychological or sexual change to varying degrees. The change may have been minimal or had a maximum effect, which in turn reflected a minimal or maximum difference in their body image. Figure 7 illustrates the differing dimensions of change and difference that could be experienced and indicates the extent to which the women were affected. By exploring the concept of maximum change and minimal change and maximum difference and minimal difference I was able to place the names of the women in the appropriate position within the figure.
Figure 7: Altered body image: the impact

Figure 7 indicates the impact of altered body image. It shows that the majority of women experienced a maximum change, reflecting a maximum difference in their body image. Eve has experienced a change but it has caused a minimum difference to her, while Anne and Irene feel different but it has not led to any change. Sarah and Leigh have experienced both a minimal change and minimal difference in their lives since their diagnosis and surgery. These aspects will be explored further below.
Maximum Change and Maximum Difference

As seen in Figure 7, Josie, Denise, Kay, Julie, Donna, Ria, Stella, and Laura indicated that following their surgery there had been a maximum change, resulting in a maximum difference. This impacted on their physical, psychological and sexual functioning.

Maximum Change and Maximum Difference: Physical Impact

Physical changes and differences were noted by Kay and Julie who have developed lymphoedema. This has had a major impact in their lives, as it has affected the clothes and shoes that they wear,

*I used to wear jeans all the time and tight things but I can’t now. I have to wear baggy things, because I can’t wear tight things up there. This pair is an old pair of my son’s. But even at the start of winter, I’ve got to go out like this. I can’t wear any boots or anything, it’s quite hard. I have to wear lace up shoes that I had all the time. And where my tummy was, it’s hard where they removed my lymph glands, it’s not flat anymore, and it seems to come out. I can’t even pull it in. I can pull this part in, but not that. Rather than being flat. It feels really hard, but that’s just where the scar tissue is. I just wear tailored trousers, although I’m conscious of um when you’ve got quite a few t shirts that are a bit shorter, but I’m very conscious even though I’ve got these trousers on still because of this protrusion I’ve got here I’ve taken to wearing like shirts that are covering this bump up. That’s frustrating because I’ve got clothes that you know I’d love to wear but I’m so conscious of this um bump and how it come round up here its not like a normal shape or feel (Kay 8.247-254, 31.1039-41, 32. 1047-50)*

*I mean I’m lucky these trousers are baggy but like jeans and things I can’t because they’re swollen more at the top and then around the ankle area. I can’t wear heels no more (sic). I had to buy a pair of shoes a size bigger than what I normally have which, size 7s anyway but I had to buy a size 8, this one’s slipping off and this one’s tight, so it’s inconvenient because you can’t buy shoes odd sizes, unless I buy two pairs. There’s clothes I can’t wear- these trousers are baggy. I buy cheap slip on shoes (Julie 26. 864-71, 27. 879)*
Julie now walks with a stick and uses a wheelchair to enable her to go shopping. This, together with constant pain in her leg, has limited her activities with her young family and causes her problems with standing to do her ironing and other housework activities,

That's why I use me (sic) stick now where I, because if it (my leg) goes on me I just, I fall down and that scares me if I fall down, break me (sic) leg or something. I do feel I can't, I daren't go too far out or venture far on me (sic) own. The supermarket supplies wheelchairs and that, which is handy for a start because I never liked anyone doing any shopping for me, so it is a matter of getting in the wheelchair and (my husband) taking me round (Julie 35.1144-6, 24.784-6)

Kay now wears special hosiery to help reduce the swelling, but noted that the whole family is involved in trying to get her stockings on,

These tights I've got on now, it takes me ages to put them on in the morning. I have to get my kids and my husband to help me. I've got one of these 'easy-glide' things to help, you put them on here and then you have to pull it up. So that sort of, if I don't have to pull them on, I could have 20 minutes extra in bed so I have to get up earlier you know when I’m working, to get myself sorted out. The tights aren’t as tight as the knee-highs. You wouldn’t believe that your legs and feet can change as much (Kay 32.1070-6)

Post-operative lymphoedema was reported by Andersen and Hacker (1983); Tamburini et al (1986) and Janda et al (2004). Although other women were not affected by lymphoedema, the surgery has still had an effect on their physical activities. For example, Stella and Leigh have less energy and find their legs ache more,

If my legs do get tired sometimes I put me (sic) support stockings on for a couple of days and I find it eases them. It helps (Stella 33. 1113-5)

(If) I walk into town and (I can) get a lift back (Leigh 27.891)

Tiredness was also noted by Moth et al (1983) and difficulty with walking was reported by Tamburini et al (1986).
Several women have areas of numbness in their legs. This is due to the nerves being severed at the time of the surgery to remove the lymph nodes in the groin. Donna and Josie remarked,

*From my knees to my hips, there is no sensation (Donna 24.584-7)*

*My legs are still a bit numb, there at the tops of my legs (Josie 66.2211)*

Loss of sensitivity and numbness in the vulva area affecting sexual function was discussed in chapter 7, Aloneness, page 155.

Julie and Stella also remarked that micturition was altered. They described it as a ‘spray’ as the urine did not flow down into the toilet,

*And I’ve noticed, well even when I had that done because of where it was, even the urine. I thought hang on, it doesn’t come straight out, it’s sort of lop-sided if you like, you know it’s very different (Stella 5. 164-6)*

*Everything feels all to be on the one side. When I go for a wee now like, I wee down me (sic) leg ‘cos it’s all, everything’s pushing this way (Julie 58. 1498-1505)*

When Julie had her monthly period, she also felt that her vaginal loss was also going down her leg rather being absorbed by her sanitary pad,

*It’s like when it’s the time of the month (monthly period) it’s all, once I thought I could try and wear the pads on me (sic) leg as well because it’s all, everything seems to push that way (Julie 46. 1525-8)*

Stella and Kay reported difficulties initially with sitting down and standing up,

*It was painful sitting down and standing up but when you sat down and laid down its just getting there that’s the problem because you seem to, when you seem to sit, it seems to pull and when you stand up it seems to, as you stand up it seems to drop if*
you know what I mean, it seems to pull down but after a bit you get used to it, it's fine
(Stella 58.1930-4)

It is hard to get out of the chair sometimes. Yes, I haven’t got the strength in my legs
that I used to have (Kay 35.1146)

Physical side effects were noted by Andersen and Hacker (1983), Moth et al (1983);
of perineal tissue, the effects of lymphoedema and altered micturition.

Maximum Change and Maximum Difference: Psychological impact

Stella, Ria, Denise, and Donna felt that their body had let them down,

Sometimes I feel as if my body has let me down. Sometimes I think why did it have to
be me, why couldn’t you know because you see so many people but you don’t know
what other people have got wrong with them. Sometimes I do. Sometimes I think you
know why did I have to have this. Sometimes I think I’d give anything to be like I was
before but then I think well I’m not, so (Stella 41.1366)

‘Cos (sic) there’s so many things gone wrong. I never catch colds; I don’t have
coughs and colds... I don’t have the easy stuff. I seem to get the major things and I
think well why? But then I think well there’s (sic) other people who get worse than I
get, you know so, but I do feel my body’s let me down, yeah. [sighs] And I don’t
know what to do about it either (Denise 33.1080-7)

Stella and Laura compared themselves with the time before their diagnosis,

It just takes some getting used to, to think that you’re different; it’s something that
takes a while to get used to, ‘cos (sic) you do look very different, you know, it’s
different to what you normally look like. I know, you know, how you should look, how
you did look and you don’t look any more (sic). It just takes some getting used to, to
think that you’re different from most people, most of the females that you know
(Stella, 5.147-951, 1697-1701, 1710)

I think it’s because it’s different, not how I was used to, used to it (my vulva) being.
Everything has changed a lot; my body’s not the same: it’s a bit different. (Laura
57.1919, 1928, 69.2295)
Denise and Stella remarked that although the change was concealed from view, they felt different,

*It doesn’t alter the way you look really, not that anybody sees it but I know it does ...But other people don’t see it (Stella 29. 969-72)*

*I am definitely not the same person – you don’t feel like you’re a normal person- you feel strange. I mean from the outside I don’t, but that doesn’t change how I feel inside, you know how I feel. I mean whether other women feel the same I don’t know, but it did affect me quite, quite seriously, It was part of my body that was (sic), never looked the same again (Denise 27.898-909, 28. 911-6, 28.926-32)*

This illustrates that although the changes were not obvious to other people they were significant to the women themselves. The concept of invisibility is explored further in chapter 10, the Lived Experience.

**Maximum Change and Maximum Difference: Impact on Sexual Function**

All 8 women in the category of maximum change and maximum difference have experienced a change in their sexual function from the onset of the symptoms of vulval cancer and it had continued into the time of their interview. Five are either unable to have sexual intercourse or only occasionally, once every 2-4 weeks, while the remaining three have had to persevere to restore their sexual relationship. As noted earlier, this impacts on the feeling of Aloneness: for want of normality.

**Maximum Change and Minimum Difference**

Only one respondent, Eve, reported that she had experienced a change in her physical, psychological and sexual function following the onset of her symptoms and subsequent operations but this had not affected her in any way. Eve had on-going VIN 3 and had required further vulval surgery,
He had to do a few operations before the vulva and then he’s done that one, and I’ve had another few since then (Eve 7.169-70)

This has affected the clothes that she is able to wear,

Yes, like I couldn’t wear jeans or anything like that. If I got hot it would start it (the itching) all off. I can’t wear nothing tight but these jogging trousers are soft and comfy (Eve 7.169, 19.460)

She also had an infection post operatively which still affected her,

He took the area of skin down below and on the side but there is a very thin piece of skin left and that is where the hole is. In the winter when it gets cold I’ll feel it (Eve 18. 446)

She is now unable to plan to go on holiday,

Every time I plan to go on holiday I am in hospital so I don’t plan nothing (sic) now, I just stay (Eve 20.494-50)

Her sexual relationship is also affected,

When you have all the operations you don’t have a sex life at all, even when the stitches come out it’s still sore, you can’t do nothing (sic) until it starts to heal up a lot more. Still now you can’t (Eve 27.658)

Nevertheless, Eve stated that these physical, psychological and sexual changes had not made any difference to her or her partner,

Because nothing’s changed, we’re still the same (Eve 33.810)

This reflected her stoic acceptance of taking everything in her stride, and she confirmed this by her description of her way of coping with her illness,
I just get used to it. I just go in (to hospital), get it done (vulval surgery) and come home (Eve 16.389, 24.579)

**Maximum Difference and Minimum Change**

Irene and Anne reported that although there had not been a change following their surgery, there was now a difference. Anne had had a radical vulvectomy and bilateral groin node dissection, but this has not changed her physically, psychologically or sexually,

*It hasn’t really changed my life in any way so. I feel I’m coping with, you know I’ve coped with it (Anne 49.1643-5)*

*I’d say I suppose it’s what I said earlier where I’d say our sexual relationship has changed over the years but it is more to do with time, age and whatever, its, that, more than the operation (Anne 44.1482-5)*

Although Anne insisted that she had not experienced a change in her life in any way, during the course of the interview she disclosed that she had now developed lymphoedema. In fact it had made quite a significant difference to her as she stated,

*I’ve probably been bothered more by the lymphoedema than anything else to be honest. Um, which I know is really stupid but um that, that bothers me more. I’ve got it, in my left leg. So.(sic) And that bothers me more because I always think well why can’t they just get rid of it, because they can’t (Anne 15.481-92)*

She also reported that sitting down for long periods of time was uncomfortable due to the loss of fatty tissue from the perineum,

*I mean I can sit on it (my bottom) no problem. It’s a bit (sic) I can feel it and it is uncomfortable because I haven’t got as much padding down there anymore (Anne 42.1398-1400)*

Irene also stated that there was no change following her surgery. She was able to put her diagnosis behind her,
I do try and cope with things. After this healed like you know ‘cos – touch wood – I’m going all one way (Irene 25.817-25.830)

She did admit though that she was worried that her cancer would return. She described the psychological impact of the fear of a recurrence as ‘living with a time bomb’

Whereas they know that sooner or later its, it is gonna (sic) come back No they said it would definitely come back but it’s just, just a matter of time. So I mean I’ve done eighteen months, oh no, yeah, at the moment, so I feel a bit like a time bomb (Irene 47.1569, 9.630 19. 639)

The fear of the formation of a new lesion and the sense of uncertainty relating to a diagnosis of cancer is also discussed later in this chapter.

**Minimum Difference and Minimum Change**

Only 2 respondents, Sarah and Leigh, stated that they had not experienced any change or difference since their surgery. Both remarked that they felt the same as they did before, although Leigh had undergone a radical vulvectomy and bilateral groin dissection and Sarah had had a wide local excision and ipsilateral groin node dissection,

\[ I \text{haven't changed; I'm still the same} \ (Sarah \ 44.1010) \]

\[ I \text{m the same person} \ (Leigh \ 31.1038) \]

The way in which women adjust to their diagnosis is partly related to their coping styles and also to the extent of the post-operative consequences. Previous studies with cancer patients have reported that respondents with a ‘fighting spirit’, ‘positive thinking’ or ‘stoic acceptance’ cope better with a diagnosis of cancer and subsequent treatment (Moorey and Greer 1989; Leydon et al 2003). This has enabled some women, who underwent extensive surgery to return to their pre-diagnosis activities, while other women have experienced a
maximum change and maximum difference, following surgery. The way in which women with cancer adjust to their diagnosis may also be related to clinical outcomes (Osborne 1999). Here, the Mental Adjustment to Cancer (MAC) scale was used to assess the adjustment of women with breast cancer (n = 632) to their diagnosis and treatment. They noted that the women’s adjustment style was a key determinant of quality of life (Osborne 1999).

The concept of All Change: a difference also refers to the effect of a delay in their wound healing. This has also led to a lasting negative effect for some women.

8.2.1 Delayed wound healing

A delay in wound healing is a common post-operative complication following surgery to the vulva and it is thought that wound breakdowns managed by delayed secondary closure occurs in between 25% (Stehman and Look 2006) and 50% of patients (DiSaia and Creasman 1993). Nine women developed a wound infection following their surgery. The treatment varied from an extended stay in hospital, to daily visits to the hospital, daily visits from the district nurse or a course of antibiotics. This is shown in Table 17.

To treat the infection, 4 women required a course of antibiotics as Kay and Denise described,

*I had cellulites (sic) I suffered terribly (Kay 13.428)*

*The only problem I had with the first operation was I had a bit of an infection so I had to go on antibiotics and I was extremely tender, which I expected to be anyway, but this was really tender. So, but I was uncomfortable, but not, you know, it wasn’t unbearable (Denise 16.535-8)*
### Table 17: The incidence of delayed wound healing

<table>
<thead>
<tr>
<th>Name of Respondent</th>
<th>Course of Antibiotics</th>
<th>Daily visits for wound dressings</th>
<th>Re-admittance to hospital</th>
<th>Extended hospital stay</th>
</tr>
</thead>
<tbody>
<tr>
<td>Anne</td>
<td>X</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Julie</td>
<td>X</td>
<td></td>
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</tr>
<tr>
<td>Denise</td>
<td>X</td>
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</tr>
<tr>
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Eve returned to the hospital daily for her wound dressing, while the district nurses came in daily to care for Irene and Ria,

*The stitches never held. They all broke so I had this massive hole that got infected, so I had to go back to the hospital every single day (Eve 8.180-4)*

*Although I have got very good healing skin and then it just broke down again you know and there was a big hole. It was a big hole as well and it frightened him (my husband), and it just went whoosh everywhere (Irene 13.428-9)*

*The doctor (GP) called round, he said, he just looked at me, he said “I’ve never seen anything like it, nothing like it (sic).” He said “The stitches are all on one side, they’ve just ripped straight through the tissue, you’ve got a big hole there and because it’s been like it for a couple of days it’s infected.” The district nurse came to make sure it was healing and to have a look (Ria 7.224-6, 34.1124-9)*
Donna had been warned that she may have a breakdown in wound healing, because of the amount of tissue that was removed. She required an extended stay in hospital of 4 weeks while Josie had to be re-admitted to the ward for a further two weeks,

*If it weren’t for the fact that he cut away so much down below anyway, but it was because they took so much stuff away, so much material it took a long time to heal afterwards. It burst. Yes, it actually burst. How can I put it? It actually burst open so it sort of had to granulate outwards and heal that way (Donna 6.128-139)*

*Then the district nurse came and took one look at me and said “I think you’ve got an infection, you’ve gotta (sic) go back.” (Josie 18.603-5)*

Josie then required daily visits from the district nurse when she was discharged home for a further month,

*Where it all had to come to a head where the drain was, it went into a hole. And the nurses just had to um pack it, so I had like two little ones, I had like a big one (cavity) there, and then there was a little one like in my groin, ’cos she did say, she thought it was gonna go into one great big one but it didn’t, it just stayed with the um, the one. So they were having to pack that, so. And the worst of that was the fact that it just used to ooze and I’d have all these pads tied round and tied round me (sic) legs in case it started to, to ooze out you know if I went out (Josie 28.947-51)*

Ria was unable to pass urine following her surgery due to the breakdown in her wound.

She also experienced psychological effects because of a post operative wound infection,

*I was thinking oh my God I still can’t, I actually thought I don’t want a drink because I don’t want to go for a wee. I was literally, it was bad enough I’d rock to and fro and sit in the bath and try to go to the toilet, and pour jugs of water every time, but this was to a point when I couldn’t go even with the crying and feeling absolute agony, it was just, I just couldn’t go. I felt at a real low ebb just after that operation, because I think I’d been all right if I hadn’t have had to have that catheter in and be in the pain I was in for long because of the infection because of the stitches breaking down (Ria 7.210-219, 21. 690-3)*

The wound healing took between 4 weeks and 4 months,

*It took 4 weeks to heal properly (Ria 34.1128-9)*
It took 4 months to heal up (Irene 15.509)

This has had a lasting effect for some women. As noted earlier, Eve now has a thin area of skin on her vulva, which is very sensitive in cold weather, and Ria also has a sensitive area of skin where her wound broke down, which has an impact on the clothes that she wears,

Some days, if I’ve got a pair of trousers on and they seem to be catching, because at the moment um where I had a lot of scar tissue, where I’ve got the scar tissue because the wound opened up and I sort of just had to let it heal as it was because there was nothing they could do about it, there’s an area of skin between sort of the areas between your bottom and your vagina, that is my bugbear at the moment. It’s absolutely horrific (Ria 12.374-8)

8.2.2  New challenges

The diagnosis of cancer has also prompted the women to re-evaluate their lives as they have faced and undertaken new challenges. Several women have returned to the sporting activities that they did previously as Leigh and Donna described,

I did bike riding um I played tennis a little bit (before my operation). I tried bike riding, but my legs, but I suppose I haven’t used my leg muscles that much at all so that was a bit of a challenge to do that. My ex-husband got me a gel seat for my bike but it was quite comfortable so I take care. But I want to get out and start doing things (Leigh 25.874-5)

I go swimming 2-3 times a week and gym 2-3 times a week (Donna 23.555-60)

Others took up new sports. Anne was unable to cycle before her surgery, but was determined to do so subsequently and Laura decided to join a gym to help to prevent the risk of developing lymphoedema,

I bought a bike actually after I’d had the operation because it made me more determined. And um I’ve got to get over this and ride a bike and I didn’t even ride one before. So I did that (Anne 35.1161-3, 42.1391-3)
So I thought well I’d better join a gym to actually get better. And that, and then that actually helps with my legs too, to fight the risk of getting lymphoedema (Laura 38.1280-2)

Kay and Julie have already developed lower leg lymphoedema and are hoping to take up swimming again to help this,

Well it’s what the lymphadoema nurse said more than anything to try and go, but its something me and me (sic) friends have talked about to each other. It’s in the evening, we’ll go on ladies night at the baths so there won’t be any men around, but I’m looking forward to it (Kay 26.1190-1202)

I used to go swimming a lot but I haven’t been for months now. I’d like to go back to swimming because that’s an all over exercise en’t it, (sic) all in one (Julie 26.850-1)

These findings reflect work by Landmark and Wahl (2002) in their study on women with breast cancer who reported that the discovery of the ability to do activities managed prior to surgery gives acknowledgement of physical strength and also enhanced feelings of achievement in every day life. Here, women appeared to consciously choose activities that provided them with meaningful experiences both for their working and private lives (Landmark and Wahl 2002). By emphasizing meaningful activities utilising physical and mental strength, the women created order in their daily living after the chaos created by illness. This was also noted by Ferrell et al (1998) who noted that cancer patients need to regain hold of daily life as it was prior to the illness.

The biggest challenge for Sarah was to re-evaluate her life leading to her decision to have a baby,

It changed me, in that I decided I wanted a baby. You know, that was quite a big change. I don't think that would have happened. I don't know, it may have done, you don't know do you, but, erm, (sic) but I think in the November, I went to see (the consultant gynaecologist oncologist) and, er, you know, I sort of asked, you know, had a check up everything, and I said, "You know, if I wanted a baby, you know, it
hasn't affected anything has it?"  "No" he said you know, "You're not getting any younger". Laugh. So it did change me for sure, to sort of think hang on, you know, you've been working all these years, and your life's not quite as you want it to really, you just carry on doing what your doing, don't you? (Sarah 37.833-842)

8.3 All change: lack of choice

The difference in the lives of the women following their diagnosis is also reflected in their feelings of powerlessness or lack of choice, compared with the time before their illness. This was characterised by their perceived lack of choice regarding their treatment options. The concept of powerlessness is an identifiable response to a diagnosis of cancer and is similar to the concept of ‘Why me?’ discussed in chapter 6, page 141. In this context, it is thought that feelings of powerlessness and helplessness may stem from the rapid succession of events from diagnosis to treatment, and is considered responsible for diminishing individual’s sense of mastery (Brockopp et al 1989). The person with cancer finds themselves catapulted into an unfamiliar learning environment, where they have little or no time emotionally or psychologically to accept the diagnosis of a life-threatening illness before they are asked to consider treatment options and deal with the physical impact of the chosen treatment (Galloway et al 1997).

The sense of powerlessness was reflected by a lack of choice over the timing of their surgery. Anne and Laura recalled how quickly they were given the date for their surgery,

*He (consultant gynaecology oncologist) was like “Right you’ve got to come in,” and I was doing my usual “Well I’m really busy at work, I could come in, in July or I could do it then,” and he’s like “No. You know you’re coming in this week.” (Anne 6.186-9)*

*They told me that straight away (need for operation), they even told me the day, and they’d even pencilled the date in – ready (Laura 10.329)*
Conversely, Denise and Sarah had to wait for several weeks to allow the site of their previous biopsy to heal. They described the impact of having to wait,

That was quite difficult because I’d just had the one biopsy, he said it had got to heal up before he could operate again, so I landed up waiting for four weeks, which is a hell of a long time when you think you’re dying (Denise 10.328-330)

Once you have got it you want be treated tomorrow. You know two or three weeks I had to wait. I would happily have gone in tomorrow and had it done (Sarah 57.1293, 1295)

Several women coped with their sense of powerlessness by exhibiting stoic acceptance and a sense of resignation, as there was ‘nothing they could do’ about their illness. Donna and Laura recalled,

I was really angry when I was first told, because I was kept in the dark and I didn’t know what was going on, I just let things happen I’ll just get on with it. It’s no-one’s fault, it just happened. It just happened to be me (Donna 25.604-10, 614-5, 27.658-9)

I got to resign myself to the fact that it’s just I’ve got to get done, it’s got to be done, so there’s no point in it bothering me (Laura 15.478)

Josie and Denise were upset initially but sought to gain some control by resolving to get on with their lives,

I’m one of these types of people that whatever hits you, you have to deal with it and that’s, that. So after that first sleepless night, the day that they, they told me what it was, after that it was down to business right, we go from here, I’ll carry on with me (sic) life, you know, I ain’t (sic) gonna worry about it. What will happen will happen. So (sic) (Josie 14.474-15.479)

Um so for the first couple of weeks I hardly slept and I cried a lot, and then after that the one day I just got up and thought sod this, I’m gonna get on with me (sic) life, (Denise 10.331-6)

Psychological adjustment to a diagnosis of cancer may be improved by involving the patient in decision making about their proposed treatment (Sarafino 1994), and some
patients have a choice over different treatments. For example women with breast cancer may be given a choice of either lumpectomy or mastectomy, whether they want a breast reconstruction or not, and the timing of this (Harcourt and Rumsey 2001). Although health care providers are encouraged to offer women a choice of treatment following diagnosis of breast cancer (NHS Executive 1996a), many women find this choice stressful particularly when the diagnosis has just been given and their capacity to process information, to think clearly and critically, and to make important decisions is adversely affected (Fallowfield et al. 1994, Rosenqvist et al 1996). Women who have cancer of the vulva do not have this choice. The primary treatment is surgery, with the aim of removing the abnormal tissue and 1cm of surrounding normal healthy tissue to achieve an adequate clearance. The only ‘choice’ is whether to have treatment or not, and all the women were keen for the treatment to be commenced and the cancer to be removed. Josie was typical in her comments,

So I couldn’t wait to get in that hospital, I just wanted rid, I just wanted it (the cancer) shot of (Josie 11.348, 67.2123)

A sense of powerlessness is also linked with coping with the uncertainty of the future for fear of a possible recurrence or another malignancy and discussed in below.

8.4 All Change: uncertainty

Since there is no guarantee that any type of cancer can be cured, the women are living with the uncertainty that the cancer may return. Donna was the only woman in the study who said that she has been able to forget about her diagnosis, and is only reminded at certain times, for example at the time of her follow up appointments or at the time of the interview,
I only think about my diagnosis if I am prompted, only today as you’ve asked (Donna 33.797)

The other twelve women were worried to a greater or lesser extent. Anne is concerned that the cancer may return, and Julie described this as a ‘nagging doubt’,

Because its not gonna go away so, and its just something you’ve got to live with and, but I know, although I’m absolutely fine now, as I say I know that if, if I needed another operation, even though it might be a minor one, that would be enough for me to like just go to pieces (Anne 38.1281-84)

It’s always that thought there is, “Has it come back again? Have I got to have any more surgery done?” I do, I do get quite anxious when the appointment time comes around I know when the results come back – ‘will it come back again?’ But there’s still a nagging doubt all the time (Julie 53.1759-61, 68-9)

Sarah tried to put it to the back of her mind,

It’s just at the back of your mind. It's always in there but yeah I try and keep it at the back, but yeah it does creep there occasionally (Sarah 55.1250, 56.1277-8)

Josie asked about the symptoms she may expect from a recurrence, to increase her awareness,

I just like to know as I said to be aware I suppose, I don’t like to bury my head in the sand, I like to know if there’s something going on what it might be, and you know whatever (Josie 50.1682-4)

Irene has been told that it will definitely recur at some time and, as noted earlier, has described this as being like a ‘time bomb’. Denise developed a recurrence two years after her original diagnosis and describes herself as living with a death penalty,

And when I had the second bout, he (consultant gynaecology oncologist) told me then, he said I can’t guarantee it won’t happen again. So I’ll always feel like I’m living sort of with a bit of a death penalty over me, so (Denise 31.1019-21)
Kay had the most advanced disease at the time of her diagnosis and is worried about the future,

*But I actually saw somebody else last time I went to him (clinical oncologist). I was asking him questions you know the different times I had got left, and how long had I got, was it three to four years. If it went now, would it have gone altogether, but he said it wouldn’t... I just don’t know what is going to happen. I said “Well what’s the prognosis then?” and he said “We can’t give you one, because it was so rare” and I thought, I was shocked because I wanted him to say I was all clear. It was a real downer if you like (Kay 9.288-293, 56.1756-9)*

Eve expects to hear about a recurrence when she attends for her follow up appointments, and Donna also has a fatalistic attitude to the future,

*It’s just when I go to the hospital I know that there is something else that is always going to happen. If it’s not one thing it’s another. You just get used to hearing bad news when you go; you just expect it every time you go up there. You just get used to it (Eve 23.558-61)*

*Nothing is a problem because I faced my diagnosis. If it’s going to happen it will (Donna 25.609, 25.610)*

Moth et al (1983) noted that half of the women (n = 8/15) were frightened of a recurrence and Corney et al (1992) reported that 30% (n = 9) were openly worried and 7% (n = 4) were preoccupied with the possibility of a recurrence, although this comparative study included women with cervical cancer as well as vulval cancer. Cox and Wilson (2003) have identified that follow up appointments in an out-patient department are a cause of stress for patients and Broyn and Froyen (1982) reported that women with breast cancer experienced more anxiety and/or depression and fear of recurrence prior follow up visits. In her study predicting well-being in breast cancer survivors, Dirksen (2000) identified that uncertainty with a negative predictor in resourcefulness led to a decreased sense of self-control and self-worth.
Three women are fearful of a new primary tumour, Stella, Donna and Irene. Stella remarked,

*I’m quite strong but it’s altered the way I think. If it had of been something with me that I hadn’t got better, it was worse, you know if the cancer came back or in different place and it was worse I don’t know how I’d be then because I haven’t had that to cope with yet* (Stella 29.976-81, 29.981-4)

Donna has had an abnormal smear and is worried that she may develop cervical cancer,

*I’ve just had a smear with borderline changes, so I have got to have another one in 6 months. I was going to have reconstruction (to my perineum) but I said ‘No’. Let’s have two normal smears, then think about it* (Donna 3.26.636, 3.26.639)

Irene had already had cancer of the cervix and in the gall bladder in the past,

*Oh it was 1976 that was (cancer of the cervix). I was 25 then. And then I had it again in 1978 in my gall bladder. Sometimes I think well where else is it going to strike? Well I thought it would just be my luck if it did come back* (Irene 5.141-2, 48.1623-6, 20. 649-51)

It is known that multiple cancers may occur in individuals because of a genetic predisposition, environmental exposure, cancer therapy or immunological deficiency. For example women with the HNPCC syndrome (hereditary non-polyposis colorectal cancer) have a 40–60% lifetime risk for colon and endometrial cancer, and a 12% lifetime risk for ovarian cancer, and a number of women with this syndrome will have more than one cancer in their lifetime (Lu et al 2005). However since there is no genetic predisposition to cancer of the vulva, these women are no more likely to develop another cancer than anyone else in the general population.
The ways in which the women coped with their uncertainties have been both positive and negative. Eve is unable to make any plans, while Ria and Stella are determined to live life to the full,

_Every time I plan to go on holiday I am in hospital so I don’t plan nothing (sic) now, I just stay_ (Eve 20.495)

_Its no good looking doom and gloom on life all the time, you’ve got to, anything can happen to anybody can’t it?...... I might outlive every bloody bugger [laughs]_ (Ria 53. 1784-1793)

_I mean we, we’ve had, the last three years we’ve had a good three years with holidays and doing what we want and when we want and living reasonably you know if we can afford it because we’re both earning. But yeah if there’s something we need to do or somewhere I need to go, or I want to go so we do_ (Stella 18.607-14)

This illustrates that positive experiences result in maintaining self-integrity and re-establishment in the world, as Stella, Ria and Irene demonstrated, while others adapt their expectations of themselves and their life style in order to cope with the disruption brought to their life by the cancer as Eve clearly showed.

### 8.5 All Change: family and friends

A diagnosis of cancer affects not only the woman but also her family and friends.

**Family**

All the women were married or had a partner except for Leigh, who was divorced. The length of time that they had had their partner was between 3.5 years and 30 years with an average time of 12.5 years, see Table 13. All the women remarked that their husband/partner was very supportive throughout their illness. Irene’s husband had encouraged her to go and seek medical advice initially,
And my husband moaned. He said “Because you’re losing too much weight, you should go and get something done.” (Irene 6.175-80)

This has also been noted by Leydon et al (2003) who reported that family and friends had encouraged respondents in their study to attend a General Practitioner following the onset of their symptoms.

The husbands/partners were also supportive during their stay in hospital and following discharged. For example Ria said,

He (my husband) tends to look after the children, which to me alleviates a worry for me because I haven’t got to worry about well who’s having them today or, I know my husband’s got them (Ria. 18.594-6)

This had an impact on their work commitments. Julie’s husband was unable to continue with his part time job, because of travelling to visit her in hospital and coping with the children,

He lost a lot of time off work but money can’t buy you health can it? “That doesn’t matter”, he said “It doesn’t matter how much it costs, or you know what inconvenience it caused,” as long as I got right (Julie 5.165-8).

The husbands/partners were also anxious to support their wives/partners at follow up appointments. Julie’s husband was typical,

My husband has been there to every appointment (Julie 9.280).

Anne had a history of precancerous lichen sclerosis, but following her diagnosis of cancer her husband started to attend hospital appointments with her,
Because as I say he never used to come years ago to outpatients, he’s always taken me to hospital and always picked me up and whatever and as, as I, the condition was getting more serious that’s when he started coming. Um, so yeah I mean he’s really, he’s really supportive (Anne 48.1592-4)

Research on gynaecological cancer patients by Fowler et al (2004) has shown that women reported lower levels of depression and anxiety and a greater sense of emotional support if they had a husband/partner. The duration of the relationship is also significant (Corney et al 1992, Fowler et al 2004). However Lindop and Cannon (2001) and Lugton (1997) noted that women with breast cancer who were married had greater needs, as they had the concerns of another person to consider. Although it may be thought of as a shared experience between the patient and her carer, in essence it may be seen as some one else to worry about (Lindop and Cannon 2001). Josie, Eve and Irene remarked that since their diagnosis, their husbands are more anxious than they are,

*My husband always worries about it more than me (Josie 53. 1763)*

*I think he stresses more than me. I just go in and he worries more than me (Eve (29.716)*

*I have to watch what I’m saying because he worries, and he panics like heck so I tend to keep a lot to myself, yeah, to stop him worrying. I offer him a valium sandwich like you know. [chuckles] I suppose that’s because he loves me and cares for me really he panics (Irene 30.989-99).*

As noted in chapter 2, van de Wiel et al (1990) found that the husbands/partners of the women suffered from a considerable amount of stress, and complained of agitation, restlessness and insomnia. This supported an earlier finding by Andreasson et al (1986) who noted that husbands/partners can feel isolated, and suffer from emotional stress following their partner’s diagnosis However this study did not investigate the consequences of the diagnosis of vulva cancer on the husband/partners involved.
**Children**

Seven women had school aged children who were also affected by their mother’s diagnosis. For example, Anne had a history of lichen sclerosis and had required surgery many times over several years. Her two sons were used to her going into hospital. She stated that for them it was a normal occurrence,

*They're used to it because I've had operations over the years. To them um, I mean I've only said “Mummy’s got a poorly tummy, don’t jump on me.” So they don’t, they don’t know what I’ve had done, I just try to get them to not jump on me when I’ve had it done. But um to them it, its normality almost, because I’ve had the operations since I’ve had them (Anne 9. 289-96)*

Other children were affected by their mother’s hospitalisation. Several children thought their mother was going to die,

*He thought his Mom was going to die (Eve 51.1200-4)*

*My daughter was crying and she didn’t think she was gonna have a mum for much longer, which was very difficult, she was only 11 years old (Denise 11.341-3)*

*I think the eldest one has felt um an awful lot through this. I think um, I took the approach that I didn’t tell him anything really about what was going on and I think it had a lot of implications. Because he picked up on words and things that we would say and he related it to that his granddad who is okay after having cancer (sic). But his Nanny Jones and his Aunty Christine are dead (Ria 46.1547)*

The women tried to keep life as normal as possible for the children during the time that they were in hospital, but Julie admitted this was a struggle,

*It was as normal as possible for them (the boys) (Donna 34.819)*

*Me (sic) mum come and helped, helped out a bit with the boys and S. (her daughter) but schooling went through the window and you know the routine all went (Julie 9.293-4).*
Several children’s behaviour at school changed. Eve and Kay recollected,

*It affected him badly. His behaviour in school started to change and what have you, and they wanted to know if there was any reason why, so my mom had to go to the school and explain to them. They noticed that every time I was going into hospital his behaviour would start again (Eve 50.1233-6)*

*She was very tearful. She was at school and she was tearful at school and the teacher saw her crying and said “What’s the matter?” And she said ‘My mum is in hospital, I was expecting my mum home, (sic) she should have come home last night, but she hasn’t and they went and fetched Andrew (her brother) out of class cos (sic) his sister was crying (Kay 48.1614-22)*

Julie found it difficult to explain her diagnosis to her teenage sons because she felt it was so personal, but they coped with her diagnosis as a family,

*It’s a personal place en’t (sic) it just to tell everybody en’t it (sic). That was the difficult part of telling the boys as well wasn’t it. We’ve been open and honest with them haven’t we? From start to finish. They said, the boys, “Okay, that’s enough, no details, we don’t want to know any more like”. We dealt with it as a family (Julie 52.1719-23, 5.138-9)*

Kay and Eve’s children were also helpful when their mothers were discharged from hospital,

*And the district nurse used to call her Nurse B and get her to help and get her involved. I didn’t really want to talk about it ’cos of the area that it was in, you know, I thought what am I going to do, but no, she was really good so (Kay 5.141-7)*

*If I lift anything they give out to me ‘Don’t be lifting’ (Eve 52.1273)*

Julie has now developed lymphoedema which has affected her mobility, and she uses a stick to walk. She described the impact this has had on her young family,

*You know. “Come on mum we’ll take you for a walk,” like I’m 99 and, you know with me (sic) walking stick. They mean well though really deep down. It is like, especially like when the weather’s not too bad and you can go out and they are trotting off in front of me and I’m saying “Slow down, I can’t walk that fast,” when*
they’re used to me like being there, running around with them and I can’t, I do get frustrated at that. But I, I try to do as much as I can but there’s limits now (Julie 33. 1078-88)

Leigh and her son used to do a lot of activities together, which they have not been able to do since her surgery. Leigh noted the effect this had had on him,

*I like to get up to the Lakes, to do things with my son you know. We used to do things together but I mean he knows I can’t do it so he doesn’t ask* (Leigh 27.896-9)

Some of the women found it hard to tell their grown up children about the diagnosis of vulval cancer because of the prognosis associated with cancer in general,

*My daughters (21 and 26) have both left home. I did, I did find it very hard but then they you know they knew something was wrong because they knew I’d been going to different, you know to the doctor.... but they were upset but then they were pleased when the results come back and everything’s okay at the moment so It does hit other people harder than you* (Stella 9.277, 18.579-8416.541-2)

*For, then I went and told my daughter, and she was very upset, more so than me mother, she just dissolved in floods of tears, ‘cos (sic) everybody’s she’s known who had cancer has died. So she was very, very upset and um (sic) told my son, he was well quite shocked really. They were all more upset than what I was* (Josie 15.499-502, 25.504-7)

**Wider family**

Most of the women had support from members of their wider family, for example parents, siblings or grown up children. Sarah took her mother to see the gynaecology oncology consultant and Eve’s mother also went with her,

*And I took my mom, because I knew A (my partner) would ask all the questions and my mom would remember all the answers* (Sarah 8.183-4)

*My mom was with me and my partner was there* (Eve 7.174)

Denise appreciated the support she had from her family,
In comparison, Donna however did not receive any support from her family although they lived locally,

_Three sisters and my Mum live 5 minutes down the road but we don’t ask (them to baby sit) Yes, they all know, but they didn’t offer to help (Donna 31.752-3, 760)_

**Friends/Colleagues**

The diagnosis of cancer has been shown to impact on the woman’s immediate family, friends and colleagues. Most of the women had friends who were supportive at the time of the surgery. Kay remarked,

_Um, but my friend, who is a really good friend, and she’s actually lost her husband as well, she came. So she was um, did everything that she could. She was one of them people that you know who came round and um she cooked the tea and everything, (Kay 6.203-7, 211-5)_

Some of the women were able to discuss their illness with their work colleagues. Sarah was able to do this, although all her colleagues were male. She found them very supportive. Leigh had a similar experience,

_Er (sic) telling my boss which was, that was quite hard because I worked with all men, at the time, so that was quite a hard thing for them to cope with, because you need to tell them, I just think they were obviously shocked, but they were really good, and flowers and cards and things afterwards. They were really, good as they could have been, you know (Sarah 15.332-54, 16.351-3)_

_I mean I had a lot of contact with people from work, although I wasn’t going in. They came to visit me at home, and didn’t avoid talking about it, which is quite nice as well; I feel that it’s quite nice. I had a lot of contact with people from work (Leigh 23.760-6)_

Kay had found that this support is still on-going,
I couldn’t wish for a better team of people to work with, even now (Kay 25.849-50)

A need to be supported in their efforts to return to their normal life as quickly as possible was also reported by Leydon et al (2003). Conversely Anne and Donna noted a lack of understanding from their managers,

I mean my left leg was really still hurting at that time as well. Um, yeah I went back um, I think I just did um three, probably three days the first week and reduced hours but they were very keen to build it up quickly. I felt almost that they thought I was skiving and I had to come up with a plan of how I was going to build up the time. To come up with a date when I would be working full time (Anne 30.986-8)

I told my line manager that I go (for follow up appointments) every 6 months, and she said she had that. I said ‘No you ain’t’ (sic) and explained all about it. She was like I didn’t realise, but I don’t broadcast it, but she knows now. I don’t go out of my way to tell people, it’s not a nice topic (Donna 33.798-801)

Josie is willing to discuss her illness with her colleagues,

But it doesn’t bother me at all (to talk about it), it’s something that’s happened, and if I could talk about it and if it would help somebody else, then that’s fine by me. I don’t want to hide it and I don’t want to shout it from the rooftops, it doesn’t bother me. If I say to people “I’ve been ill, I was off work,” blah, blah, blah, if it comes up in to conversation they’ll say oh “what’s been the matter?” and I tell them, it doesn’t bother me to tell them. You know (Josie 40.1334-9)

The shock of the women’s diagnosis on friends and family is also associated with Aloneness: for want of awareness and openness and this is discussed in chapter 7.

8.6 Summary

This chapter has described the concept of All Change and how the women perceived that their lives had changed since their diagnosis, both physically and psychologically. The impact on their immediate family and friends is also described. The relationship the women have had with the health care professionals involved in their care is also
highlighted. The concept of All Change is interwoven with the concepts already discussed, for example in Aloneness: for want of awareness and is developed further in the following chapter. Here the change is associated with the relationship with the health care professionals involved in their care, and is referred to as ‘Professional Connectivity’. Both positive and negative aspects are described and changes are noted to have taken place following the women’s diagnosis.
CHAPTER 9  
PROFESSIONAL CONNECTIVITY  

9.1 Introduction  
This chapter focuses on the concept of Professional Connectivity and describes the relationship between the women and the health care professionals during the woman’s journey from diagnosis to rehabilitation. They included GPs, consultant gynaecologists and consultant gynaecology oncologists, and practice, district, ward and specialist nurses. The level of expertise that the women experienced ranged from practised care and understanding, to indifference and ignorance.  

An overall view of the UK health care system was provided in chapter 1, and here it is noted that the women in the study had access to a range of health care professionals within the community, cancer units and cancer centres. The experience of these women may be located within the framework of care provided in different settings, within the community and hospital environments. This is summarised in Table 18.  

Table 18: Table to show the health care professionals involved in the women’s care  

<table>
<thead>
<tr>
<th>Community setting</th>
<th>District General Hospital/ Cancer Unit</th>
<th>Cancer Centre</th>
</tr>
</thead>
<tbody>
<tr>
<td>General Practitioner</td>
<td>Consultant gynaecologist</td>
<td>Consultant gynaecology oncologist</td>
</tr>
<tr>
<td>Practice nurses</td>
<td>Genito-urinary clinic</td>
<td>Clinical Nurse Specialist</td>
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<tr>
<td>District nurses</td>
<td></td>
<td>Ward based nurses</td>
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</table>
It is noted that the relationship between the women and their GP, and the women and their hospital based consultant gynaecology oncologist changed from the onset of the symptoms of cancer to the rehabilitation phase. Overall the women had both positive and negative experiences with the health care professionals, and this had an impact on their journey of care from the onset of their symptoms and into the recovery phase. The experiences were related to the professional’s knowledge of cancer of the vulva, and have had on-going implications. In some cases it led to a loss of faith in individual health care professionals, and in others it led to a greater dependency on them. Communication channels between professionals working in different areas of the health service have also varied, between being positive and supportive, to negative and unhelpful.

This was linked to the time element where the women perceived that the health care professionals either had plenty of time for them or the contact was too brief for their needs. Communication with the women themselves in the form of addressing their informational needs has already been examined in chapter 6 on page 132, but in this context it refers to the provision of verbal or written information specifically relating to the surgery and post operative advice.

The concept of Professional Connectivity is shown below,
The knowledge base of health care professionals regarding the symptoms and management of precancerous and cancerous lesions of the vulva is discussed initially.

### 9.2 Knowledge

Four women, Eve, Ria, Anne and Josie, had the precancerous conditions of lichen sclerosis or VIN 3. The probability of one of these conditions developing into invasive cancer has been described in chapter 1, and yet Anne and Josie felt that their GPs did not have any
knowledge about the implications of this. Josie, who was searching for advice on controlling her symptoms of itching due to lichen sclerosis, was not aware that this condition may develop into invasive cancer of the vulva,

My own doctor had never told me... “You must get this looked at every year” (Josie 8.200-4)

One of the GPs at Anne’s practice queried her need for steroid cream to control the symptoms of itching,

She really annoyed me, a woman doctor, because I went for something else and she said sarcastically like “By the thickness of your file I’m surprised you’ve walked here,” sort of. And then she said “I’ve been looking through at all these letters on there and um we, we won’t be diagnose (sic), uh giving you any more prescriptions for steroid cream until you know we, we have a look at this.” In other words it was like this is a load of rubbish (Anne 60. 2015-23)

Ria’s GP admitted that he did not have much knowledge about VIN as it is an uncommon condition,

“And I was trying to get help, I went to see my GP and spoke to him. He was honest with me, he wasn’t sort of trying to fill me with rubbish, he said “I don't know much about the condition,” he said “I really don’t,” he said “I can’t say I’ve ever come across it myself,” he said (Ria 3.97-101)

Eleven women went to their GP on many occasions before they were referred, leading to a delay in diagnosis. Laura and Kay recalled,

He just said, took what I said, gave me a cream and sent me away. Whether he wasn’t bothered I don’t know (Laura 4.129-35)

He said “Well, if it hasn’t gone in a couple of weeks, then come back to me.” So of course it hadn’t gone and by then it was quite a bit bigger, and my lymph glands were swollen on the right hand side. I went back again, he give me (sic) some more antibiotics and said um “Your lymph glands swell up because of the infection.” And he sent me away again, if it hasn’t gone, come back (Kay 2.42-3, 1.16-8, 25-9)
The need for recurrent visits to the GP was also reported by patients with various types of cancer (n=17) by Leydon et al (2003) who noted that GPs did not always have the appropriate training to diagnose malignancy. This may have contributed to the women’s anxiety, as greater uncertainty promotes a decreased sense of self control (Dirksen 2000).

Sarah and Julie recalled that their GP provided false reassurance when they presented with vulval irritation which is a symptom of vulval cancer. The symptoms were attributed to benign conditions noted in their previous medical history and many women recalled that when they saw their GP, he/she did not look at the vulval area. This has been discussed in chapter 6 on page 137.

Detection of vulval cancer relies on the presence of vulval symptoms and the accuracy and the knowledge of the healthcare provider inspecting the vulva. However Stehman and Look (2006) commented that a diagnosis of invasive cancer of the vulva is generally not difficult since most women present with burning, itching, bleeding, or pain in the vulva, and there may be a visible lesion accessible to biopsy. A delay in diagnosis may therefore be attributed to the GP’s lack of knowledge and experience (Jones 1999). Studies on women with breast cancer imply that there may be an association between the length of survival and the duration of the presenting symptoms inferring that the disease is at a more advanced stage because of this (Wilkinson et al 1979). Other studies show that delay is not a significant factor (Fisher et al (1977); Tartter et al 1999). The two women who had the most advanced disease, Laura and Kay, experienced a delay of 9 months and 12 months respectively which was a shorter time than some of the other women. It is not possible to
show if this delay has had an impact on survival since the women were interviewed only once.

Twelve of the women did not attach any sense of blame towards their GPs for not diagnosing the condition earlier. Leigh was magnanimous in stating,

> Obviously going to the GP and them not knowing what it was they couldn’t diagnose it, but that doesn’t matter, no. I suppose I don’t know you feel if you don’t see it every day it must be very hard to detect (Leigh 19.625-7)

Denise however feels angry toward her GP at the way she was treated. She said,

> I actually went to the lady doctor, thinking I might get a bit more sympathy, um and to be honest she wasn’t very good at all...I was quite angry actually about the way I was treated So I think the, the care I had beforehand was not very good from the GP, I think to be honest she was not, not a very good GP (Denise 1.29-34, 2.55-57)

At the time of the interview, it is interesting to note that two women recounted that their GP now shows greater interest and understanding. Kay remarked that her GP has more time for her now. Leigh feels as if she has educated her GP about the condition and she views this in a positive way,

> I would say one thing about the GP now he, I get the impression now that he can’t do enough for me. Because I’ve only got to make an appointment with him and he sees me straight away, and gets me a prescription...Whereas before, he was the sort of doctor who I felt couldn’t wait to get me out of the surgery, you know but now he’ll see to it. He gives me that impression [laughs] Kay (57.1901-8)

> And even with my own GP when I got back, he was asking how it had gone, you know and things like that, and fortunately my GP was good so and he was interested just to know how I am, especially he wanted to know what it was as well (Leigh 19. 614-7)

The impact of a lack of medical knowledge resulted in inappropriate referral to other health care professionals. For example, Josie was seen by skin specialists,
So I’d be back down the doctor’s again and he just kept trying different creams, and that’s how we carried on really… with visits in between to the skin, skin (sic) specialists who um again just did the same thing (Josie 1. 24-29)

Three of the women, Leigh, Donna and Denise, were referred by their GP to a Genito-urinary clinic as it was thought that they had a sexual transmitted disease. Denise and Donna recalled,

She (GP) was giving me different creams and stuff and eventually she told me to go to the GU clinic (Denise 1.33-4)

I even ended up in the GU clinic. They said there was nothing wrong, and they gave me laser treatment. I had two lots of laser treatment (Donna 2.42-3)

A fourth respondent, Julie, was referred to the GU clinic by her local hospital doctor. The feelings of stigma associated with the referral to the GU clinic were referred to in Aloneness; for want openness, chapter 7, page 172.

Several women recalled that the gynaecology consultants at their district general hospital displayed a lack of knowledge about the aetiology of cancer of the vulva. Stella and Julie remarked,

For four or five years I had gone to Hospital B and they kept telling me there was nothing wrong with me They kept telling me it was thrush. I said “I’ve had thrush before, it’s not like this” (Stella 27.904)

I was in and out of hospital for months up here in X they didn’t know what was wrong, couldn’t find nothing (sic) wrong (Julie 1.11-13)

The perceived lack of knowledge also led to feelings of anger towards the doctors involved. Donna recalled her anger with a consultant gynaecologist. He had laughed at her when she had asked for a second opinion,
I said I felt something was wrong but he said it was all in my mind, and there was nothing wrong with me. He just laughed at me, but I knew it wasn’t right so I asked for a second opinion (Donna 1.19-21, 3.66-67)

Anger towards health care professionals involved in the diagnostic experience has been shown to have implications for on-going care in terms of satisfaction and trust in the care they receive (Leydon et al 2003). Both Donna and Denise demonstrated this at the time of the interview, and have lost of faith in these health care professionals. This is discussed later in this chapter.

The lack of knowledge of these health care providers also led to the women’s perception that they had experienced a fragmentation of care. Eight women were seen at several different hospitals by many different doctors before their diagnosis was made. Preti et al (2005) have reported that multiple different healthcare providers, including dermatologists, gynaecologists, GPs and those providing care in sexually transmitted disease clinics may be involved in the investigative process leading to a diagnosis of cancer of the vulva.

Positive experiences of the referral by their GP to a consultant were recounted by several women. Anne’s GP had attended a lecture given by a consultant oncologist who specialised in the care of women with lichen sclerosis. As a consequence, she was referred immediately. She recalled,

And fortunately the doctor I saw, a woman doctor that time had been to see... at one of his lectures and as soon as she saw my skin condition she said um “I need to refer you to a specialist.” (Anne 2.37-40)

Two other women, Irene and Sarah, were referred to a consultant gynaecologist immediately by their GP. Sarah was treated in the private sector, as she received private
health insurance as part of her employment and received her appointment the following week,

*I was in BUPA (private health insurance scheme) with my job, at the time, I’ve remained in BUPA, because they seemed good to me, um, so he (GP) arranged for me to go and see a gynaecologist at X* (Sarah 3.61-3)

Irene recalled her GP’s reaction,

*The doctor’s (GP) reaction was “Oh God, that’s got to go.” [laughs] (Irene 1.36)*

Irene was seen within 14 days at her local hospital, according to the NHS Cancer plan Guidelines (DoH 2000). The speed of her referral alerted her to a possible diagnosis of cancer,

*I went to the gynaecology clinic first and that was eight days later I got the appointment, and then she passed me over to A. Which was about, that was exactly a week... It was very quick. Very quick (sic). That’s when I thought, I had an idea that it is a cancer, because of the speed of the treatment* (Irene 2.57-64)

Ekwall et al (2003) also emphasised the value of coordination between the various hospital department and health authorities in her study of 14 women with a gynaecological cancer.

To summarise, the women had both positive and negative experience in their relationship with the medical team involved in their care. Involvement with members of the nursing profession reflected similar contrasting experiences.

9.2.1 Nursing knowledge

Hospital-based registered nurses showed a lack of knowledge about VIN 3 and vulval cancer. This is possibly due to the fact that they are rare conditions and they may not have
encountered other women with the same diagnosis. Eve had attended a casualty department with an unrelated problem, and she saw the fact that the staff had immediately put gloves on before they gave her any nursing care. She presumed that the nurses did not have any knowledge of VIN and they had thought it was a sexually transmitted disease. Leigh also remarked that a friend who was head of midwifery and psychiatric care had not heard of vulval cancer,

*It was just in the Accident and Emergency. They thought it was a sexual disease and they put gloves on. My Mom had to explain* (Eve 41.1003)

*And there’s someone else who’s a very close friend of my sister-in-law she’s um, she’s head of midwifery and psychiatric care and she’d never heard of it (cancer of the vulva)* (Leigh 39.1314-7)

Anne was treated in the private sector and recalled a lack of nursing knowledge in her perioperative and post operative care. She felt that the nurses did not understand the importance of measuring the fluid in the redivac drains following the removal of her lymph nodes. She attributed her post-operative lymphoedema to a lack of care. She felt that this was due to the nurses’ lack of experience with women following vulval surgery and it resulted in a loss of confidence in the nurses, who were looking after her,

*They didn’t, they weren’t even measuring the lymph fluid that was coming out even though (consultant gynaecology oncologist) was asking them to do it. Um so he couldn’t measure whether I’d got to have the drains out or not. They left one bottle - where I’ve got the lymphoedema - closed so they put a new bottle on but left it closed. I called the (sic), well I told the nurse that my leg was burning up, it was really hurting and they said “Oh I don’t know.” So I called a nurse and they unlocked the bottle but by that time this leg was really inflamed and sore. So that didn’t instil me with any confidence. They (the nurses) going privately they weren’t used to my operation (sic)* (Anne. 26.867-9, 26.871-9, 28.945-6, 36.858)
The inexperience of the nurses who were caring for Anne appeared to have been endorsed by the consultant gynaecology oncologist as the nurses were reluctant to remove Anne’s stitches post operatively,

*And I mean even when I went to have the stitches out... they were like you know “What are you doing here, you could have gone to your local doctor’s.” He (consultant gynaecology oncologist) said “I thought they might just be interested in like seeing it (Anne’s care) sort of all the way through and having the experience that this is an unusual case and you know that they would benefit from it (Anne 28. 920-926)*

Following the development of her post operative lymphoedema, Anne was referred to a local hospital for specialist care but received inappropriate advice. This may have been because the care of lower limb lymphoedema is highly specialised,

*I got referred to C for the lymphoedema before I saw ... (Lymphoedema CNS) um and they to be honest didn’t really know what they were dealing with. They gave me um like a compression stocking, an electrical one to compress and whatever, but it was just pushing all the, the lymph fluid up to where I’d got the problem (Anne 92.1764-9)*

Anne also found that the practice nurse based at her GP’s surgery showed a lack of knowledge and understanding about her illness. The lymphoedema Clinical Nurse Specialist had suggested that she called at her GP’s surgery for some antibiotics for post operative cellulitis. She recalled the practice nurse’s lack of understanding, until she had to physically demonstrate the extent of her surgery by lifting her skirt to show her the vulval area. This may be attributed to the practice nurse’s lack of experience of women following a vulvectomy.

*I was trying to explain to her and she was saying “Well you know you can’t have any antibiotics without seeing a doctor.” And then I was trying to explain to her that, that I had done and she obviously didn’t understand and um, so I said “Well shall I show you?” and she said “Yes,” so I lifted my skirt up because I hadn’t got any*
knickers on or anything and she was like, she didn’t expect to see the scarring or whatever that I’d got and she was like “Aagghh, lie down on the couch.” Her attitude changed immediately and she said “I’ll go and get the doctor to see you now.” But um, but she saw the scars and the stitches and she wanted me to lie down immediately. Where up to then she, she (sic) hadn’t even said “Take a seat,” I was standing (Anne 67.2231-2252)

She summarised her experience as,

*I just didn’t feel I was getting the support (I needed) (Anne 27.897)*

For the majority of women, the nursing care within the cancer centre was generally perceived as being very good. This is probably due to the nurses’ experience in the care of these women over many years,

*They were brilliant, they were all really nice, it is my second home (Eve 11.269)*

*Everyone was very very (sic) good, they treated you as if you were special (Leigh 7.233-6)*

*I couldn’t fault them, very caring (Irene 62.1751)*

*I couldn’t have got better care from any of them (Josie 47. 1897-1909)*

These nurses showed an understanding in addressing the women’s needs. The needs of the women were anticipated when they were being seen by the doctors post operatively. This was associated with the number of doctors involved on each occasion. Denise and Kay recalled,

*I do find the staff there quite um understanding about how you feel and if, it’s not the best place to have looked at. In fact I think that part of my body is probably more famous than the rest of me…I do find with the staff at X have been quite sympathetic towards the way you feel, you know, they, they understand I think to a certain extent (Denise 17.572-9)*

*But the nurses were good if I didn’t want too many people (Kay 15.483-4)*
Josie was seen by the district nurses daily on her discharge home following a postoperative wound infection. She felt that they showed their knowledge of wound healing by advising her to have a high protein diet. Josie became involved in trying to help herself, and responded from feedback from the district nurse,

*She (the district nurse) told me to so eat protein, so I packed, packed (sic) protein, you know, to just sort of heal and she used to say every time she come in, “I can’t believe how you’re healing,” she said “every day I come in here and you’re healing is (sic) before my eyes so to speak,” you know the cavity was healing so fast (Josie 29. 967-977)*

Ria’s wound also broke down post operatively. Her practice nurse anticipated that she may have difficulty with micturition and suggested an in-dwelling urinary catheter,

*And we went down first thing to see them (GP and practice nurse), the nurse came in to see me and she said “Have you managed to for, been for a wee?” I said “I went,” I said “but it was absolutely excruciating, it’s just awful.” And she had a look, she said “We can’t dress it,” she said but she gave me like a little squeezy bottle of gel that you could put in the actual hole that had developed there. And I, and she put a catheter in for me, so I had that in for about two and a half weeks (Ria 7.223-8)*

To summarise, the knowledge base of the health care professionals contributed to two contrasting feelings. Some women felt a strong sense of dependency on their carers with a heightened sense of trust, while other women demonstrated a loss of faith for any future care that may be required.

### 9.2.2 Dependency

Leigh and Sarah recalled the trust they had in the medical and nursing team. This was based on their knowledge of their condition,
I couldn’t have asked for anyone better. I was in the best pair of hands (Sarah 9.198, 14.319)

I felt safer with people who knew what to do (Leigh 18.601-10)

Julie was willing to travel over 100 miles for her lymphoedema treatment rather than going to her local hospital. It was partly due to the long waiting list locally, but also because she had developed a dependency on the health care team, who had cared for her,

She (Clinical Nurse Specialist) said “It sounds as though it’s lymphoedema,” so they’d write to my doctor to get me transferred up here to see the lymphoedema nurse but it hasn’t worked out. I’m going back to X, because of the enormous waiting list up here. As I said we didn’t mind that one little bit because you know you’re going to get the treatment down there (Julie 23.740-6)

The two women who are treated in the private sector, Sarah and Anne, voiced their anxieties if they were discharged from their consultant’s care. Sarah described her feelings of panic and Anne stated that she would worry,

It's a comfort to know, you know, there's things I can't see there and he has got the microscope and he can see anything before it's visible. I would panic. I would have a major panic if ever I didn’t see him (Sarah 56.1268-70)

I often wonder what would happen if he retired or whatever because I've only ever seen him ….. So suddenly [laughs] you know if that all went I'd probably worry then (Anne 52.1729-30, 1743)

A dependence on the doctors involved in the care has been noted in the study on gynaecological cancer patients by Ekwall (2003) who emphasised the importance of continuity of care with the doctors and by Mast (1998) in a study on breast cancer patients. Tishelman and Sachs (1992) also emphasised that cancer patients thought it was ‘important’ or ‘very important’ to see the same doctor at every visit. However this opinion was not remarked upon by the women who are being treated in the National Health
Service, where there is a team approach of medical staff with registrars and sub speciality trainees seeing patients.

To summarise, the findings note that a woman’s dependence on the doctor may arise prior to the women’s diagnosis, and continue into the rehabilitation phase. This was reflected in chapter 6, page 137 as the majority of women appeared to return to the same doctor for further appointments in their search for a definitive diagnosis prior to their referral to a specialist and the commencement of treatment. Here, the women expressed feelings of dependency on the medical team for many years after their diagnosis.

9.2.3 Loss of faith

In contrast to feelings of dependency, four women reported that following the onset of their symptoms leading to a diagnosis of cancer, they have lost faith in their doctors. Anne and Denise have lost faith in their GPs. As her GP indicated that she had little knowledge of lichen sclerosis, Anne will not see her again, while Denise confided that she required counselling as she felt so angry towards her GP,

She (GP) said “We won’t be... giving you any more prescriptions for steroid cream until you know we have a look at this.” In other words it was like this is a load of rubbish...and so I never saw her after that again; I wouldn’t go and see her (Anne 60.2015-23)

I went to my GP. She was completely at a loss and I really don’t think she was a very good doctor. I did land up having counselling in the end and I was extremely angry um towards this doctor about the way things went (Denise 2.57-64)

The GP’s lack of knowledge has also extended into the recovery phase for Denise. She now feels unable to go back to her GP for her cervical smear as she is worried that the GP
has not seen a post-vulvectomy patient before. She prefers to have her smears at the cancer centre,

I wouldn't want to go anywhere to have smears or anything done because I don’t know whether them people (sic) would have ever seen anybody looking like me. So it would be really difficult for me to do that. Um in fact if, if they hadn’t have done it at the hospital, which they did, I wouldn’t have gone to my doctors for it. Although I have discussed it with one of the nurses and she said “oh don’t worry, we'll sort it out,” I wouldn’t feel comfortable with it, I really wouldn’t (Denise 33.1096-1102)

She compared her care at the hospital with her GP when she remarked,

The care at the hospital was wonderful compared to what happened at our doctors (Denise 48.1610)

Donna and Julie have lost faith in their local hospitals. Donna was seen by three different consultant gynaecologists, but her cancer was not detected. Her feelings towards this hospital are noted in her remark,

If I hear that anyone is going up to Hospital M, I’d say ‘Don’t bother’. I wouldn’t trust them further than I could throw them (Donna 26.628)

Julie was seen at her local hospital for over 12 months, before being referred to the Genito-urinary clinic. Following a biopsy she was not told her diagnosis for a further 4 months. She has now lost faith in the hospital staff,

I was having investigations for over 12 months. They never really said anything, they just kept saying they didn’t know what it was, they didn’t know what it was (sic).... I was messed about for months on end... I’ve literally lost faith in Hospital X (Julie 3.74-85)

A loss of faith in the health care providers has been shown to be linked to the concept of searching, page 137. As noted earlier, it resulted in a delay in diagnosis of cancer. While it
is not known if the women’s prognosis has been affected by this delay, it supports the study by Leydon et al (2003) who noted that the diagnostic experience has implications for on-going trust in the care they receive. Confidence in a health care provider may also be linked to the manner in which information should be given and the women demonstrated a variety of ways in which the doctors communicated with the women themselves, and with their colleagues in the hospital and community settings.

9.4 Communication

Effective communication is widely regarded to be the key determinant of patient satisfaction, compliance and recovery particularly in the care of cancer patients (Faulkner 1998, Fallowfield and Jenkins 1999). Good communication relies on the voice, the words used, the tone and manner, facial expressions, eye contact and expression and body language (Cooley 2000) but also needs to incorporate therapeutic skills, organizational skills and educational skills (Burnard 1997).

Several women received appointments at the cancer centre but were unaware of their diagnosis. Leigh and Denise had previously had biopsies at other hospitals and it is not known why they had not been given their results earlier, especially as health care professionals have a legal, moral and ethical duty to inform patients of all developments of their progress (Franks 1997). Leigh and Denise described their shock,

*I had the biopsy in the August and got the appointment in the October. I wasn’t actually thinking anything because nobody had broached me and sort of said you know with the results, it could be this or it could be that. Nobody said anything. It was just that you know you’ve got an appointment at A. And that time I didn’t know like that A was anything other than just a normal hospital; I just thought it was just for the gynae area, that was all. So I didn’t know until... (consultant gynaecology oncologist) actually said. It was a shock (Leigh 4.126-35)*
He (consultant gynaecologist) did a biopsy and the next thing I knew I’d had, I had a phone call from (consultant gynaecology oncologist’s) secretary asking me to go there. But nothing was said at the time that he, (sic) it could have been what it was (Denise 2.37-42)

The manner in which a diagnosis of cancer is communicated to people is pivotal in adjusting to what may be an uncertain future. The way in which the women were told their diagnosis varied considerably.

Irene suspected her diagnosis as she was told indirectly over the telephone by a consultant gynaecologist,

She (Consultant Gynaecologist) phoned up and she says uh (sic) “You need to be seen by somebody else.” She didn’t tell me over the phone that it was cancer, “No”, she said uh (sic) “I think you’ve, you’ve got your own ideas.” (Irene 4.113-24)

Julie and Kay recalled the shock on being told that had cancer,

And I was, I was in shock, I just I, I didn’t know what to say or what to do (Julie 3.93-6)

So I just thought it was like the end. The first thing I thought about it was cancer because obviously I’ve got two children. That’s it (Kay 3.70-1)

Donna recalled her anger at the time as she felt she had been misdiagnosed by a doctor previously and Stella described her lack of preparation for her diagnosis,

I was expecting something minor as the doctor at the other hospital said it was all in my mind. I felt angry, really angry. You’ve just got no idea what you are going to be told, no indication at all). I felt angry, really angry. I was so angry and if that other doctor had been anywhere near me I would have strangled him (Donna 3.55, 3.65-6)

They kept telling me I had a little skin infections or something but nothing prepared me for him actually telling me I’d got a cancer tumour (Stella 7.220-1)
The findings from a study by Leadbetter (2001) (n=10) showed that those who suspected that they may have cancer or those who had been prepared, were able to understand and retain information compared with other patients. This has also been noted in a study by Leydon et al (2003) that minimal or no orientation to cancer possibilities could influence levels of satisfaction with subsequent care.

In recent years, more attention has been paid to teaching communication skills in both undergraduate and post graduate nursing and medical training (Maguire and Pitceathly 2002). However doctors also need the appropriate knowledge and understanding about the disease in question (Meredith et al 1996). Since there are only 1000 new cases of cancer of the vulva each year, it may be that doctors may not have an adequate knowledge base regarding the importance of staging the disease and the treatment available. Meredith et al (1996) reported that 60% of patients wanted to be told by a hospital specialist, who would be able to support them and provide information about their cancer and treatment. A study by Corney et al (1993) on 105 women has also shown that women with a gynaecological cancer worry more about their condition than patients with cancer in general. Ekwall (2003) also notes that the point at which a diagnosis is given constitutes a significant point in their lives.

Anne and Eve were being followed up for precancerous conditions were told by doctors that they had previously met at other hospital out-patient appointments. Ekwall et al (2003) reported that the least painful way of being informed of their cancer was to be given the information by a doctor that they knew.
At the time of the interview, Ria was still unsure of her exact diagnosis, and it is causing her some distress,

When I saw... then for my biopsy results, I said what were the results? And all he said was there was some cancerous cells there. And I did say to him, “Does that mean I’ve got cancer or does that mean I’ve got VIN 3?” And have I been able to get any answers? No, nothing at all (Ria 10.242-254)

This reflected the nature of anxiety was also noted by Meredith et al (1996) who reported that 96% patients had a need or an absolute need to know if they had cancer.

Four women were told on their own, without support from their husband/partner although one of the recommendations in ‘How to break bad news’ advises that patients should have a relative or friend with them when they are given a diagnosis of cancer (Buckman 1992). This number may be fewer than expected from the study by Corney et al (1992) who noted that 66% of women (n=105) had been told on their own. Sarah had attended her appointment on her own, because she was not expecting to hear the news, 

(My partner) would have come with me because it's only just down the road, but he had a tennis match that Wednesday night, because he plays league tennis. I said, "No, you know, I'll be fine". So no I went on my own, which was a bit hard. (Laughs). In hindsight I wouldn’t have gone on my own (Sarah 10.223-233)

Donna had also seen the consultant by herself, 

I never dreamt it was cancer. It was just a total shock I was just on ‘automatic pilot’. I never heard anything that he said after he said the word cancer. It’s an automatic reaction just to think the worst. I was expecting something minor (Donna 2.47-50)

The doctor who informed Denise ensured that her husband was with her when she was told her diagnosis. Laura also appreciated the support she had from her family.
This registrar came and called me and took me in to this room. I um still didn’t think anything and um he said “Have you got anybody with you?” And I said “Yes, my husband,” and he sent the nurse out to fetch my husband and she came in and I still didn’t think anything, I must have been a bit thick really. And then he actually told me that it was cancer and I was absolutely dumbstruck (Denise 8.264-71)

I’ve been quite lucky, ‘cos when, every time I’d gone to hospital someone always come (sic) with me (Laura 8.264-5)

The development of a good relationship involves the utilisation of good communication skills. This was illustrated by several women,

The doctors were all very nice they didn’t sort of talk to you like you were an idiot. Like I said that’s, a lot of doctors are very arrogant I found them. No understanding. But there was nobody like that up there, I found they were all quite compassionate and caring and kind. Yes. People are always there to answer questions (Josie 59.1962-6, 25. 817-9)

He sat there like on the couch with me and he made me feel so at ease straight away with his, his mannerisms and the way he was and he explained everything in as much detail as he could explain so I could understand you know there’s all the medical jargon but he tried to explain it in the way I could understand it (Julie 35.1156-9)

For Donna and Denise, this applied to all the members of the gynaecology oncology team,

When I go to the clinic, everyone’s helpful, not just (consultant), all the nurses and doctors. They talk to you and tell you things (Donna 32.784-6)

Some of the (nursing) staff, they’ll come and just sit and talk to us and I mean it really helps, you know, if you’re sort of, the staff’s approachable which they were. I mean all the ones who I’ve dealt with have been really nice. This last time I was in it was a lot busier, um there was the one girl who was on still came and sat and talked to me (Denise 15. 488-96)

Stella found her consultant gynaecology oncologist was less easy to talk to,

He was very honest, bluntly honest (Stella 7.210-11)
She justified this by saying that she had asked him to be honest with her regarding her diagnosis and as a result she was able to cope with her treatment. This display of a ‘fighting spirit’ was referred to in Chapter 8, All Change on page 194.

*Its upsetting and you have a few tears and that but when I came out I thought well I’ve got to deal with it (Stella 6.186-9)*

Anne however was treated in the private sector and felt that while she was able to talk to her consultant, he was the only person she could talk to and that was only briefly,

*And because he (consultant gynaecology oncologist) was the only one that you saw, I mean he was visiting every day but that was like five minutes every day where you feel you can talk to somebody (Anne 27.884-6)*

In addition, Anne did not appear to be able to talk to the nursing staff, as she recalled that she had had minimal contact with them,

*I’ve only ever seen like the nurses there um, but that’s just to take your blood pressure or whatever (Anne 11.356-7)*

Only one of the earlier studies refers to the communication the women had with their health care team (Weijmar Schultz et al 1986). Here 9/10 women interviewed had satisfactory contact with the medical and nursing team during their stay in hospital and the doctor in the out-patient department was also a source of support post operatively (Weijmar Schultz et al 1986).

The manner in which the women were communicated with may depend on the personality of the health care professionals involved and their years of experience within the health care system. The positive remarks from the women included adjectives such as ‘nice’,
‘helpful’ and ‘caring’, while the women who had negative experiences described the staff as ‘blunt’, ‘arrogant’ and ‘providing inferior care’. Nevertheless both doctors and nurses have a duty of care to their patients to treat their patients politely and considerately, meeting their needs and serving their interests and this is a necessary obligation stated by the professional affiliations of the General Medical Council (2006) and Nursing Midwifery Council (2004).

Communication between health care professionals in the hospital setting and care in the community varied considerably, and it was noted in Chapter 6 page 144 that there was a delay in the referral process between hospitals. Examples of good communication may be related to close working relationships within the same hospital or geographical area. For example, three women were seen by a consultant gynaecologist and referred to the consultant gynaecology oncologist in the same hospital. Stella and Laura recalled the ease with which this referral took place,

*It was the Dr X (consultant gynaecologist) who told me about the cancer. And because she’d discussed it with him and referred me on to him, and then he came across to have a word with me as the clinics were running at the same time. Yes, they told me when I had to come back into hospital straight away, they even told me the day; they’d even pencilled the date in - ready! [laughs] (Laura 10.329-10)*

*I saw Dr A (consultant gynaecologist). Um I think it was Dr A and then she said, she went to fetch ... (consultant gynaecology oncologist) to come and have a look because his clinic was next door or something, (Stella 4.118-9)*

There was also good communication between the nurses within the hospital setting and the district nurses who worked in the community,

*She sent the district nurse in (Ria 34.1128-9)*
They’d (hospital nurses) arranged for the district nurses to come in. The district nurses came in the following day (Josie 18.594-605, 19. 643-52)

Kay recalled a delay in her referral for treatment of her lymphoedema. She felt that this should have been arranged sooner,

So I hadn’t actually seen the lymphoedema nurse, cos they said they’d try to get me an appointment and fit me in, and that was the first time they could fit me in which I thought was a bit much. I think, I think it should have been sooner. But then I couldn’t have um, I was just waiting around in August, waiting for my radiotherapy to start. I was certainly expecting to see the lymphoedema nurse before I did actually (Kay 33. 1105-7)

Laura was also treated in the National Health Service and felt that she did not receive the support she needed as she was not given a set of vaginal dilators to use after her surgery. She subsequently developed vaginal stenosis and she is now unable to have intercourse, as discussed in Aloneness: for want of normality, chapter 7, page 150.

Two women commented that they did not feel that their GP was kept fully informed of their treatment. Anne felt that her GP did not know enough about the surgery that she had had in the hospital and Laura made a general comment,

Because you think either (consultant gynaecology oncologist) would say to you beforehand “You need to have this time off so this is what you need to do,” or if when he sent the letter the doctor should contact you or ring you and say: “Are you OK, I understand you’ve had this operation privately?” And, because if you think my doctor is not sort of involved in it, because I’ve been seeing (consultant gynaecology oncologist) for so long I just go and see him, I have the operations and then they just get a letter, they don’t really know me. So that, there is a bit of breakdown in communication (Anne 22.726-32)

The GP practice I have nothing to do with them. ‘Cos I, I’ve moved from one surgery to another in the last twelve months, so they have had nothing to do with this, it’s all gone through the hospital (Laura 61.2039-41)
9.4.1 Time element

Good communication with between the health care professional and the respondent is also dependent on the amount of time that is spent during the consultation (Attree 2001). Time, within the National Health Service tends to be viewed in a linear way in terms of minutes, for example the standard eight minute appointment time at the General Practitioner’s surgery, and days, for example the fourteen days between the date of a referral letter for a patient suspected of having cancer to being seen by a consultant (NHS Cancer Plan 2000). Follow up appointments are given at three to six monthly intervals. Given time, however, is the time provided by health care professionals to ‘be with’ patients to provide psychological support, to answer questions, provide information and enable them to assimilate this information. Given time provided by nurses is seen as non-linear as the experience lives on into the present and the future (Jones 2001).

Although very little research has been done about how given time has been valued by patients (Jones 2001), the women viewed the time given to them by the doctors or nurses caring for them in either a positive or negative way. Both Julie and Kay referred to the brusque way in which that were told their diagnosis,

But it was so matter of fact that, just went in to the consulting room and this doctor just blurted it out, said “It’s cancer, we’ve got to do a vulvectomy and a lymphectomy,” (sic) and just given two pamphlets and that was it, and “Go and wait outside” I just, I was crying all the time, the blunt way they told me like, it was so hard (Julie 3.89-91, 12.379-85)

Well, the doctor just came out with it. I thought it was a Bartholin’s cyst, you know and I’d had the surgery because it was only like three weeks later that they said it was cancer. They just came out with it and said that they had analysed it at the time and it was cancer (Kay, 3.68-78)
Several women felt that the doctors in the hospital did not give them enough time to answer their questions, and the atmosphere was too rushed,

*The doctors have been good but again I don’t feel through no fault of their own that they have enough time to sit and spend and explain to a patient. Not just me I’m sure it’s the same for everybody, the National Health waiting list is stretched that tight. Not enough time to sit and explain (Ria 89.2976-2996)*

*It’s not relaxed enough, the atmosphere, if you was (sic) in a more relaxed sort of situation you may be able to talk about... (any concerns), but it isn’t, you sort of go in, you’re examined and you’re sort of chucked out like, you know. So it’s not really, it’s not really the right environment I don’t think (Denise 41.1354-68)*

*It’s just people don’t have the time in modern day hospitals to spend as much time with patients (Stella 55.1851-2)*

This may have been due to the fact that out patient clinics are busy and time with patients tends to be limited. The apparent sense of being rushed during their clinic appointment may be a reason why the women did not feel able to discuss the impact of their surgery,

*I perhaps might have asked them if there was someone else I could have talked to – I always felt he was a very busy man (Josie 66.2217-24)*

Ekwall et al (2003) found that adequate time for talking to healthcare staff was perceived as an important aspect of health care quality.

Perceived inadequacies within the NHS were also noted by Leydon et al (2003) on 17 cancer patients. Here the respondents presumed that treatment within the private sector would be superior, but in this study it did not appear to occur in every case. Anne and Sarah were treated privately by two different consultants. They had varying perceptions about the amount of time their consultant gave them. As noted earlier, Anne recalled,
And because he (consultant gynaecology oncologist) was the only one that you saw, I mean he was visiting every day but that was like five minutes every day where you feel you can talk to somebody (Anne 27.884-6)

In contrast, Sarah had a positive experience,

You could ask him anything and he would always spend the time and he would give you an honest answer and he wouldn't mind at all. I was able to ask (consultant gynaecology oncologist) any questions we wanted. Just cos (sic) it’s private, well perhaps you do get a bit more attention, you perhaps get a bit more time being private (Sarah 9.192-3, 23.516-7)

Good communication also involves the provision of information which is known to reduce anxiety, develop coping skills and enhance recovery (Mills and Sullivan 1999).

9.4.2 Information provision

Informational needs may vary according to the stage of disease trajectory, be it at the time of diagnosis, surgery, adjuvant treatment, rehabilitation or in discussing prognosis. As already mentioned, many women with vulval cancer may be diagnosed at one hospital and then referred to another hospital for staging and further treatment. Information about proposed treatment may not be available. This may be because of the rarity of the condition (Janda et al 2004). However the Improving Outcomes in Gynaecological Cancer (DoH 1999) recommend that all sexually active women and their partners should be offered specific information with the emphasis on the effects of surgery and treatment on their relationship, to minimise any adverse effects. The women were asked about information at just two points of their cancer journey prior to the surgery and post operatively. Twelve women had received pre-operative verbal information. This information may have been provided by the consultant gynaecology oncologist, Clinical Nurse Specialist or one of the ward nurses. This is shown in Table 19.
Table 19: Access to pre-operative information by the women

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Only one woman said that she had not received any verbal information and this was Anne. She was treated in the private sector, and had multiple previous operations. She was unaware that she was going to have a vulvectomy,

*I didn’t, I didn’t (sic) realise at the time as I say what I’d actually had done (Anne 10.339)*

Cortis and Lacey (1996) recommend that written information should be given to reinforce verbal information. Only 5/13 women recalled receiving any pre-operative written information. Laura remarked that her written information was not very helpful, but she found that her pre-admission appointment was more constructive,
I mean I was, well what I found more helpful was what they told me. And then when I went for my pre-check before the operation that was even more helpful Pre op, the staff nurse drew me a diagram which was helpful (Laura 12. 392-8, 60.2019)

The remaining 8 women did not receive any written information. Specific information on vulval cancer is not readily available in the private sector, but it is not clear why the other women did not receive any. It may be that the interviews with the respondents were conducted between six months and five years after their surgery and it may have been forgotten, as Donna and Josie mentioned,

I can’t remember if I had any written information (Donna 9.223)

No written information, not that I remember, no (Josie 22.714)

The women were also asked if they received any information after their surgery. Eleven women stated that they had received post operative verbal information and only 5 received post operative written information. This is shown in Table 20.
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<th>Name</th>
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Denise and Donna reported positively,

*He (consultant gynaecology oncologist) tells you, I mean that was brilliant cos (sic) he tells you everything I was given loads of information to come out with and a phone number (Donna 6.148, 18.438)*

*I felt all my questions had been answered (Denise 12.393)*

Two women treated in the private sector, Sarah and Anne, stated that they were not given advice,

*I don't think I was (given any advice). I knew I couldn't drive (Sarah 33.744)*

*I wasn't given a booklet to read when you got home or any advice, No (Anne 20.660)*
Several women remarked that while some information was given, they were not fully informed of the extent of their surgery or the impact this would have,

_They gave me leaflets and different things but just on cancer which I suppose doesn’t prepare you for actually having the whole front bit removed, I thought he was just gonna (sic) take the tumour away. He didn’t tell me that they were actually gonna (sic) take the clitoris away (Stella 19.337-4, 10.328-9)_

_Because he’ll just say like, we are taking this and that. It’s never just 2 or 3 stitches. It’s always like 2 or 3 stitches everywhere, not just in one part. You find it’s gone right around it and you have more stitches than what he says (Eve 43.1049-53)_

_All of the leaflets don’t really explain, which I suppose is hard for them to do, your particular case. Like the woman who goes in before you may only have the size of, I don't know, a tiny little bit taken away and she probably may not notice an awful lot of discomfort. They don’t sort of say well if you’re having a large area you can expect to be in absolute agony to go for a wee, nobody ever told me it was gonna (sic) be like that (Ria 24.784-90)_

_There could be more information, easier to understand (Laura 60.2005-6)_

Kay did not receive enough information about the risk of lymphoedema or the side effects of radiotherapy,

_It was just said ‘lymphoedema’ well it was like a vague explanation, so I just thought oh its just a minor thing, and they asked me if I knew and I said yes because you have to, you have to tell them that just in case. But I wasn’t really expecting it to be as fast, as speedy and as life-changing as it has (Kay 32.1055-59)_

Previous studies also noted that there was a variation in the amount of information provided, as discussed in chapter 2, Table 2. The deficit in the provision of information was also noted in Aloneness: for want of awareness, chapter 7, page 168.

However Eve and Josie stated that they would not have wanted any written advice,

_I didn’t get any written information – I wouldn’t have wanted any (Eve 9.231-3)_
These comments emphasise the dilemma that nurses have in providing appropriate information at the time that it is needed and highlight the need for information to be based on what patients’ require, rather than the professionals’ assumptions of their needs. Women should be provided with individualised information about their surgery for cancer of the vulva and the post-operative consequences, as recommended by Ekwall et al (2003). Weijmar Schultz et al (1986) noted that even if the quality of information, coping and communication are classified as sufficient this does not automatically result in complete sexual rehabilitation, nor does insufficient information, coping and communication exclude complete sexual rehabilitation. It is clear that information should be tailored to the needs of the woman and her partner and available and adaptable to their requirements at all stages of the disease trajectory. The fact that information is an individualized aspect of care for newly diagnosed cancer patients is also noted by Mills and Sullivan (1999).

The comments made by the women may also be examples of the consultants displaying a paternalistic attitude towards women in their care. Although a paternalistic attitude was prevalent in the 1960-1970s, when the doctor decided what information the patients required for ‘the good of the patient’ (Mills and Sullivan 1999), patients now have a right to be told the truth about their condition and treatment is now seen as a partnership between the patients and the professional (Adams 1991). A study by Grahn (1996) noted that staff may still be acting paternalistically by filtering information to patients in a way that they consider to be appropriate. Steginga and Dunn (1997) supported this by noting that physicians were sometimes seen as providing inadequate information and practical support to gynaecology patients. The most desirable attribute in professional practice
according to Fallowfield et al (2002) is that of honesty and truth-telling and consistent information is paramount in the provision of good quality care.

At the time of the interview, many women wished that there were more leaflets about cancer of the vulva available in the community in order to raise awareness among the general public. Sarah and Eve noted,

_I think that's quite a good idea if there's a leaflet in the (GP) surgery, because my friends had never heard of it_ (Sarah 57.1309)

_When you go to the doctor’s surgery or even into the hospital it's always breast cancer or something else or something for the men but you don't see posters up about it (VIN or cancer of the vulva) (Eve 39.956-7)_

Leigh remarked that if there had been more awareness in the community, it might have made a difference to her,

_If they (women) knew what to look out for like, if I'd known that it could have been cancer you know, then I would have been more likely to go the GP before. But not even thinking that it could be, I mean it never entered my head_ (Leigh 39.1291-3)

Only one woman did not think that having a leaflet in the GP’s surgery would be beneficial because of the rarity of the disease. Anne said,

_I don't think so because I mean breast cancer is probably the most common isn't it and you're told about examining yourself for lumps. You're not told um with this but its very unusual isn’t it, so_ (Anne 50.1689-92)

Janda et al (2004) also reported that women desired to have more information about the presenting signs of vulval cancer.
9.4.3. Information provider

While the provision of information may be considered to be the remit of all members of the gynaecology oncology team, it may be seen as one of the particular responsibilities of the Clinical Nurse Specialists (see Appendix 2). Eight women had access to a CNS, while the remaining 5 did not, as shown in Table 21.

Table 21: Respondents’ access to a CNS

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Sarah and Anne were treated in the private sector, where specialist nursing support is not generally available. Sarah thinks she would have liked this support, whereas Anne had the opposite view,
I think I would have found it helpful to talk to someone. Someone who was separate from the family would have been helpful. It would definitely have been a comfort (Sarah 20.454, 21.46, 23.527)

I wouldn’t want a specialist nurse... being the type of person I am because I tend to just push myself to carry on and I’ll put a barrier up. I’m OK, I put the barrier up: “I’m fine,” sort of “leave me alone,” I’m that sort of person (Anne 14.458-64)

Two of the others, Eve and Ria, had early stage disease and had not been referred to the CNS. The remaining respondent Donna had in fact been seen by a CNS but she was not aware that this nurse was a Clinical Nurse Specialist or her role in Donna’s care,

I was going to see an oncology nurse, but I never got around to it. I never actually got an appointment (Donna 12. 274-5)

The women who did see a CNS remarked that the care they received from them was helpful,

I think if you hadn’t got somebody (CNS) to discuss things with and sort of, I think you’d have a lot of build-up, with worries and doubts there. I mean at least I’ve got somebody to talk to and it was nice that was. It would have made a big difference (Leigh 22.735-8)

I saw a specialist nurse; it was very helpful (Josie 22. 744-53)

As the provision of information is a key component of the CNS role, the association between the information given and access to the CNS was compiled. This is shown in Table 22.
Table 22: Association between access to information and CNS

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<th>Name</th>
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<td>Sarah</td>
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<td>Eve</td>
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<td>Donna</td>
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<td>Josie</td>
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Table 22 demonstrates that although there was contact with the CNS, the women stated that their informational needs had not been met. These findings support a study conducted on ovarian cancer patients to assess informational and emotional support (Jefferies 2002) which noted that 34% of respondents did not receive any written information and 31% indicated that it only asked a few of their questions. Findings from studies on breast cancer women (Luker et al 1996; Bilodeau and Degner 1996) also indicated that although breast care nurses should be a source of information for their patients, there was a deficit between the amount of information desired and the amount provided.
At the time of the interview, several women wished that there was more post operative support from health care professionals. Donna remarked,

No one asks you what you are thinking or what you are imagining. They'll ask if everything is okay physically, but not ask how you are psychologically (Donna 34.827-8)

The need for pre- and post operative counselling was also noted in earlier studies and discussed in chapter 2. Donna and Denise felt the ideal time was about six weeks post operatively,

After the first check-up, after you get out. You know ‘how are you, is everything okay?’ The patient may be a bit emotional, but maybe you’d get more about what was worrying them (Donna 34.821-3)

I think some kind of support afterwards that would be good, I think that would be a real help. You could do with having somebody talk to you about perhaps six weeks after, not right away ‘cos it’s all too new or two months after, just go in and just have a, a relaxed chat with somebody about it, you know (Denise 48.1615-7, 40.1335-7).

Although the timing of the counselling was suggested for the first follow up appointment which is 6 weeks post operatively, findings from a focus group of 9 women with either a breast or gynaecological cancer (Bruner and Boyd 1999) noted that women would prefer discussions on their sexuality to take place between 6-12 months post operatively.

Stella implied that she would be too embarrassed to talk to someone about information regarding sexual function, even if it was available. She said,

I don’t know because it’s the sort of thing that’s very personal and not, I mean I can talk about it to you now but I couldn’t, it’s not the sort of thing you could actually go to somebody and say “We can’t have sex because it’s too awkward.” I think I would be, even at my age and what I’ve been through, I would be too embarrassed to sort of go to somebody and say that (Stella 40.1480-1484)
In addition to post operative support for themselves, several women wished that there had been more support for their husband/partner. Kay said,

*I think there should be a bit more help for my husband, because I think they should have approached him, because all the help has been all about me, it might have helped him feel better* (Kay 59.1959-60)

However some women said that their husband would not have wanted to attend. Josie said,

*I’ve never really thought about it, it’s not the type of thing that Bill would have discussed anyway with anybody. He’s not that type of person, he uh, he’s the total opposite to me. Bill don’t (sic) want to know about anything as I want to know about everything, he’s total opposite to me, so he wouldn’t have wanted to have discussed anything like that anyway. He would rather us have been left to get on with it in our way if you know what I mean, as we want to. So it wouldn’t have helped him, no* (Josie 45.1504-1510)

This highlights that there may be a need for individualised care from the health care team according to the wishes of the woman and her partner.

### 9.5 Summary

This chapter discusses the concept of Professional Connectivity and details the relationship between the women and the health care professionals involved in their care. It has focussed on their knowledge base, and the manner in which they communicated with the women and the information that was provided. It has shown that the women had both positive and negative experiences during the referral process from the onset of their symptoms and this effect has continued into the recovery phase. The positive experiences in the relationship with the health care providers were associated with caring medical and nursing staff. The personality of individual health care providers and their years of experience may be contributory factors. The negative aspects related to a lack of knowledge and awareness
regarding this condition, resulting in a delay in the diagnosis and treatment for vulval cancer. The women demonstrated that their informational needs had not been met fully, particularly regarding anticipatory information concerned with sexual function.

Chapters 6-9 have described the concepts of Searching, Aloneness, All Change and Professional Connectivity which arose following the analysis of the interview transcriptions. The following chapter discusses the lived experience of these women arising out of this analysis.
CHAPTER 10
THE LIVED EXPERIENCE

10.1 Introduction
This study is an exploration of the lived experience of 13 women, aged less than 50 years, who were diagnosed with cancer of the vulva and underwent surgical treatment. A review of the literature highlighted a paucity of knowledge, as little was known about the impact of the presenting symptoms, the referral pathway for treatment and post operative recovery. Many of the studies were conducted during the 1980s and 1990s and investigated sexual functioning only. The wider issues that affect these women after their diagnosis and surgery and how these changes may affect their relationship with their husband/partner had not been explored. Neither had any long term impact of the treatment, for example how it had affected the women’s return to work and resuming their previous activities, been identified. Since there was no available data, it was not known what this group of women needed to support them throughout their disease trajectory or how their needs could be provided by health care professionals.

The study sought to address this by posing the question, ‘What must it be like to be diagnosed with, and have surgery for a cancer of the vulva?’

The data from this phenomenological study led to the identification of four interrelated themes that summed up the experiences of these women, Searching, Aloneness, All Change and Professional Connectivity. These have been considered in the context, Lived Body, Lived Relationship, Lived Space and Lived Time (van Manen 1990).
This chapter focuses on the lived experience of the women in its entirety and describes the ‘essence’ of the experience, chapter 3 page 52. Van Manen expresses this concept when he states that the essence is ‘that what makes it what it is and without which it would not be what it is’ (van Manen 1990, p 177). I considered the stories that the women had related and the findings that arose from the data analysis and then sought an appropriate means of describing what their lived experience really meant to the women themselves. I wanted to portray the ‘big picture’, an overview of the unique experiences of women who shared a common bond: a diagnosis of cancer of the vulva that had been treated by surgery. The women were expressing their feelings of:

*I went back and it was probably three or four months of just going back and forward to the doctor getting no response whatsoever; and nobody examined me (Ria 1.24-28)*

*It’s something many people haven’t heard of that and you say to people “I’ve got cancer and where” and people say “Well I’ve never heard of that,” this is one that is not really known about (Laura 45.1493-5)*

*There was no kind of information about vulval cancer. No, it’s whether there’s not information or you don’t know where to look (Stella 53.1781-3)*

*No-one talked about how our lives might be different (Josie 45.1499)*

*I can’t talk about it because nobody really understands (Denise 31.1024)*

In summary, the women noted ‘no-one can see it’ ‘nobody examined me’, ‘no-one had heard of it’, ‘there was no information’ and ‘no-one talked about it/I can’t talk about it’. The word that appeared to epitomise all these feelings is reflected within the concept of **Invisibility**. The word invisibility is expressed here as an adjective associated with the noun invisible. Invisible is the opposite of visible, which is associated with the verb ‘to see’ meaning something that is noticed or detected, something that is examined, or something that is understood. It may also refer to something that is discovered,
encountered or anticipated (Oxford Complete Thesaurus 2005). Here, the definition of the word visible may be summarised as referring to something that one can see, one has heard of and understood its nature and something one can talk about. Thus the notion of being invisible has the opposite meaning, and refers to something that is not noticed or detected, or something that is not examined. This infers that it may be hidden, or be too small to be seen. It may also be invisible as it is not heard of or talked about and consequently not understood. In summary, the word invisible may be defined as referring to something that:

- No-one can see
- No-one has heard of
- No-one talks about

In the context of this study, the characteristics of the concept of ‘Invisibility: no-one can see it’, ‘Invisibility: no-one has heard of it’ and ‘Invisibility: no-one talked about it’ has had both positive and negative effects and adds insight into the meaning of these women’s experiences. It may also be thought of as an ‘invisible thread’ that links the shared experiences of these women with each other and also to wider society.

This may be shown diagrammatically below,
The intention now is to transform the lived experience of these women into a textual expression (Van Manen 1990) to describe the concept of Invisibility. In this way, the essence of the women’s lived experience may be expressed in a way that makes it meaningful (van Manen 1990). Findings from the concepts of Searching, Aloneness, All Change and Professional Connectivity within the existentials of the every day world, Lived Body, Lived Space, Lived Relationship and Lived Time are used to illustrate the various characteristics of Invisibility. The characteristic of Invisibility: no-one can see it is discussed first.

10.2.1 Invisibility: no-one can see it

Van Manen (1990) refers to the fact that we are always bodily in the world. In our physical presence, we both reveal something about ourselves and we also conceal something at the same time. Over the years, social policies, popular culture, religious teachings and laws have led people living within a particular society to understand what is acceptable and
what is not acceptable, and dictates what is suitable, for example in terms of behaviour, dress and language. In this way, people come to know what is allowed to be visible, or what must remain hidden, or invisible, to fit with societal norms at a moment and time. The lived experience for the women with cancer of the vulva was influenced by the fact that it involved an area of the body that is usually hidden, as it is considered to be a ‘private’ area of the body that should remain hidden and invisible in everyday life. Exceptions to this may be at times of childbirth or for health checks such as cervical smears.

The concept of ‘Invisibility: no-one can see it’ depicts two perspectives: firstly the feelings of the woman herself and secondly her husband/partner, friends and family and wider society. Cash (1990b p51) has referred to this as the ‘view from the inside’ which he describes as a person’s own unique perception of themselves or their ‘internal’ representation and ‘the view from the outside’ which is the external rating. Cash (1990b) uses this analogy in referring to the concept of altered body image, but I suggest that it may also be applied in a wider context to women with cancer of the vulva.

The majority of women reported that they had visited their GP many times, for many months or years before their diagnosis of cancer was made. The invisibility of the disease is illustrated by the remarks made by some women that their disease was not seen, as the doctors had not looked at the area and examined them,

*He (GP), he didn’t even look at the vulval area underneath, he didn’t give me an internal and he just said it is a cyst (Kay 2.42-3)*
Presumptions were made that the symptoms were caused by a benign condition as Ria recalled,

Because I was pregnant it was an automatic assumption I had thrush, so I had the Canisten. Went home, put that on religiously, no improvement so I went back and it was probably three or four months of just going back and forward to the doctor getting no response whatsoever; and nobody examined me (Ria 1.24-28)

The invisibility of cancer of the vulva is also demonstrated by the fact that it may be too small to be seen with the naked eye. In some cases the vulval tissue does not look grossly abnormal and the ‘invisibility’ of the precancerous condition VIN 3 was highlighted by Eve, who remarked that it is only when she is seen in the vulva clinic and acetic acid is applied to the area, that any abnormality is detected. Stella also remarked about this,

There’s not really much to see. It’s usually only on the cameras that they can see it and they put a dye on. Then you can see it on the camera. If you were at home you wouldn’t know any different (sic) (Eve 37.899-902)

They couldn’t see anything; the naked eye couldn’t see anything (Stella 2.60-61)

Some women were seen by consultant gynaecologists at their local district general hospital where the condition was not recognised and diagnosed,

He (consultant gynaecologist) said “You’ve got nothing to worry about, it is just a wart or a cyst” (Sarah 5.104-5)

The diagnosis may not have been made because it is rare condition. Kay and Leigh referred to their GPs as not having ‘seen’ it before,

I think some of the doctors haven’t seen it before as it is so rare (Kay 55.1854)

He (GP) wanted to know what it was as well (Leigh 19.616-7)
Four women were referred to a Genito-urinary clinic as a sexually transmitted disease was suspected. Other women recalled their experience of going from one hospital to another, trying to find a resolution over a period of time and were seen by different doctors in various hospitals,

So I went to see the GP and he sent me to Hospital A. and then to Hospital B. The GP sent me to an Obstetrician at C. They said there was nothing wrong. I asked for a second opinion, and so I went to D. It was about 4 years from the time of my first symptoms (Donna 1. 15-19, 2.41-2)

The women described their main symptoms as itching, a spot or mass, or an ulcer which impacted on them physically as micturition was affected and their sleeping pattern was disturbed. The impact of these symptoms was unseen by society and as the women gave an outward appearance of looking well, they were able to preserve the invisibility of their illness. For example they adapted the clothes they wore,

The only thing I was comfortable in was cotton and nine times out of ten it was better if there was nothing there at all, but that’s not feasible is it, [laughs] to go to work, but um yeah, it was much easier if I didn’t wear anything at all. I haven’t worn tights, no jeans for years (Stella 3.76-83)

I bought this long vest; it came to my knees. I just went round with long skirts on and (did) not wear anything underneath (Josie 9.29, 63.84-6)

In summary, the notion of something being invisible because no-one can see it illustrates various examples of the verb ‘to see’. Here, the doctors did not ‘see’, ‘look’, or ‘examine’ the women. At other times, the presentation of the disease was too small to be seen with the naked eye. It is manifest within the component of the Lived Body as the illness affects an area of the body which is normally hidden from view. It is also evident within the component of Lived Time through the women’s experiences of a delay in obtaining a diagnosis. It is connected to Lived Space. In the example cited, the Lived Space is the
Genito-urinary clinic and the stigma associated with this and the local hospital where the disease was not recognised.

The impact of the ‘invisibility: no-one can see it’ resulted in the women recalling the way in which they searched for a definitive diagnosis. It had caused some women to fear that they were imagining their symptoms and they expressed their relief when the diagnosis was eventually made,

*I think I felt relieved in a way that something had happened that they’d found something wrong with me because I’d been going to X and the doctors up there for such a long time and they kept saying nothing was wrong with me. They kept telling me I had a little skin infections or something but nothing prepared me for him actually telling me I’d got a cancer tumour…* I think at the back of my mind I was quite pleased that somebody had found something, albeit not pleased what it was but something you know to say well I knew I wasn’t going round the twist really (Stella 7.217-226)

The Lived Relationship with the health care professionals involved in their care was also affected as the women recalled that the doctors could not ‘see’ the disease and therefore make a diagnosis. This had led to a loss of faith in the doctor or the hospital concerned, as discussed in chapter 9 Professional Connectivity.

The invisible nature of their surgery has had a positive impact for some women. Anne and Stella compared themselves more favourably with women with breast cancer as the effects of the surgery were ‘hidden’ from view,

*It’s different to a mastectomy, because people can see it where you know with this nobody would know (Anne 16.540-1)*

*I suppose if its breast cancer or something like that they can see it and it’s (sic) you know how it should be (Stella 30.995-6)*
Other women are unable to hide the invisibility of their condition as they have developed lower lymphoedema which is visible to society. The invisible nature of vulval cancer is also related to the rarity of the disease. The women expressed the sentiment that not only had the doctors not ‘seen’ it before, no-one has heard of it.

10.2.2 Invisibility: no-one has heard of it

Four women had lichen sclerosis or VIN 3. Eve who had VIN 3, and Josie who had lichen sclerosis, held the opinion that no-one had heard of these conditions,

When you say to someone VIN, they haven’t got a clue what it is. It’s like a new thing out that no-one’s heard of. When I told my mom and that, she just said what? We had to tell them and all the rest of the family, they didn’t know what it was (Eve 39, 959-960)

You always hear of eczema, you always hear of psoriasis but nobody’s heard of that (lichen sclerosis). Nobody’s heard of that (Josie 61.2037-2041)

The women reported that their GPs were unfamiliar with the precancerous conditions and unaware of the significance of the pre-invasive nature,

I went to see my GP and spoke to him. He was honest with me, he wasn’t sort of trying to fill me with rubbish, he said “I don’t know much about the condition,” he said “I really don’t,” He said “I can’t say I’ve ever come across it myself, but I looked it up a little bit” (Ria 3. 97-101)

But nobody had ever told me, my own doctor had never told me but till the Chinese doctor told me, he was a Western doctor as well as a, you know, a (specialist in Chinese medicine) doctor, um that lichen sclerosis can be precancerous. ‘Cos he was the one that told me “You must get this looked at every year,” but …nobody had ever told me that before (Josie 6.200-3)

Following their diagnosis of vulval cancer, several women reported that they, their family and their friends had never heard of it,
I didn’t know you could get cancer there (Irene 41.1357)

Nobody ever heard of it. I can’t say I’ve spoken to anyone that has; they’ve all said “What’s that?” (Josie 60.2025-6)

It’s something many people haven’t heard of (Laura 45.1493)

This is also linked to a lack of knowledge about the female genital area as several women had friends, who presumed they would need a hysterectomy,

And I remember a lot of people when I told them: “What are they gonna do, are they gonna give you a hysterectomy then?” And I think well why would they give me a hysterectomy, there’s nothing wrong with my womb, it’s my vulva (Ria 76. 2558-2561)

And if you say to people you’ve had cancer of the vulva they all think of a hysterectomy, they don’t really know, most people, or a lot of people what the vulva is (Josie.48.1614-6)

This demonstrates that the disease is largely unknown and therefore invisible, to the general public. ‘Invisibility: no-one has heard of it’ is also associated with the availability of information. The invisible nature of the disease and the impact of surgery may have a greater impact due to a lack of pre-operative and post operative information.

The invisibility of information about precancerous conditions were voiced by Eve and Ria who recalled,

But none of, nobody seems to know any information on it. So to me it, you know we all know the same. And we can’t sort of tell, I can’t give Kerry (friend with VIN) any more information than she can give me because we don’t know anything (Ria 74. 2473-80)

It’s like the VIN, there’s not much about it. There’s not much information about it like I got some books but none of them mentioned it. There was everything else but that (Eve 32.787-8, 795-6)
All the women perceived that their verbal and written informational needs had not been met. This included information given at the time the diagnosis was made, as well as information regarding their surgery. Julie recalled,

>This doctor just blurted it out, said “It’s cancer, we’ve got to do a vulvectomy and a lymphectomy,” and just given two pamphlets and that was it, and “Go and wait outside. They gave me a leaflet up at (Hospital) and I read it and I thought ‘Oh God’. (Julie 3.90-2, 13.433-5)

Some women recalled that although they received a general leaflet, they would have preferred one containing more precise details regarding their specific surgery,

>(I was given) just general information, but I didn’t have leaflets as I remember, no (Josie 22.714)

>They gave me leaflets, but it doesn’t prepare you (Stella 19.337-42)

That is one thing that I would say, all of the leaflets don’t really explain, which I suppose is hard for them to do, your particular case. Like the woman who goes in before you, may only have the size of, I don't know, a tiny little bit taken away and she probably may not notice an awful lot of discomfort. They don’t sort of say well if you’re having a large area you can expect to be in absolute agony... nobody ever told me it was gonna be like that (Ria 24.784-490)

It meant that the women had searched in the library to no avail or tried to access the internet for clarification about their condition, as noted in chapter 6, page 133. The lack of information regarding cancer of the vulva was compared with other types of cancer, in particular breast and testicular cancers was also noted earlier on page 134.

In summary the concept of ‘Invisibility: no-one has heard of it’ was voiced by the women themselves as the ‘view from the inside’, and also by GPs and family and friends as ‘the view from the outside’ as described earlier by Cash (1990b). It is reflected within the existentials of Lived Body because of the area affected, and the women’s Lived
Relationship with health care professionals and her family and friends. The characteristic of ‘no-one had heard of it’ demonstrates a lack of awareness, page 168. The women recalled a deficit of information at the GP’s surgery, local hospital and in the cancer centres, as reflected in Lived Space, and it is also linked to Lived Time as the women’s informational needs were not met throughout the disease trajectory. As a result of this, the women searched for information and described their increased sense of isolation and aloneness, and feeling that they were the ‘only one’ with this condition. Comparisons were also made with the more common types of malignancies, such as breast cancer.

The concept of ‘invisibility: no one had heard of it’ is also associated with the perception that no-one talks about either the precancerous conditions associated with this disease or the disease itself.

10.2.3 Invisibility: no-one talked about it

‘Invisibility: no-one talked about it’ denotes that the invisibility of cancer of the vulva also has a ‘muted nature’. There are several strands to this. Firstly there is the ‘view from the inside’. It reflects unwillingness on the part of the women themselves to talk about their diagnosis and treatment with their family and friends, and also with the health care professionals involved in their care. The doctors also displayed a reluctance to talk to the women about their diagnosis and how the impact of their treatment may affect them physically, psychologically and sexually. While the physical aspects may be ‘seen’ by the doctors and the women themselves, for example with the development of lymphoedema, the change in psychological and sexual functioning remains ‘unseen’ except to the woman herself and her husband/partner. In addition, cancer of the vulva and precancerous changes
are rarely mentioned in the media and this contributes to the opinion that no-one has heard of it. This is probably due to the fact that the disease affects an area of the body which is considered private. Although in recent times there has been more publicity about other hidden areas of the body, for example the importance of self examination for testicular cancers as noted earlier by Eve and Denise, the vulva remains an area which is seldom talked about. Denise remarked on this,

*This kind of thing isn’t talked about. I think it’s because you feel its part of your body that you don’t normally talk about, you know... this part of your body isn’t and it’s a part that’s not normally talked about* (Denise 28.944-8)

Occasionally articles are published in women’s magazines, with the aim of highlighting awareness of vulval cancer. For example, the September 13th 2007 edition of ‘That’s life’ carried the headline of ‘The shame between my legs’. The inside article, which was entitled ‘No more shame’, recounted the personal story of a 30 year old woman with VIN 3 who had painful laser surgery, followed by a radical vulvectomy. She felt ashamed of her condition because she also had Human Papilloma Virus (HPV), which she had associated with a sexually transmitted disease. However I felt that the emphasis was on the association between the Human Papilloma Virus (HPV) and cancer, rather than the precancerous condition of VIN 3. This article could have been an opportunity to highlight the other presenting symptoms of vulval cancer, and provide a balanced medical view of the likely treatment and follow up care. Sarah recalled one of her friends had seen an article in another magazine,

*I think it was quite a scary article so I'm glad I'd never read and I'm glad I never saw it* (Sarah 54.1237-8)
Many of the women found it difficult to talk to their families because it involved a hidden and private part of the body. Denise and Julie remarked about this,

*And, and because you just feel like you don’t want to talk about it, it’s too private, you know, you don’t, you don’t wanna sort of... I don’t talk to my family about it, you know that’s, just the type of operation I’ve had and things like that, they just, they know I’ve had an operation and that’s it* (Denise 29.945-7, 29.952-963)

*Very close friends I’ve been able to tell them in, in quite detail of what I’ve had done but other friends it’s just “I’ve had cancer and I’ve had an operation and I’m all right now,” sort of thing. It’s a personal place en’t (sic) it just to tell everybody en’t it (sic). That was the difficult part of telling the boys as well wasn’t it... They said, the boys, “Okay, that’s enough, no details, we don’t want to know any more like,”* (Julie 51.1711-1713, 52.1717-1722)

Eve also found it difficult to tell her family and her friends continue to find it difficult to discuss it. This was related to their lack of knowledge and awareness as previously discussed,

*When I was telling my friends they hadn’t got a clue. I think some of them still don’t know. It’s like they didn’t like to bring the subject up. They like come away from it. I don’t think they knew what to say* (Eve 39.966-8)

The women also demonstrated the ‘muted nature’ of the invisibility of vulval cancer as they were reluctant to take the initiative in talking to their doctor. This may be linked to the gender of the doctors, the majority of whom were male. Josie recalled,

*I suppose especially being a man because a man wouldn’t understand like a woman would: the emotional side of things* (Josie 66.2217-24, 67. 2241-2)

There may also be a sense of embarrassment and a lack of openness as discussed by Stella and Denise,

*I don’t know because it’s the sort of thing that’s very but I couldn’t, it’s not the sort of thing you could actually go to somebody and say “We can’t have sex because it’s*
too awkward.” I think I would be, even at my age and what I’ve been through, I would be too embarrassed to sort of go to somebody and say that (Stella 44.1480-6)

But it got to the point where I had to, but I think perhaps if it was more open, you know, you’d perhaps be more comfortable with going to the doctor and discussing these things, if, if it was more, ‘cos (sic) it’s just never talked about is it? (Denise 45.1504-7)

There was also a time element involved, as Josie felt that the medical staff were too busy,

I perhaps might have asked them if there was someone that I could talk to if he (consultant gynaecology oncologist) hadn’t got the time because I suppose he’s a very busy man. I might have asked if there was somebody I could talk to about it (Josie 66.2217-9)

I’ve been up to see W before now, but because he’s a bloke um, and he is, he’s the sort of person, you are straight in there and he does what he has got to do. He doesn’t give you the impression that you can sit down and talk to him about things (Kay 40.1345-9)

In summary, ‘Invisibility: no-one talks about it’ reflects the lack of media coverage and the manner in which the women themselves were reluctant to talk about their illness with their family and friends and also to the doctors involved in their care. The doctors mirrored this by displaying a reluctance to talk to the women.

Several women recounted that at the time of their referral to the cancer centre, ‘no-one’ had talked to them about their probable diagnosis, and consequently they were shocked to be told they had cancer. Leigh and Denise recalled,

I had the biopsy in the August and got the appointment in the October and that was when I came to (cancer centre). I wasn’t actually thinking anything because nobody had broached me and sort of said you know with the results, it could be this or it could be that. Nobody said anything. It was just that you know you’ve got an appointment. And that time I didn’t know like that it was anything other than just a normal hospital; I just thought it was just for the gynae area that was all. He just had a look and said ‘I’ve got to take it out; because it was cancerous’ It was a shock.
Yeah. It was, it was, I mean I just wasn’t accepting it. We had just come down for the day, and we weren’t expecting it (Leigh 3.108-9, 4.126-31, 5.147-8)

They referred me from the GU (Genito-urinary) clinic to the local district hospital and (consultant gynaecologist) took some biopsies. And then the next thing I had was a phone call from the secretary asking me to go to an appointment on the Friday. I was a bit taken aback when they told me what it was (Denise 5.167-173, 6.203-7)

I never dreamt it was cancer. It was just a total shock I was just on ‘automatic pilot’. I never heard anything that he said after he said the word cancer. It’s an automatic reaction just to think the worst. I was expecting something minor as the doctor at the other hospital said it was all in my mind. I felt angry, really angry (Donna 3.47-50)

Prior to the surgery, none of the women recalled that they had had an opportunity to discuss how their lives may change subsequently and there appeared to be a lack of anticipatory information about adapting to the consequences of their surgery,

No-one talked about intercourse. It’s just not being told; you don’t know how it’s going to feel or what it’s like inside (Donna 30.700-3, 719-22)

No one talked to me about how my sex life might change after my operation (Eve 30.745)

Irene recalled that there was a presumption that she would not be interested in post operative sexual function,

They didn’t ask how things were for me. No. I, I think they’ve probably got the idea that I wasn’t interested any more [Laughs] (Irene 34.1122-24)

The lack of specific information regarding the possibility of post operative lymphoedema was also apparent. For example, Kay was aware that she was at risk of lymphoedema but did not realise the impact this would have on her subsequent life style,

I didn’t know what it was, it was just said ‘lymphoedema’ and I didn’t know. Um, it was just said ‘lymphoedema’ well it was like a vague explanation, so I just thought oh its just a minor thing, and they asked me if I knew and I said yes because you have
to, you have to tell them that just in case. But I wasn’t really expecting it to be as fast, as speedy and as life-changing as it has (Kay 32.1054-58)

The lack of specific guidance for the women may be linked to the personality of the individual health care providers. For example, Sarah recalled her consultant gynaecology oncologist saying,

*He said, “I'll look after the physical side. I'm conscious that I have looked after the physical side” but he said, “I have never asked you anything, you know, anything about, you know, your relationship with (partner) or anything like that”. He never has done...I suppose he realises that it's not looked after (Sarah 66.1508-11).*

It is known that people with an illness which is invisible to the wider public have more choice about disclosure than those whose illnesses are visible (Joachim and Acorn 2000). Here the invisible nature of vulval cancer is related to its rarity as very little is known about the disease and it is rarely discussed in the media or in society generally. It also affects a private area of the body, the Lived Body. The lack of communication between the women and their doctors, family and friends is associated with the women’s Lived Relationship. This was evident prior to the diagnosis and continued throughout the disease trajectory. It also concerns Lived Time, as the women perceived that the doctors were too busy to talk to them. As a consequence the women felt that their informational needs had not been met, and their feelings of aloneness and isolation were compounded. The women also felt that there was a lack of openness as they themselves felt unable to talk about their condition and equally no-one talked to them or their husband/partners.

In summary, the invisible nature of cancer of the vulva is shown to be linked to the feelings that no-one can see it, no-one has heard of it and no-one talks about it. The impact of this
invisibility led to the women to perceive that they had a lack of understanding about their illness and consequently there was a lack of support.

10.3 Impact of invisibility

As a consequence of the invisibility nature of vulval cancer, the women described their feelings of,

_They didn’t understand and it’s like they didn’t like to bring the subject up. They like come away from it. I don’t think they knew what to say. I think it was harder for them because they didn’t understand it (Eve 36.966-969)_

_You don’t get any support, you don’t get any help, nobody tells you what it is, what to expect, from it all. You know I was totally oblivious to what I was gonna (sic) have to go through in the last fifteen, sixteen months in having all the treatment (Ria 74.2496-9)_

This was an additional impact on the women who described their feelings that ‘other people didn’t understand’ and ‘you don’t get any support’. These further characteristics of the concept of invisibility may be described as the ‘Invisibility of understanding’ and ‘Invisibility of support’ and are shown diagrammatically below,

**Figure 10: The Impact of Invisibility**
10.3.1 Invisibility of understanding

The women expressed a lack of understanding about the aetiology of their disease. Eve and Ria had VIN 3 and which had progressed to early invasive cancer. They both had recurrent multi-focal disease and explained their difficulty in understanding this,

*It seemed that the more they were taking it away, the quicker it was coming back. He (consultant) said he had done someone before and they had no problems for 5 years, it never came back. With me it never seems to go* (Eve 37. 922-3, 12.278-9)

*For me, that is the bit that I find the hardest is getting to understand what I have got, and what does that mean to me…One minute I’m told that… I’m just as likely to get breast cancer as I am to ever have cancer there, but then they’re telling me I’ve had cancerous cells in it. Well that to me is very confusing, it’s sort of, they’re not telling me one thing or the other… I don’t know what superficial invasion means and I don’t know what cancerous cells means* (Ria 13.439-450)

The invisibility of understanding by friends and colleagues was related to a lack of knowledge about the condition. In particular, Eve, Laura and Donna stated,

*I think it was harder for them because they didn’t understand it. I think if you had breast cancer or something like that I think they would be more different because everybody knows about it but with this sort of thing nobody knows about it* (Eve 39.968-972)

*And you have to explain it again and again* (Laura 45.1525)

*I told my line manager that I go every 6 months, and she said she had that. I said ‘No you ain’t (sic) and explained all about it. She was like I didn’t realise, but I don’t broadcast it, but she knows now* (Donna 33.798-80)

An invisibility of understanding was also shown by the health care professionals. Stella and Donna expressed their feelings that the doctors showed a lack of understanding about her initial symptoms,

*They tried all that years ago, they kept telling me it was thrush and I kept telling them it wasn’t, I said “I’ve had thrush before, it’s not like this.” And it’s very difficult to*
talk to a doctor or whoever if they don’t understand what you’re saying because you know your own body (Stella 27.903-6)

I said I felt something was wrong but he said it was all in my mind, and there was nothing wrong with me... I knew it wasn’t right (Donna 1.19-20)

Other women expressed the feeling that some nursing staff showed a lack of understanding of their post operative needs. This was noted particularly with nurses who worked in the private health care sector and a practice nurse and noted in Professional Connectivity, chapter 9.

The ‘Invisibility of understanding’ is related to the rarity of the disease and the fact that there is little awareness or knowledge about the condition among the general population and also some members of the medical and nursing profession. It was compounded as these professionals were reluctant to talk about the aetiology of the disease and the likely post operative changes. It is manifest within the four existentials of Lived Body, their Lived Relationship with family and friends and health care professionals, Lived Space and Lived Time. The perceived lack of understanding had both a positive and negative impact. Some women searched the internet and contacted the Cancer Backup website (www.cancerbackup.org.uk) as Anne had done,

It was just to look up information and research that had been done and um, but yeah like because I knew it could lead to lymphoedema trying to find out more on what that was about (Anne 25.839-42)

For other women it increased their sense of loneliness and the feeling that they did not know to whom to turn. This appears to have an on-going impact for some of the women as the ‘invisibility of understanding’ has also led to a lack of support.
10.3.2 Invisibility of support

The women recalled an ‘invisibility of support’ and it was apparent by listening to the women’s stories that it was evident from the time of their presenting symptoms. It is a consequence of the perception that ‘no-one can see vulval cancer’ ‘no-one has heard of it’ and no-one talked about it. Components of the ‘invisibility of support’ have previously been discussed and are related to:

- The lack of preparation prior to the women being told they had cancer
- The blunt way in which the doctors informed them of their diagnosis
- Only 8/13 women had support from a Clinical Nurse Specialist
- Lack of peer support from others with the same diagnosis
- The perceived lack of pre and post operative information and counselling for themselves and their husband/ partner.

For example, Anne recalled that her consultant gynaecologist oncologist presumed that owing to multiple previous operations for lichen sclerosis, she already had a degree of sexual dysfunction and Stella was warned that post operatively sexual intercourse may be different. However, no further help was offered,

*Um I can recall one conversation where he was saying “Oh um with a vulvectomy you lose your clitoris,” but I’d had so many operations and so much scar tissue he was saying “You know you’re probably not functioning fully down there anyway”*(Anne 46.1550-4)

*M did mention that things would, may be different but nobody enlightened us to how, I think that was just trial and error. Its like anything like that its just trial and error, and you’re thinking that ain’t (sic) quite right you know and sort of adjusting yourself to the, to the situation* (Stella 42.1414-7).
The women also perceived a lack of support regarding their lymphoedema care. Anne felt that she was given inappropriate advice at her local hospital. Julie was told that she would have to wait 7 months for an appointment at her local hospital, so she prefers to go to the cancer centre.

*I got referred to Hospital C for the lymphoedema... and they to be honest didn’t really know what they were dealing with. Um, they, they gave me um like a compression stocking, an electrical one to compress and whatever, but when I saw the lymphoedema CNS she said “Well stop using that straight away because its just pushing it all up,” it finished here and it was just pushing all the, the lymph fluid up to where I’d got the problem (Anne 53.1764-1770)*

*It is the same now with this lymphoedema thing. I phoned up, they sent a letter through to the hospital to see the specialist over here, the lymphoedema specialist. It would be May, or June before I’d get to see them. That is what they said, seven months. I phoned the cancer centre and they said “We’ll see you within the month...” If we hadn’t made that phone call, it actually would have been seven months, which is ridiculous (Julie 12.385-490)*

The invisibility of support was noted by the women in relation to the changes in their Lived Body and their Lived Relationship with health care professionals. It is manifest throughout the women’s journey from the onset of her symptoms prior to her diagnosis and into the rehabilitation phase. It is also associated with the Lived Space, for example their local district hospital. It led to a loss of faith in some instances and a greater dependency on those individuals who were seen to provide the support the women needed.

In summary, the lived experience of cancer of the vulva has been shown to be underpinned by its invisible nature, which has led to a lack of understanding and support.
10.4 Conclusion

A phenomenological approach was chosen for this study as I wanted the women to tell me their stories, what their feelings are and their understanding following their diagnosis and treatment for cancer of the vulva. This chapter has focussed on an overview of their lived experience. It has been described by using the concept of Invisibility and the characteristics that ‘no-one can see it’, ‘no-one has heard of it’ and ‘no-one talks about it’ as the women and wider society had not heard of it or encountered it before. The invisible nature is reflected in the concept of Searching, Aloneness, All Change and Professional Connectivity, and within the four existentials of the everyday world, Lived Body, Lived Relationship, Lived Space and Lived Time. It is shown that these facets are not separate but are inter-related.

It is clear from the findings that although the prognosis for early stage cancer of the vulva is good and many women may expect to be cured of their disease, the invisible nature of the condition and the resulting lack of understanding and support may continue for a considerable period of time. For some women this results in a cyclical effect whereby women continue to experience feelings of Searching, Aloneness, and All Change as every aspect of their every day life and in their relationships may be affected. The women’s relationship with the health care profession may also be affected and have an impact on their care in the future. This is illustrated in Figure 11.

The insights offered by this study mean that the invisible nature may now be challenged. Theoretically it will be possible to break this cycle of Invisibility by considering how the
care of these women may be improved in the future and this is addressed in the final chapter.
Figure 11: The Lived Experience

Components of Every day Living
Lived Body
Lived Relationship
Lived Time
Lived Space

Concepts
Searching
Aloneness
All Change
Professional Connectivity

Invisibility
No-one can see it
No-one has heard of it
No-one talks about it

Impact of Invisibility
Lack of understanding
Lack of support
CHAPTER 11
IMPLICATIONS AND FINAL REFLECTION

11.1 Introduction

This study is the first one to have been conducted exclusively on women with cancer of the vulva who reside in the UK. The aim of the research was to describe the lived experience of the women to provide a deeper understanding (van Manen 1990). Van Manen (1990 p 32) uses the term ‘logos’ to ‘bring into nearness that which tends to be obscure’ or in other words to make something which is invisible, visible to the researcher initially and then to the reader. This is mirrored by the invisible nature of vulval cancer which was described in the chapter 10, page 255. This invisibility has been addressed by creating an opportunity for the women in this study to make their voices heard and therefore visible. The aim now is to maintain this visibility by making tentative suggestions to improve and influence service provision, to create better outcomes for this group of women in the future. A personal reflection from me, as the researcher, concludes the work.

11.2 Giving a voice

Participation in the study has allowed the women to voice their lived experiences of their illness from the time of the presenting symptoms. The concepts of Searching, Aloneness, All Change and Professional Connectivity were developed from the data analysis, and the whole lived experience was characterised by its Invisibility. The research may have had the potential of reducing the women’s sense of aloneness, as they asked me about the experiences of other women. For example, Josie and Irene enquired about other women’s symptoms,
I know what my symptoms were but are everybody’s symptoms the same? (Josie 49.1629)

I’d have thought all this tiredness would be all while I’d got it, got the cancer, not after. It all seems to be working the opposite way round. Has anybody else said that they’re more tired after? (Irene 54.1808-1810)

Several women asked if the impact of the treatment had been similar for other women.

Denise and Anne asked,

I mean from the outside I don’t (look any different), but that doesn’t change how I feel inside, you know how I feel... I don’t know whether other women feel the same... (Denise 27.909-913, 28.920-1)

I don’t know, you’ve seen people that are similar to me, am I unusual in my response to this or is this (typical)? (Anne 54.1800)

Several women stated that participation in the research had been beneficial. Kay and Stella remarked,

I would probably say this is the most time I have ever talked at length about how I really feel about things, do you know what I mean? All in one go. It’s helped that’s why I have talked so much (Kay 59.1989-1991, 60.1995)

I don’t normally talk this much (Stella 56.1867)

Several women wished to help other women,

If I can help other people then I don’t care (Ria 1.18)

It wouldn’t bother me if there was somebody that was sort of um, you know was really worried, frightened about it and if they were, and if they were saying “If only I could talk to somebody who has had it,” I would be happy to talk to somebody (Josie 63.2103-7)

Josie and Stella also wanted to help me as the researcher,

I hope it helps you in some way (Josie 64.2150)
The women’s desire to help me is facilitated by the unique circumstance of the interview which enabled me to become privy to the invisible nature of their lived experiences. However before considering implications for practice the limitations of the study should be considered to put these in context.

11.3 Limitations

Interviews were held with thirteen women. Eleven were treated within the NHS system and two were treated in the private sector in the same geographical region of the UK, giving a perspective of two health care systems. The purposive sampling identified Caucasian women and while knowledge of spoken English was necessary for the study, other ethnic groups may have had other concerns which were not identified.

No effort was made to re-interview the women, return the transcripts for their comments or to interview other women of different ages. Although the rationale for this was discussed in chapter 4, it is recognised that a longitudinal study may have resulted in a different pattern of findings.

Sample sizes are of necessity small in qualitative research studies where the focus is on depth of insight but a larger number of women may have given different responses.

Despite the limitations of the study, patterns have emerged which may contribute to the provision and delivery of care in the future for other women.
11.4 Considerations for practice

The women highlighted a lack of awareness of vulval cancer within health care professions and society in general. For health care professionals, this may be facilitated by highlighting the need of these women by the publication of articles in medical and nursing journals and through oral and poster presentations at conferences.

Increased awareness for the general public may be addressed by a communication strategy with the aim of making this condition more visible, for example, the provision of posters or leaflets which could be displayed in GP’s surgeries, Well Woman clinics and Genito-urinary clinics. The leaflet could draw attention to the presenting symptoms of vulval cancer, for example, persistent symptoms of thrush despite treatment, or an ulcer or lesion which does not heal. It could also mention that 40% of cases of vulval cancer may be related to the Human Papilloma Virus (HPV) infection. Since this virus is also linked to the development of cervical cancer and the HPV vaccine will become available to young girls of 12-13 years in 2008, this knowledge may prompt women to address any concerns about vulval symptoms with their GP or practice nurse. This information may also be linked to the existing web site ‘tellher.com’, which is concerned with the HPV vaccine and cervical cancer. This may lead to health care professionals gaining further knowledge of vulval cancer, as well as women in general.

As vulval cancer is a rare condition, a ‘checklist’ of the symptoms could be available to GPs, which may be similar to a ‘risk of malignancy index’ (RCOG 2003). This index has recently become available for women who may present to their GP with ovarian cancer
which is also rare, and is designed to prompt GPs to refer women to a consultant
gynaecology oncologist immediately.

Some of the women who attended the cancer centre were unaware of their diagnosis, and they felt that insufficient information had been provided prior to this appointment. Although it may not be known what treatment would be involved, I suggest that a leaflet detailing the name of the consultant to whom she is to be referred, the name of the Clinical Nurse Specialist, a contact telephone number, and the likely radiological investigations she would undergo could be provided. It would also be beneficial if she was given the date and time of her appointment at the cancer centre before she left the referring hospital.

Other women perceived that there was a lack of support in adapting to the post operative impact of their diagnosis and surgery. This may have been compounded by the lack of sufficient anticipatory information regarding their surgery and possible biopsychosocial consequences. Pre-operative counselling with the woman and her husband/partner may facilitate this. Discussions relating to the proposed surgery could involve diagrams to depict the normal appearance of the vulva, and then showing the post operative changes. A mirror may also be used to facilitate the discussion by pointing out the areas of vulval tissue that would be removed. Any pre-existing sexual dysfunction may be noted and it would be an opportunity for the health care professional to build a relationship with the couple, which ideally could continue post operatively and into the rehabilitation phase.

Post operatively I suggest that in addition to the follow up clinic led by the gynaecology oncologist, a parallel clinic may be held with a Clinical Nurse Specialist and/or psychosexual counsellor with designated appointment times to explore any
biopsychosocial consequences experienced after the surgery. These clinics would provide holistic care, rather than continuing with the present day physical assessment only. As the out-patient clinic rooms are not always conducive to an intimate discussion, a quiet relaxing atmosphere could be instrumental in eliciting any issues relating to their post operative recovery. By holding parallel clinics with the gynaecology oncology team, a multi-disciplinary team approach to care would be ensured and allow individualised information to be given to each woman at every stage.

Since women who require surgery for pre-invasive disease are at risk of post operative sexual dysfunction, I suggest that they should be able to access the same psychosexual counselling and emotional support as women with cancer. This support could be offered long term, as this study has shown that women may experience problems five years after treatment. The principles of holistic assessments and suggestions for counselling may also be transferred to other domains of care for other rare conditions, for example men with breast cancer.

However health care professionals should be prepared to be flexible according to the couples’ needs as it was noted that this was not supported by all the women. The implementation of pre and post operative support may be problematic owing to the rarity of the disease, the knowledge base of the health care team and the complexity of developing additional parallel clinics involving a small number of women. There are also financial constraints in establishing such a service.

Several women expressed the feeling that they were the ‘only one’ with this condition. A support group for these women may address their feelings of aloneness and isolation. It is
known that if women meet others with a similar diagnosis they can enhance the quality of care and reduce a sense of loneliness and anxiety in some patients (Cain 1986), but this may not be achievable due to the rarity of the condition and the practical difficulties in arranging for the women to meet together.

In summary, the women demonstrated that the lived experience of Invisibility and its subsequent impact may have a cyclical effect, leading to on-going feelings of Searching, Aloneness and All Change, with an effect on their relationship with members of the health care profession, as shown in Figure 11. These interventions may theoretically assist in breaking the cycle. Further research on this patient group may be considered in the future.

11.5 Considerations for further research

The research findings have illuminated other areas for potential research studies. These may be focussed on:

- Determining the most effective interventions in facilitating pre and post operative support for these women and their husband/partner
- The impact of multiple surgical procedures for precancerous and early invasive cancer and quality of life
- The lived experience of the husband/partners of women diagnosed with vulval cancer

This study has provided an answer to the research question and has identified and explored a number of issues experienced by women with cancer of the vulva. It has noted what it is like to struggle with the invisibility of a disease, from the time of the onset of their
symptoms and for many years after their surgery. It notes the women’s feelings of searching for information and support and an increasing sense of aloneness and change, both in their body image and in their relationship with their husband/partner, family and the health care professionals involved in their care. It has also shown that this disease has an impact on their family and friends. The findings support those from earlier studies and notes areas for potential research in the future. The thesis concludes with a personal reflection on my own lived experience of undertaking the study.

11.6 Final reflection

The final reflection concerns my own research journey and is acknowledged here as Heidegger refers to his philosophy as an activity between the researcher and the participants within a circle of understanding or hermeneutic circle. As I studied the lived experience of these women, the research study in itself was a lived experience for me.

The opening quotation in the Introduction, chapter 1, notes the words of Socrates (470-399 BC),

*Wisest is she who knows she does not know.*

It described my lack of knowledge of the issues that concern women with cancer of the vulva at the commencement of my research journey. My curiosity concerning this patient group had developed through my clinical experience, and with the realisation that there was a paucity of published literature, I formulated the research question in order to gain an understanding of their lived experiences. It involved interviewing 13 women and asking
‘How was it for you?’ The analysis of the findings revealed the complexity of issues and has led to my acquiring further knowledge about these women.

The research study is depicted in Figure 12 and my research journey is represented as a single line. The letter A represents the point at which I began to develop my thoughts and posed my research question. Letter B represents the research study itself. It is shown as a circle, as Heidegger refers to research being an activity between the researcher and the participants within a circle of understanding. The circle incorporates the development of the interview schedule, interviews with the women, analysis of the data and developing the concepts. Letter C represents the presentation of the findings and the completion of the research. As there is now greater knowledge and understanding, the body of knowledge has now ‘grown’ and this is represented by the distance between Letter A and Letter C. The pointed arrow at Letter C indicates that further research may now be undertaken as this study has added to the body of knowledge about this patient group.
However, this is not the conclusion of my work. The Hermeneutical circle of understanding shown in chapter 3, page 53, shows that apart from the participant and the researcher, there is a third person involved, the reader. By undertaking this research I have gained an understanding of the lived experiences of these women and although may not be 'wise', I am wiser than before. It is now my aim to share the findings with medical and nursing colleagues nationally and internationally to highlight the invisible nature of the lived experiences of women with cancer of the vulva and to ensure that their voices are heard.
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Appendices
Appendix 1  Role of the Gynaecology Oncology CNS

A Clinical Nurse Specialist is a registered nurse, who after a significant period of experience in a specialised field of nursing and with additional education, is authorised to practice as a specialist with advanced expertise in a clinical speciality which involves clinical practice, management, teaching and research (Corner et al 2003). Clinical nurse specialists are an essential and integral part of the multi-disciplinary team (MDT) (Carson et al. 1997) and their role is crucial in facilitating effective communication and offering social, sexual, spiritual, emotional and psychological support to the patient and the family from the time of diagnosis and throughout the natural history of the disease and the course of its treatment (Otto 1997). Although the role of the Clinical Nurse Specialist (CNS) may vary according to the needs of the user population, the multifaceted components are education, facilitation, collaboration, research, and co-ordination of services as well as ensuring that support and nurture is available for patients and their families. Above all they are there to provide specialist advice, accurate information, support and continuity of care. The challenge for CNSs is to take a holistic approach towards the patient and her family, while keeping up to date with new medical advances.

Gynaecological cancers are a very diverse group, with different presentations and prognoses affecting a wide age group of women. It can have far reaching effects on the patient and her family, not only in terms of the treatment modalities and outcome but also on associated factors such as fertility and sexuality and can leave the patient, family and friends feeling isolated and uncertain about what to expect. A gynaecological cancer can penetrate to the very core of womanhood and affect not only a woman’s perception of herself, but also the way in which she perceives and interacts with those around her. This is
followed by a potential role transition, as her role as provider, protector, wife, mother, daughter and lover can be threatened. Holistic support at the point of diagnosis and throughout the cancer journey is crucial to the well being of the patient and her family as emotional and psychosocial support can have a positive effect on physical health, mental well being and social functioning (Jefferies 2002). There is now evidence to show that newly diagnosed women will benefit from robust psychological support and suffer less anxiety and depression (DOH 1999)

The role of the Clinical Nurse Specialist encompasses the physical aspects of providing information and practical advice, the emotional support vital as the patient and her family adjust to the diagnosis, and the implications of the treatment and the psychosocial issues involved in a disfiguring procedure, including those related to self esteem, body image and sexuality. Further support is needed if a patient requires neo-adjuvant treatment such as radiotherapy and/or chemotherapy. Some Clinical Nurse Specialists have developed their own nurse-led clinics according to the needs of their patient group, for example radiotherapy advisory clinic for women receiving pelvic radiotherapy.

Clinical Nurse Specialists view the support needs of family members as integral to those of the patient. Families are one of the most important resources to provide informal support to patients, although support cannot be assumed just because of the presence of family members and it is important to ascertain who is available to provide practical help. Practical ways of allowing families to access support in the community also needs to be explored. These may include referral to the district nurses, hospice teams or social services. It is known that coping by using adaptive strategies, such as seeking emotional and social
support appear to moderate the experience of distress from the cancer diagnosis and
treatment (Lutgendorf et al 1999). Families may also help a woman to adjust to her altered
body image and change in family dynamics, ensuring that she feels loved and accepted,
and still able to contribute to family commitments.

Unfortunately some women are diagnosed of gynaecological cancer when it is already at
an advanced stage. Palliative care provides for all the medical and nursing needs of the
patient for whom cure is not possible and for all the psychological, social and spiritual
needs of the patient and the family, for the duration of the patient’s illness, including
bereavement care (Woodruff 1993). It is concerned with quality of life, and is about
making the most of the time left, and enabling the woman to come to terms with her
limited prognosis and preparing the family for her death. It involves good listening and
communication skills to explain the options available, as well as monitoring and advising
on symptom control and providing emotional, psychological and spiritual support.
Information should be provided in a sensitive way, and questions answered honestly. It is
also important that the woman expresses her choice about her own treatment and care.
Although there needs to be a sense of ‘hope’ and achieving goals, these should also be
realistic and attainable.

Many patients are in-patients in acute hospitals for the terminal phase of their life.
Assessment and control of pain and other symptoms needs to be maintained so it does not
detract from their quality of life. Ethnic, racial, religious and cultural factors also need to
be considered and religious advisor or cultural leader involved in the care if wished. Some
patients prepare for the end of their life by preparing their will, organising their funeral and
writing letters to loved ones. This can provide a sense of achievement and ‘putting one’s house in order’. Children also need to be fully informed and their questions answered. Some mothers are able to prepare their children by collecting special items for a ‘Memory Box’. Parents must be informed where they can obtain advice about how to deal with the needs of their children, particularly if their mother has incurable disease. Palliative care also continues after a patient’s death. It is often provided informally by the community in which the family lives, or through their religious organisations. In addition, bereavement support may be available through local palliative services.

For further reading:


Appendix 2  Cancer of the vulva

2.1 Aetiology of cancer

Cancer has been defined as a malignant disease or tumour, caused by abnormal and uncontrolled cell division. Cancer cells differ from normal healthy cells by following their own agenda for reproduction and continue to proliferate after the time that normal cells would die. There are a number of different mechanisms that either alone or in combination causes abnormalities in cell growth and multiplication. For a cancer to develop, it requires alterations or mutations in genes within cells. The mutations occur through errors in the replication of deoxyribonucleic acid (DNA) during cell division and may occur following exposure to a carcinogen, such as tobacco, alcohol and drugs, or radiation. Other influences may be due to genetic or familial reasons, diet, viruses, occupation, and air or water pollution. There may be a considerable time lag between the exposure of a carcinogenic agent and the formation of a tumour.

Cancers may be categorised according to the site in the body from which it arises and also according to how well they resemble these tissues. This is known as the degree of differentiation. For example, a tumour that closely resembles normal tissue is well differentiated or grade 1, whereas tumours that lose all resemblance to normal tissue is poorly differentiated or grade 3. Moderately differentiated tumours show intermediate degrees of resemblance. The differentiation also has a bearing on the effect of the cancer, with poorly differentiated tumours tending to be more aggressive and metastasise readily while well differentiated grow more slowly and tend to recur locally. Cancers may also be
classified according to the tissues in the body: epithelium, connective tissue, muscle and nervous tissues. Epithelial tumours involve the skin and are known as carcinomas. They are further divided into types according to their microscopic appearance. The types of vulval cancers are shown in Table 23, on the following page.

Cancers also have the ability to invade surrounding tissues and form new blood vessels, which is an integral part of their growth. They are also able to migrate to distant sites to form metastases via the blood stream or lymphatic system. Lymphatic spread occurs when columns of tumour cells invade the walls of small lymphatic vessels and then clusters of cells break free and are carried in the lymph stream towards the regional lymph nodes. The carcinoma cells then grow into a secondary tumour. Spread may then occur from lymph node to lymph node.

### 2.2 Anatomy of the vulva

The vulva consists of those portions of the female genital tract that are externally visible in the perineal region, lying between the genitocrural folds laterally, the mons pubis anteriorly and the anus posteriorly. Included within the vulvar vestibule are the clitoris, the labia minora, labia majora and the mons pubis (Moore-Higgs 2000). The vestibule of the vulva is composed of stratified non-keratinising squamous epithelium. Structures within the vestibule include the urethral orifice, vaginal orifice, and openings of the Bartholin’s gland ducts and openings of the minor vestibule glands. The labia majora are two longitudinal folds of skin, which extend from the mons pubis. They are covered with stratified squamous epithelium, which is hair bearing in the lateral and mid portions of the labial surface and hairless on the medial surfaces. The hair is associated with sebaceous glands and sweat glands. The labia minora lie between the labia majora. The blood supply
to the vulva is abundant and comes from branches of the internal and external pudendal arteries. A network of lymphatic vessels that drain to the inguinal and femoral lymph nodes drains the vulva and the perineum. The perineum is supplied by the pudendal nerve and its branches, as well as fibres from the fourth sacral nerve. Autonomic nerves supply the clitoris from fibres from the inferior portion of the pelvic plexus.

2.3 Aetiology of vulval cancer

The aetiology of vulval cancer indicates that it may develop in more than one way. An infection by the human papilloma virus, (HPV-16 in particular) may be implicated in the development of vulval intraepithelial neoplasia and the subsequent progression into cancer. Vulval intraepithelial neoplasia (VIN) is an uncommon condition but the incidence is thought to be increasing by up to three-fold (Joura et al 2000). The increase may be partly due to an increase in the number of young women who have a human papilloma viral infection (HPV). Although the link between HPV, cervical intraepithelial neoplasia (CIN) and cervical cancer is well known, the situation is less clear for women with HPV and VIN. Recent studies have shown a disparity of results concerning this link. It has also been shown that a prior history of genital warts increases one’s risk of VIN (Al-Ghamdi 2002, Rusk 1991).

In addition, patients with maturation disorders such as lichens sclerosis have an association with this disease (Spinelli 2000). Lichen sclerosis is a benign inflammatory disease of unknown aetiology resulting in patchy white changes on the vulva with associated pruritus. For women with lichens sclerosis, there is an approximate 5% lifetime of developing vulval cancer (Scurry and Vanin 1997). Other risk factors associated with vulval cancer are immunosuppression, cigarette smoking, obesity and diabetes.
### Table 23: Types of cancer of the vulva

<table>
<thead>
<tr>
<th>Type</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Squamous cell carcinoma</td>
<td>The most common type of lesion found on the vulva. They vary from small pigmented flat lesions to large fungating neoplasms. The vast majority are well differentiated lesions.</td>
</tr>
<tr>
<td>Verrucous carcinoma</td>
<td>This is a type of squamous cell carcinoma and presents as a florid white papillary growth. They invade surrounding tissue and rarely spread to the lymph nodes.</td>
</tr>
<tr>
<td>Basal cell carcinoma</td>
<td>This is a relatively rare type, accounting for 2-4% of vulval cancers.</td>
</tr>
<tr>
<td>Basaloid (cloacogenic carcinoma)</td>
<td>This is a rare lesion that appears deep within the labia majora.</td>
</tr>
<tr>
<td>Neuroendocrine</td>
<td>These are very aggressive tumours that frequently spread to regional and distant metastases. They have a poor prognosis.</td>
</tr>
<tr>
<td>Adenocarcinoma and Bartholin’s gland carcinomas</td>
<td>Most adenocarcinomas arise in the Bartholin’s glands, although they may also appear in the vestibular glands or the sweat glands. They represent 2-3% of all vulvar cancers.</td>
</tr>
<tr>
<td>Other malignancies</td>
<td>These include Paget’s disease of the vulva, and other rare conditions such as malignant melanoma or sarcomas</td>
</tr>
</tbody>
</table>

Moore-Higgs (2000)
2.4 Incidence
In the United Kingdom there are around 1000 new cases of vulval cancer diagnosed each year which is approximately 3-5% of all female genital malignancies. Although 80% of patients are aged over 55 years of age, increasing numbers of younger women are being diagnosed due to the effect of the human papilloma virus, vulval intraepithelial neoplasia and the subsequent invasion of the vulva epithelium (Moore-Higgs 2000). Squamous carcinoma is the most common type of vulva cancer and accounts for 85% of diagnoses but all skin cancers can affect the vulva. These include verrucous, basal cell and malignant melanomas.

2.5 Screening methods
In the United Kingdom, there are no guidelines for the routine screening for vulval cancer, neither is it recommended routinely by the American Cancer Society in the United States or the Canadian National Taskforce guidelines for Screening for Gynecologic cancers.

2.6 Natural History
It is now commonly thought that vulval cancer progresses from intraepithelial neoplasia, to carcinoma in situ, to invasive cancer. The intraepithelial disease may persist for long periods of time: case data indicate 10 years or longer for the in situ phases (Moore-Higgs 2000). However when the disease has penetrated the epithelial layer and lymphatic dissemination occurs, the spread is more rapid. Vulval cancer spreads by direct extension to adjacent organs, for example the vagina, urethra and anus, via the lymphatic system and via the blood stream to distant organs, such as the lungs. Other areas on the vulva may also become malignant leading to multifocal disease. The lymphatic spread is a progressive
infiltration to the superficial inguinal nodes followed by the pelvic nodes. The involvement of the lymph nodes is increasingly likely for tumours over 3 cm in size.

2.7 Signs and symptoms

The most common symptom associated with vulval cancer is pruritus, which occurs in 80% of patients. Less common symptoms are pain, itching, burning, soreness, bleeding, an ulcer or a lump. There may also be colour changes of the affected area. Ninety per cent of all vulval cancers will have an easily visible lesion at the time of first presentation, which may look superficial or deep and ulcerated, raised, warty, or as a firm lump. Metastatic disease presenting as a lump in the groin may also be seen at presentation. Most squamous cell malignancies arise as unilateral lesions on the labia majora, but other primary sites include the labia minora, clitoris or mons pubis. Multifocal lesions occur in 10-30% of cases (Modesitt et al 1998)

2.8 Diagnosis

All women suspected of having cancer should be able to see a specialist within two weeks of the general practitioner deciding that they need to be seen urgently according to the NHS Cancer plan (2000). A biopsy confirms the histological diagnosis. This will determine what type of cancer it is, the depth of invasion, whether the lesion was completely removed so that the margins were clear and if there was any other invasion for example into the blood vessels or lymphatic system. For lesions less than 2 cm in diameter, the biopsy should include a 1-cm margin of healthy skin around the lesion.
The management of the patient should be determined at a gynaecology cancer centre by the multidisciplinary team. It will include investigations to ascertain the extent of the disease through a staging procedure. This will include a chest X-ray, MRI scan (Magnetic resonance imaging) and a full blood count and biochemical profile. The patient is also examined to determine her general fitness and the operability of a lesion with reference to its proximity to the urethra or anus. The staging of vulva cancer was initially by the TNM system of tumour-node-metastasis, but this was modified by the International Federation of Gynecology and Obstetrics (FIGO) in 1989 to include a surgical staging system as shown in Table 24 on the following page.

2.9 Treatment

Surgery for vulval cancer consists of surgical removing the tumour and if it is greater than 1mm depth invasion, bilateral inguinal lymphadenectomies. This is achieved via three separate incisions (triple incision technique), a radical vulvectomy or hemi-vulvectomy, depending on the site of the tumour. Lateral lesions that are less than 2cm in size can be treated by unilateral inguinal lymphadenectomy. Radiotherapy is given pre-operatively for large inoperable lesions to decrease the volume of disease and subsequent decrease in the extent of the surgery. This will also involve the formation of a stoma.
Table 24: Surgical staging of vulval cancer

<table>
<thead>
<tr>
<th>Stage</th>
<th>Tumour (T)</th>
<th>Node (N)</th>
<th>Metastases (M)</th>
<th>Clinical Findings</th>
</tr>
</thead>
<tbody>
<tr>
<td>0</td>
<td>CIS</td>
<td>N0</td>
<td>M0</td>
<td>Carcinoma in situ: intraepithelial carcinoma</td>
</tr>
<tr>
<td>1a</td>
<td>T1</td>
<td>N0</td>
<td>M0</td>
<td>Lesions 2 cm or less, with stromal invasion no greater than 1.0mm</td>
</tr>
<tr>
<td>1b</td>
<td>T1</td>
<td>N0</td>
<td>M0</td>
<td>Lesions 2 cm or less, with stromal invasion greater than 1.0mm</td>
</tr>
<tr>
<td>2</td>
<td>T2</td>
<td>N0</td>
<td>M0</td>
<td>Tumour confined to the vulva, more than 2 cm in greater dimension</td>
</tr>
<tr>
<td>3</td>
<td>T3</td>
<td>N0-1</td>
<td>M0</td>
<td>Tumour of any size with adjacent spread to the urethra, vagina, or anus, or unilateral regional lymph node metastases</td>
</tr>
<tr>
<td>4a</td>
<td>T1-4</td>
<td>N2</td>
<td>M0</td>
<td>Tumour invading upper urethra, bladder mucosa, rectal mucosa, pelvic bone or bilateral regional node metastases</td>
</tr>
<tr>
<td>4b</td>
<td>Any T</td>
<td>Any N</td>
<td>M1</td>
<td>Any distant metastases, including lymph nodes</td>
</tr>
</tbody>
</table>

2.10 Adjuvant treatment

Post-operatively radiotherapy of 45-50 Gy to a depth of 8mm is given if the tumour infiltrates two or more lymph nodes or one node shows extracapsular breach. It may be given in conjunction with weekly chemotherapy. Early and late side effects of treatment is described in the nursing care for these women, Appendix 3

2.11 Prognosis

The prognosis for vulva cancer depends on the stage of the disease, as shown in Table 24, with the best outlook dependent on the size of the tumour, and whether it has spread to the lymph nodes.
Appendix 3 The nursing care of a patient following surgery for vulval cancer

In the Gynaecological Cancer centre where this research study was undertaken, patients are asked to attend a pre-operative assessment in the outpatient setting several days prior to the surgery. A medical history is taken together with an electrocardiogram, and the patient has an opportunity to meet the nurses involved in her care. A provisional plan is also made for post-operative care and early referrals are made to social workers for planning discharge back into the community and the physiotherapists for post-operative deep breathing exercises and mobilisation. The patient is admitted to the ward at least one day pre-operatively. This allows her to become familiar with the layout of the ward and be prepared both physically and psychologically for her surgery.

Information is given to the patient regarding her surgery, including getting her ready for her operation, wearing anti-thrombolic stockings and the immediate post-operative care. This will include pain relief, the use of anti-emetics, care of lymph drains, intravenous infusions and the urinary catheter. She will also be seen by the Clinical Nurse Specialist to repeat any information, answer her questions and try to allay her fears and reduce anxieties. Early postoperative problems include primary haemorrhage, decreased intravascular fluids and respiratory compromise due to the anaesthetic. Careful monitoring of the patient is therefore vital to ensure that she is in a stable condition and pain free. Most women are allowed to drink and have a low fibre light diet within 24-48 hours of surgery if well enough. Care should be taken to avoid constipation through adequate fluids and appropriate diet. Redivac drains may be placed under the incision sites when women have had lymphadenectomies. They are to prevent the build up of serosanguinous fluid, which may lead to the formation of lymphocysts or wound breakdown. These are kept in situ until
the drainage is less than 50 mls in 24 hours. They may then be removed, which may be 7-10 days post-operatively. The stitches are removed from the vulva and the groins about 14 days postoperatively unless they are dissolvable. This may take up to four weeks.

Once the patient has recovered from the initial effects of the surgery, early ambulation is encouraged to prevent the possibility of deep vein thrombosis. The most common postoperative complication is wound breakdown, which can occur in 50% of women (DiSaia and Creasman 1993). This is due to the amount of tension on the wounds and the lack of tissue adherence to underlying tissue delays healing and increases the risk of infection (Moore-Higgs 2000). In addition, the site of the vulva is a difficult area to dress and keep clean, with the close proximity to faeces and urine. Wound healing is also compromised following pre-operative radiotherapy as the blood supply to the area is affected, and also if the patient has other medical problems such as diabetes or obesity.

Lymphoedema is also a post-operative complication, and is an incurable progressive condition characterised by chronic swelling of a limb and sometimes the adjacent quadrant of the trunk. It is defined as an excess of fluid tissue proteins and lipid causing chronic inflammation and fibrosis due to lymphatic failure (Mortimer 1995). Prophylactic advice is given to women, which includes care of the skin and toenails, prevention of infection and gentle exercises. Once lymphoedema has occurred it becomes a chronic problem and referral to a lymphoedema Clinical Nurse Specialist is advised. She will be able to instigate two phases of treatment. The first is the intensive/drainage phase, which comprises skin care, exercise and a form of lymphatic drainage techniques and compression bandaging. It is aimed at reducing the size of the limb, improving the condition of the skin and
subcutaneous tissues and moulding the shape of the limb to the other one. It also encourages the flow of lymph in both legs. The second maintenance phase comprises skin care, exercise and using compression stockings (Moore-Higgs 2000). Rehabilitation starts immediately after the surgery and should be undertaken by all members of the multidisciplinary team initially. It involves encouraging the woman to return to her pre-treatment level of health by encouraging her activities of daily living, mobility, skin integrity, sexual function and decreasing the risk of long term complications related to the disease and treatment (Moore-Higgs 2000).

Adjuvant radiotherapy is required post-operatively for some women, and advice includes coping with the early side effects of the treatment, such as the care of the skin, cystitis and diarrhoea. Women may be encouraged to wear long skirts and avoid wearing underwear to allow air to circulate around the area and the application of gentian violet to the skin. Late side effects include sexual dysfunction caused by vaginal stenosis and narrowing of the introitus. The Clinical Specialist Nurse discusses the return to pre-treatment sexual function, with both the woman and her partner. The provision of vaginal dilators and advice about their use assists this, together with advice on the use of additional foreplay, vaginal lubricants and different positions for intercourse. Telephone contact and regular appointments with the woman and the Clinical Nurse Specialist maintains their therapeutic relationship in order for questions to be answered. This support needs to be continued for some time after the surgery as the women now need to become accustomed to a new normality following their rehabilitation (Salter 1997). Post-operative chemotherapy is seldom given for women with vulval cancer.
Follow up appointments with the gynaecology oncology consultant continue for five years following diagnosis. Any recurrences, which may be local or distant or both, tend to occur with this timeframe. Further surgery may be available if the recurrence is small or radiotherapy to the recurrence if it has not already been given. The other treatment option is to give chemotherapy. If chemotherapy is given, the advice involves covering the care of the mouth and dietary issues. Rest is also important, as women can feel very tired throughout their treatment and after its completion. Women should also be warned about the risk of immunosuppression and the importance of seeking prompt medical attention if they develop pyrexia.

The Clinical Nurse Specialist is also involved at the time of the recurrence, as the woman enters the palliative phase of their illness. This care provides for all the physical, psychological, social and spiritual needs of the woman and her family when a cure is not possible. It is concerned with quality of life and making the most of the time left. It involves good listening and communication skills to explain the options available, as well as monitoring and advising on symptom control. Palliative care also includes bereavement support for the partner and the family after the woman’s death.
Appendix 4 Interview schedule

Hello, I am Hilary Jefferies. You must be Mrs/Ms………

Thank you for agreeing to take part in the study. As I said, my name is Hilary and I am a clinical nurse specialist at X.

There are a few things to go through, before we start, if that is okay with you.
Have you read the information sheet that was sent about the study? Were there any questions you would like to ask me?

Make sure the respondent knows the purpose of the study and what her participation will involve.

Answer any questions.

Description of the study

We are interested in the experiences of women like you who have had surgery for a cancer of the vulva. We are particularly interested in how you have been since your operation. There will also be plenty of time for us to talk about things that are important to you, if they don’t come up during the interview.

Your participation will involve this interview. I shall also let your GP and hospital consultant knows that you have taken part.

Can I just check with you that it is okay with you if I tape-record this interview? It is much easier for me to concentrate on what you are saying if I don’t have to write everything down. I may have to turn the tape over half way through. I hope you won’t find it too distracting. The tape recording will be typed up later, but the typed copy will be completely anonymous and your name will not be linked in any way to the cassette. Are you happy for me to use the tape recorder?

Also, just to reassure you no one will have access to the data except me.
If we can just go through the consent form.

Read out and ask respondent to sign.
Was there anything else that you wanted to ask before we begin?

Section 1

Can you tell me why you went to see your GP in the beginning?

*What symptoms did you have to make you go and see him?*

*Did you have any thoughts about what might be wrong?*
Was there any particular reason why you went to the GP then?

   Had you waited for any reason before making the appointment?
   Did you have to wait a long time for the hospital appointment?

**Can you think about the first time you went to the hospital, and were seen in the outpatients department?**

Did the doctor explain to you what was the matter?

   Explore what happened during the consultation.
   Did you have to have a small operation first?
   How did you feel waiting for the results?

So when were you told about your diagnosis? Can you tell me how you felt about it?

   Were you on your own?
   Was your husband/partner involved in the discussion?

How did you cope with the thought of coming into hospital?

   Were you a long way from home?
   How did your family cope without you?

**Were you given any information about what to expect when you were admitted to hospital?**

   Was it the doctor who explained to you or one of the nurses?
   Did you understand it okay, or were you feeling a bit shocked

Was this verbal information, or were you given a booklet to read?

   Do you think you would have liked a booklet to read at home?
   Would it have explained your illness a bit better?

**Some hospitals have specialist nurses who provide support and information for women like you. When you were in the outpatients, do you meet one of them?**

   If yes, Can you tell me how she helped you?
   Did she give you a contact number for you to phone her up?

   If no, do you think it would have helped to know that there was a nurse at the other end of the phone to be there for you, and answer any questions?
Did you have to have a MRI scan, before you came in? I know they are very noisy, and some people find them a bit claustrophobic, did you cope okay?

Are you able to tell me what happened when you were admitted to the ward?

How did you feel about coming into hospital?
Did the nurses explain what was going to happen to you?
The anaesthetist usually sees patients to talk about the anaesthetic. Did he see you?

How did you feel after your operation?

Did you have any pain?
Were you feeling sick at all?
Can you tell me how you felt when the doctors came round, as there are usually a team of them at the same time?

Did you have to stay in hospital a long time?

How did you feel about having to stay in longer than other patients did?

Are you able to say if your operation healed up okay afterwards?

Did you get an infection after your operation?
Did you feel embarrassed with the nurses and doctors looking at an intimate part of you?

Were you given any advice about going home? For example what you could do, and not do?

Were you given a booklet to take home?
Would it have helped if you had?
Did you have a contact number to phone in case you were worried about anything when you were at home?

We have talked a bit about your time in hospital, is there anything else you would like to add at this stage?

Section 2

Please can we talk about the time since your operation?

Have you been able to go back to work?

What do you do?
How did you feel when you went back? Tired? Back to ‘normal’?
What about coping with the housework? Have you needed any help around the house?

Was your partner able to help?
Did you mind that you were unable to do things yourself?

Were you able to go back to doing any sports or things that you did before your operation?

Are you able to give any examples of the sorts of things you do now?
Is there anything that you feel you can’t do?

Have you been able to have a holiday? How do you feel when you are away?

Are you able to go on the beach when you are away?
How do you feel about going swimming?

Some women develop a condition called lymphoedema after an operation like yours. How have your legs been since your operation? Have you developed any lymphoedema?

Were you warned that this might happen?
How has this affected you?
Have you been receiving any treatment?
Has it affected your lifestyle- are you still able to garden?
Is walking okay for you?

Section 3

We have talked about how you have been physically since your operation, do you mind if we talk about how you have felt emotionally?

Do you find you become tearful easily?
Do you ever find yourself becoming angry about what has happened?
Can you explain why you feel like this?
Are you able to talk to someone about how you feel, or do you find that you ‘bottle’ things up?

We have talked a bit about how you have been physically and emotionally since your operation. Do you mind if we talk about how you feel about your body now?

How do you feel about your scars?
Have you lost your pubic hair? How do you feel about that?
Do you feel as if your body has let you down?
Are you able to say if you feel embarrassed about your body (partner’s reactions)?
For some couples, their sexual relationship is very important part to them. For other couples it is a less important part of the relationship. Health care professionals also need to aware if a patient’s relationship has changed following an operation. Are you able to talk to me about your sexual relationship with your partner before your operation?

*Have you been together (married) for a long time?*
*Was sex okay for you both?*

Are you able to say if your sexual relationship was very important to you before your operation?

*Were you able to enjoy regular intercourse?*
*Were there any difficulties?*

Following an operation on the vulva, it may affect a couple’s sexual relationship. Have you found that your sexual relationship has changed since your operation?

*Are you able to achieve intercourse now? If no, have you been able to find other ways to satisfy each other?*
*If yes, do you feel less interested now than you did before?*
*Is it painful? Or, are you concerned about that you might get some pain?*
*Some women find that they feel a bit inhibited because of the possibility of pain, and sex is less enjoyable. Do you feel like this sometimes?*

*Sometimes finding different positions for intercourse is helpful. Have you tried other positions?*
*Achieving an orgasm is also difficult sometimes following an operation on the vulva. Is that something that concerns you?*
*Do you worry about your partner’s feelings?*

*Some couples find it helpful to talk to a psychosexual counsellor. Have you been to see anyone about the physical part of your relationship?*

**Section 4**

Do you mind if we talk a bit about how your partner has been involved in your care? Did he come with you to see the doctor and go to the hospital?

*Did he come with you to the outpatient department?*
*Was he there when the doctors talked to you about your operation and treatment?*
*Was there an opportunity to talk to a doctor or nurse about how your lives may be different after your operation?*
*Did he have a chance to talk to the doctor on his own?*
Do you think he should have been involved in your care more?

Would you have liked to meet other women who have had similar surgery?

Would you be interested in going to a support group?

Is there anything else you would like to add about how your life has changed since your operation?

How are things now, are you being followed up at regular intervals?

Do you worry about going back to the hospital for check ups?

Does your diagnosis still concern you at times?

We have talked about your symptoms, your operation and how you have been since your surgery. We are also interested in how you feel about the care you received.

How do you feel about the way the nurses and doctors looked after you?

Can you suggest any improvements in the care we provide for women with a similar diagnosis to you?

I know we have talked a lot today about what has happened to you, is there anything you feel we haven’t covered?

Is there anything we haven’t talked about that is important to you about what has happened to you?

I said at the start that this tape will not identify you in any way, and will be stored in a locked cabinet. I am hoping that the results of my research will be published, but again you will not be identified.

Thank you very much for taking part.
Appendix 5 Information regarding the study

Patient Information Leaflet

Research study for women who have had surgery to the vulva

Why is the research being done?

The study is looking at how patients may have been affected by their operation and if their activities have changes in any way. It will also look at the ways patients have coped after their operation. There has not been much research done recently for this group of patients especially in this country. The information from the study will be used to help patients in the future.

Who is running the study?

The study is being led by Hilary Jefferies, Macmillan Clinical Nurse specialist at the Birmingham Women’s hospital. Her contact number is 0121 472 1377 ext 4110. She is undertaking this research as part of her studies at the University of Birmingham.

Why have I been asked to take part?

You have been asked to take part as you have had an operation on the vulva recently.

What does the study involve?

If you decide to take part in the study, Hilary Jefferies will contact you and arrange for a convenient time to come and see you in your home. She will interview which will be recorded in a portable tape recorder. The tape will not record your name or address and the information will be kept confidential. The tape recording will be typed up and both the tape and the typed record will be stored in a locked filing cabinet.

Will my doctor be informed?

Your GP and our hospital consultant will be informed if you decide to take part in the study.

What happens to the information provided by the study?

The information on the tapes will be studied by Hilary Jefferies. She will find out the main concerns of patients following their operation, how they coped and how their activities have been affected. This information may be used to help patients in the future in planning their treatment and care.
Will the results be published?

The results of the research study may be published in a medical or nursing journal. If so, the identities of the patients taking part in the study will be completely anonymous.

Do I have to take part?

No, you do not have to take part. If you decide not to, this will not affect your care, treatment and follow up visits to your consultant. If you decided to take part and then change your mind this will not affect our future care either.

If I have any question about the study, who shall I contact?

Please contact Hilary Jefferies on 0121 472 1377 extension 4110
Appendix 6  Letter inviting the woman to participate in the study

Dear

I am writing to you as you have recently had an operation on the vulva.

I am doing a research study, which is looking at how patients may have been affected by their operations and if their activities have changed in any way. I enclose a patient information leaflet, which explains more about the study.

You may have some queries about taking part. If so, please contact me on (Tel) and I will be happy to talk to you.

If you would like to take part, please return the reply slip at the bottom of this letter. If you decide not to take part, this will not affect your future care in any way

Thank you for your help

Yours sincerely

Hilary Jefferies
Clinical Nurse Specialist in Gynaecological Oncology

I would like to take part in the study. Please contact me to arrange an interview

Name…………………………………………………………………………………………
Address…………………………………………………………………………………………
Tel…………………………………………………………………………………………
Appendix 7 Consent form

Research Study for Women who have had a vulvectomy operation

Consent Form

Name………………………………………………………………………………………………………..
Address……………………………………………………………………………………………………
                                                                                          
I agree to participate in the above research study. I understand that I will be visited in a
place of my choosing by Hilary Jefferies, the nurse who is undertaking the research. The
interview will be recorded on an audiotape, without revealing my name or address. The
tape recording will be typed up and both the tape and the typed record will be stored in a
locked filing cabinet.

I understand that I can withdraw from the study at any time, and my care, treatment and
follow up will not be affected.

Signed…………………………………………………………………………………………………..
Date……………………………………………………………………………………………………..
Appendix 8  Letter to the hospital Consultant and GP

Dear Doctor

Re:

The above named patient has agreed to take part in a retrospective research study to explore the physical, psychological, and sexual consequences following their surgery for cancer of the vulva. The study is being conducted by Hilary Jefferies Macmillan Clinical Nurse Specialist at the X Hospital as a post graduate study degree at the University of Birmingham.

The patient will be interviewed in a place of her choosing. The audiotape and transcribed interview will remain confidential and stored in a locked filing cabinet. The results may be published in a nursing journal but the identities of the respondents will remain anonymous. The respondents are able to withdraw from the study at any time should they wish to do so, without it affecting their future care.

If following the interview, the respondents require any additional psychological in-put Dr A at the B Hospital has agreed to see them.

Any additional information about the study may be obtained from Hilary Jefferies on Tel

Kind regards
Yours sincerely

Hilary Jefferies, Macmillan CNS
Appendix 9  Copy of the ethical approval

South Birmingham Local Research Ethics Committee
4th Floor, Nuffield House, Queen Elizabeth Hospital,
Edgbaston Birmingham B15 2TH

Tel: 0121 627 8733 [internal 3404]
Fax: 0121 627 8575 [internal 3168]

Chairman: Professor C Clifford
Administrator: Mrs A P McCullough

Hilary Jefferies
Birmingham Women's Hospital
Metchley Park Road
Edgbaston
Birmingham

Dear Ms Jefferies

LREC reference number 0654
A Retrospective Study into the Physical, Psychological and Psychosexual Consequences of Surgery for Cancer of the Vulva

South Birmingham Local Research Ethics Committee are happy to Approve your Study subject to the following:

- Satisfactory indemnity arrangements being in place.
- Clearance from your Trust or relevant employer.
- Subject to submission of an annual report in line with Good Clinical Practice Guidelines.
- Active Approval is required until the Study has been completed.
- The Committee would wish to be kept informed of Serious Adverse Events, Amendments and any modifications to Patient Information Leaflets and Consent Forms.

Approval is given for three years, however, if it is intended to continue the Study after THREE YEARS from the date of this letter South Birmingham Local Research Ethics Committee would wish to re-examine it.

Would you please communicate this approval immediately to all members of the investigating team and where appropriate the sponsoring commercial company. Please also advise your Research and Development Office of this approval.

Yours sincerely

[Signature]
Professor C Clifford
Chairman
Local Research Ethics Committee

cc: Appropriate Trust

Research Ethics Committee
20 APR 2001
APPROVED
Appendix 10  Letter from LREC requiring further clarification for Study

South Birmingham Local Research Ethics Committee
4th Floor, Nuffield House, Queen Elizabeth Hospital,
Edgbaston, Birmingham B15 2TH

Tel: 0121 627 8733 [Internal 3404]
Fax: 0121 627 8575 [Internal 3188]

Chairman: Professor C Clifford
Administrator: Mrs A P McCullough

Hilary Jefferies
Birmingham Women’s Hospital
Metchley Park Road
Edgbaston
Birmingham

Dear Ms Jefferies

LREC reference number 0654 - Hilary Jefferies
A Retrospective Study into the Physical, Psychological and Psychosexual Consequences of Surgery for Cancer of the Vulva

The members of South Birmingham Local Research Ethics Committee have considered your application and have the following comments to make:

1  How will the patients be recruited? The section on recruitment states that only women in an active heterosexual relationship will be recruited, but this is not reflected in the Patient Information Leaflet.

2  An interview such as this can be quite disturbing to these patients.

3  Is there a good reason for confining the study to heterosexual woman?

4  It is not very clear at what stage post-operatively this group will be accessed. Please clarify.

Subject to a satisfactory response the Committee will reconsider your application.

It would be helpful if any amendments to the Patient Information Leaflet could be highlighted so that the modified text can be identified quickly and easily. Please let me have a copy for my file.

Yours sincerely

Dr J Winder
Vice Chairman
Local Research Ethics Committee
Appendix 11 Letter awarding £1500 from Owen Mumford Ltd for secretarial support

11th June 2001

Ms H Jeffries
Macmillan Clinical Nurse Specialist
Birmingham Women’s Health Care NHS Trust
Metchely Park Road
Edgbaston
Birmingham
B15 2TG

Dear Hilary

Re: Retrospective study into the Physical, Psychological and Psychosexual Consequences of Surgery for Cancer of the Vulva

Further to your letter of 17th May 2001 requesting funding support for the above study and our subsequent telephone conversation, I am pleased to confirm that Owen Mumford would be willing to supply initial funding for this project of up to £1,500. As discussed, the funds for this would be available after 1st October 2001.

We have assumed that Owen Mumford would be acknowledged in any subsequent paper/findings published and when appropriate, we would welcome sight of such a paper before publication. I do trust that this is acceptable to you. It would also be useful to receive a copy of the final study protocol when prepared.

We do wish you every success with this study and look forward to liaising with you later in the year.

Kind regards,

Yours sincerely

Keith A. Shankland
UK & Ireland Divisional Manager

cc: Barbara Doyle
### Appendix 12  Costs of completing the study

**Secretarial support:**
Typing 13 interviews at £9.00 per hour  
£ 1165.50

<table>
<thead>
<tr>
<th>Patient Number</th>
<th>Date</th>
<th>From Home</th>
<th>Destination</th>
<th>Number of Miles</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>22/08/2003</td>
<td>“</td>
<td>Aldridge</td>
<td>9 miles</td>
</tr>
<tr>
<td>2</td>
<td>05/09/2003</td>
<td>“</td>
<td>Bordesley Green</td>
<td>28 miles</td>
</tr>
<tr>
<td>3</td>
<td>07/11/2003</td>
<td>“</td>
<td>Exhall, Coventry</td>
<td>60 miles</td>
</tr>
<tr>
<td>4</td>
<td>06/02/2004</td>
<td>“</td>
<td>Stratford upon Avon</td>
<td>64 miles</td>
</tr>
<tr>
<td>5</td>
<td>09/02/2004</td>
<td>“</td>
<td>Handsacre, Rugeley</td>
<td>30 miles</td>
</tr>
<tr>
<td>6</td>
<td>09/03/2004</td>
<td>“</td>
<td>Stourbridge</td>
<td>21 miles</td>
</tr>
<tr>
<td>7</td>
<td>28/05/2004</td>
<td>“</td>
<td>Berkswell, Coventry</td>
<td>48 miles</td>
</tr>
<tr>
<td>8</td>
<td>09/07/2004</td>
<td>“</td>
<td>Erdington</td>
<td>16 miles</td>
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<tr>
<td>9</td>
<td>25/06/2004</td>
<td>“</td>
<td>Willenhall, West Mids</td>
<td>34 miles</td>
</tr>
<tr>
<td>10</td>
<td>24/06/2004</td>
<td>“</td>
<td>Newtown, Powys</td>
<td>173 miles</td>
</tr>
<tr>
<td>11</td>
<td>23/07/2004</td>
<td>“</td>
<td>Bucknall, Stoke-on-Trent</td>
<td>50 miles</td>
</tr>
<tr>
<td>13</td>
<td>22/11/2004</td>
<td>“</td>
<td>Loughton, Stoke on Trent</td>
<td>44 miles</td>
</tr>
</tbody>
</table>

Total number of miles = 583 @ 38 p per mile  
£221.54

Copies of articles from the Hospital Library, photocopying, stationery, Cassette tapes, tape recorder  
£300.00

Total cost  
£1687.04