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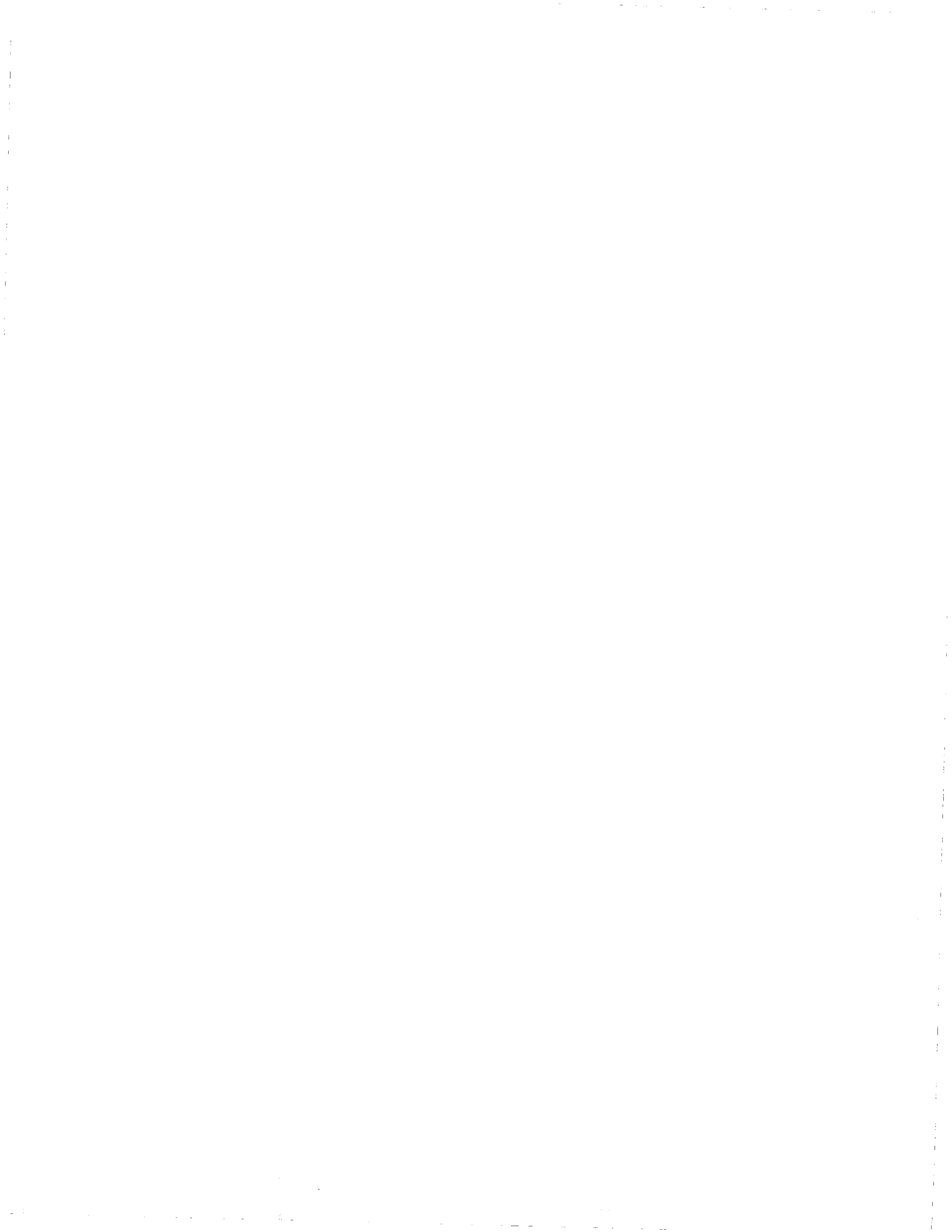
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Experiences of Treatment and Sexuality for Women with Cervical Cancer

by

Maureen Reynolds

**A Thesis
Submitted to the Faculty of Graduate Studies
through Sociology
in Partial Fulfillment of the Requirements for
the Degree of Master of Arts at the
University of Windsor**

**Windsor, Ontario, Canada
2009**

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Abstract

What is the experience of cancer treatment and sexuality after treatment for women with cervical cancer? Although the number of women with cervical cancer is low in North America, the potential for sexually devastating treatment side effects is high.

Eleven women, aged 33 to 71, were interviewed from April to August 2008 using a qualitative research design intended to capture their subjective experience. All women had received treatment from 2003 to 2008 at a small cancer centre in Ontario.

Most women felt an ongoing loss of sexual pleasure and desire, and several experienced continuing pain and discomfort during intercourse. Although individual experiences varied, all women found brachytherapy treatment, which was administered without sedation at this centre, difficult and some women implicated the trauma of this treatment in later sexual problems. Women felt that more comprehensive information and support may improve women's treatment and sexual experience.

Dedication

This thesis is dedicated to the women who courageously stepped forward to tell their stories so that other women's experiences may be improved.

Acknowledgments

My sincere thanks are extended to the 11 courageous women who agreed to participate in this study and who shared their experiences that were sometimes painful and uncomfortable. Their desire to improve the experience of cervical cancer for other women was inspirational.

My deep appreciation and gratitude go out to Dr. Eleanor Maticka-Tyndale, who, as my thesis advisor, gave generously of her time to guide me through the research and writing process and helped me understand the importance of my work. She kept me on track, bolstered my confidence when it was running low, and expertly filled in the gaps in my knowledge. I thank Dr. Maticka-Tyndale for her continuous encouragement, unending patience, and commitment, which were crucial to the completion of this project.

Thirty years ago Dr. Barry Adam first had me thinking about social justice issues. More recently his work has served as an inspirational example of the work that could be done in health research. I was honoured to have him take the time to sit on my committee as a second reader.

I also need to thank Dr. Dale Rajacich for her enthusiasm for this project from the first time I approached her to be an outside reader. Her perspective has been invaluable throughout this study and I appreciated her expertise as a health care professional.

And most importantly, I thank my family. To my husband and two children, thank you for giving me the help and encouragement I needed to take on and complete this work. All of you have pitched in to allow me time to embark on this journey and follow it through its often unanticipated path to completion. You have all patiently experienced my moments of panic and uncertainty; thank you for your unending love and support.

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Chapter 1

INTRODUCTION

I listened to the story of a young woman with cervical cancer who decided that she would rather die than live with her body as it is after treatment for this disease. Since the end of her treatment she has made attempts at being sexual with the men that she dates. Intense pain and bleeding during intercourse have become tangible reminders of her body altered by disease and treatment. Her fear of rejection causes her to conceal her condition from her sexual partners prior to sex and both she and her partners are traumatized by these experiences. When I heard this story I was compelled to ask more women about their experience of cervical cancer.

I am in awe of the eleven women who agreed to meet with me to talk about their experiences. I was amazed by these women who bravely and some painfully told me their stories. I learned something from each of them. I learned that some women would push themselves to talk about their sexual behaviours and sexuality for the first time in their interviews with me. I also learned that some women found the experience of the interview itself cathartic. What I eventually learned about sex and cervical cancer is that this experience is different for each woman.

There are several reasons why the study of the experiences of sexuality after cervical cancer is important. First, aging baby boomers are feeding the growing number of people diagnosed with cancer as they enter the high risk age group, increasing the population of survivors. These increases are expected to continue over the next 15 to 20 years (Cancer Care Ontario, 2003). Second, more and more women are surviving cervical cancer because of earlier detection through screening and more effective treatment

(Frumovitz et al., 2005) and although increased survivorship is desirable, living after cancer creates its own challenges. Sexual fulfillment after cancer is one of them.

Third, if we take the position of the Pan American Health Organization and the World Health Organization in their recent documents, all human beings have the right to sexual health, sexual pleasure, and comprehensive sexuality education across their lifespan (Pan American Health Organization & World Health Organization, 2000). These documents make it clear that healthy sexuality is essential for all persons, for their relationships, and society as a whole. They also push us to take sexuality more seriously and to ask our patients what sexuality and sexual pleasure mean to them and help them achieve their desired outcomes.

And finally, concerns about the quality of life of cancer survivors are echoed in the 2007 National Research Corporation study that indicates that over all types of cancer 82% of women with cancer felt that they did not have adequate information about sexual activity changes that can result from their cancers or cancer treatments (National Research Corporation Picker, 2008).

Working within a cancer centre as a non-medical professional uniquely positioned me to observe and interact with people with cancer across the trajectories of their cancer experiences. These often included diagnosis, treatment, recovery, and sometimes palliation¹. Early in my term at the cancer centre I was able to learn about cancer patients' symptoms, issues, and concerns through my position as their counsellor. In this role I provided information, advocacy, and support to cancer patients and their families. These connections allowed me a privileged glimpse into their lives through very different eyes than most of my medical colleagues. I had the luxury of time in a role that centred

¹ Used in this instance to mean end of life.

on listening to experience rather than treating illness. In more recent years I planned, implemented, and managed a Supportive Care Program that continually sought to understand and meet the quality of life concerns that people encountered over the course of their cancer experience.

My objective for this research was to explore the sexual experiences of women who have undergone treatment for cervical cancer through listening to their stories. I use this understanding to create resources to both aid in patient / health care provider discussion of sex and to share the coping strategies described by the women in this study with other women who will undergo similar treatment.

The remainder of this introduction is divided into two sections. The first describes the cervical cancer experience based primarily on educational materials provided to women at the cancer centre and my own experience working with health care providers and patients, although key references from the literature are included as well. The second section reviews the literature on sexuality and the experience of sex for women with cervical cancer, as well as the work of three sociologists who provide a broader context for this discussion.

Cervical Cancer Experience

Etiology

Cervical cancer is somewhat unique among cancers since it can, in many cases, be directly linked to sexual activity and sexually transmitted diseases. The Human Papilloma Virus (HPV), an extremely widespread sexually transmitted disease, is the most significant risk factor for cervical cancer (Tiffen & Mahon, 2006, p. 527).

There are over one hundred types of the HPV; only some of which are linked with cervical cancer. The HPV is the most prevalent sexually transmitted disease in the United States with approximately fifteen percent of the population affected and a lifetime risk of infection at about seventy-five percent. Not all HPV infections lead to cervical cancer and the vast majority are harmless; however, currently there are fifteen HPVs that are known to be associated with cervical cancer. The risk for acquiring the HPV increases with the number of sexual partners and can be acquired even when a condom is used (Tiffen & Mahon, 2006, p. 527-528).

Although the HPV is the most significant risk factor of cervical cancer, there are other risk factors. These include use of the birth control pill for more than five years, multiple pregnancies, poor diet, having other sexually transmitted diseases such as Chlamydia or HIV, low socioeconomic status, a family history of cervical cancer, and a history of exposure to diethylstilbestrol (DES) while still in the womb. In addition, smoking increases the risk for cervical cancer in women who have already acquired the HPV (Tiffen & Mahon, 2006, p. 528).

This quick review of the risk factors for cervical cancer illustrates a connection between sexual activity and cervical cancer for many women. However, it would appear from the literature that women, themselves, do not make this connection, at least this was not the case as recently as 2005. Costanzo, Lutgendorf, Bradley, Rose, & Anderson (2005, p. 975) studied women's perceptions of the causal attributes for women with cervical cancer and found that "women rated genetics or heredity, followed by stress, God's will, and hormones as the most important causes of their [cervical] cancer". This understanding of the causal attributes was inconsistent with scientific understandings at

the time. These women did not include the more accurate risks of “smoking, early intercourse, and multiple sexual partners” and believed that stress was a more important risk attribute than any of the actual risk factors (p. 977).

Women’s reported understanding of cervical cancer causes may reflect more than a lack of information. Although not specifically referring to the level of sexual activity, Costanzo et al. (2005, p. 979) conclude that women who attribute the cause of their cancer to activity under their control experience increased levels of distress. It may be that by under-identifying the real causes of cervical cancer, women were protecting themselves from higher levels of distress.

Women’s perceptions of risk factors are a question worth exploring again given recent events. In July 2006 Health Canada approved the HPV Vaccine and in September 2007 a school based voluntary vaccination program was launched for females in grade 8. This was accompanied by a massive media blitz that made a clear link between HPV and cervical cancer. Although the vaccine and the advertisement campaign targeted nine to twenty-six year olds, it seems likely that most women have seen and been educated by the commercials and print ads. Additional information has been in the news as a result of the debate about the safety and effectiveness of the vaccine. Whether the increased visibility of information about the connection between HPV and cervical cancer impacts the way women understand their cervical cancer is an open question.

Screening

In Ontario, the guidelines for cervical screening through a PAP test and pelvic examination recommend that women be screened every one to three years once they become sexually active and that screening should continue even if they are no longer

sexually active. Some women who fail to be screened may do so because of the intimate and invasive nature of the procedure. The Canadian Cancer Society (2008a) website describes the procedure as follows:

Your doctor will use a small wooden spatula to gently scrape the surface of the lower part of the cervix to pick up cells. A special brush called a cytobrush is used to obtain cells from the upper part of the cervix that leads into the uterus. The cells are then smeared onto a glass slide and the sample is sent to the laboratory where they will be examined under a microscope.

Women who are diagnosed with cervical cancer may have been following screening guidelines, may have been screened less frequently than recommended, or may never have had any screening. According to Blomfield (2007, p. 122), 80 percent of women presenting with invasive cervical cancer have not had regular cervical screening.

The PAP tests are effective in identifying early squamous cell carcinoma but are not as reliable in picking up early adenocarcinoma (Blomfield, 2007, p. 122). This means that even women who are diligent with their screening can have their cancer diagnosed at a point where they require aggressive treatment, the type of treatment that is the focus of this study.

Diagnosis

The path to diagnosis is not homogeneous. Women have vastly divergent experiences. Some women with cervical cancer are diagnosed through a routine PAP smear. For these women there is often a more direct and swift path to treatment. The abnormal PAP test sets in motion follow-up testing and appointments with specialists such as gynaecologists and oncologists. These specialists are able to confirm a diagnosis of cancer and initiate a plan for treatment.

For some women the journey is far from this straightforward. Since early stage cervical cancer offers no symptoms, many patients who have not been diagnosed at an earlier stage through screening, are diagnosed when their cancer has progressed and become invasive. According to Blomfield (2007, p. 122), these women may suffer from persistent symptoms that prompt a visit to their family physician or a gynaecologist. Blomfield outlines the common presentation of symptoms.

The most common symptoms of cervical cancer are abnormal vaginal bleeding and vaginal discharge. Sexually active women experience postcoital bleeding, but for women who are not sexually active, intermenstrual and postmenopausal bleeding may eventually occur. Large tumours can become infected and cause an offensive serous discharge. Rarely women presenting with advanced disease will experience pelvic pain and discomfort, pressure symptoms, vaginal passage of faeces or urine (due to fistulae) and anuria from ureteric obstruction.

Women living in areas that are under-serviced by family physicians and specialists describe challenges and delays in access to appropriate medical professionals even after symptoms are apparent and have become worrisome. Without family physicians, some women use walk-in clinics for their care and see a different physician each time they visit. Some women describe situations where the attending physician minimizes the symptoms and sends the patient away without a diagnosis. Some women I have met in the course of my work have confided to me that telling their story repeatedly without having their problem properly investigated is a harrowing experience.

This experience does not seem to be limited to patients without family doctors. Some women describe intense frustration in their attempts to get their own family physician to attend to their distressing symptoms. These women go home from physician visits and live with the symptoms and the worry until their distress level forces them to try

once again to get the medical attention that they require from a physician who will take their symptoms seriously. Some women become resigned to the fact that their own family doctor is not helping them determine the cause of their problem and they begin to get 'second opinions' through visits to walk-in clinics and hospital emergency rooms.

Once women achieve a diagnosis, their cancer will be at one of many different stages and be identified as either squamous cell carcinoma or adenocarcinoma. Blomfield (2007, p. 123) notes that the incidence for cervical cancer in Canada is 77 per 100,000 and the mortality rate is 2.3 per 100,000. For women who have repeatedly been to doctors with their symptoms anger and frustration may accompany a later stage diagnosis.

Cervical Cancer Treatment

Treatment options vary according to the type and stage of cervical cancer at the time of diagnosis. The variety of possibilities are too broad and technical for this study; however I can provide a general discussion of the treatment possibilities. Women who have been diagnosed with cervical cancer will have treatment options that may include surgery ranging in invasiveness from minimally invasive to complete hysterectomy, chemotherapy, external beam radiation, and brachytherapy (explanations to follow). A thorough management of the disease may require combinations of these treatments.

The women in the present study have had combinations of surgery, external beam radiation, brachytherapy, and chemotherapy (Cisplatin²). When surgery is part of the treatment plan, a woman will be admitted to hospital and the surgery will be performed under local or general anaesthetic. A stay in hospital of up to several days may be required. When external beam radiation is administered a woman will be required to come to the cancer centre for a series of outpatient treatments. The experience is much like having an

² Chemotherapy agent used to treat solid tumours.

x-ray. Each treatment, which aims the radiation directly at the area to be treated, takes from 15 – 30 minutes. General radiation treatment education is provided and additional information related to the specific treatment plan will be given by the oncologist, primary care nurse, and the radiation therapist.

When chemotherapy is a component of the treatment plan, a woman will visit the cancer centre and will usually receive Cisplatin by intravenous infusion. The chemotherapy nurse will provide the patient with specific information about the treatment protocol and more general information is available through attendance at an introductory chemo class. During the late 1990s there was new evidence of the effectiveness of concurrent chemoradiation in improved survivorship and now most women are offered this treatment (Trimble, Harlan, Gius, Stevens & Swartz, 2008).

Women scheduled to undergo brachytherapy will attend a radiation therapy education class that is by design intended to provide general information about radiation treatment. The details of the brachytherapy treatment will be given to the patient on a one-on-one basis by the radiation oncologist, the radiation therapist, and the primary care nurse. A more detailed account of brachytherapy treatment follows to allow for a thorough understanding of this invasive treatment.

When a woman with cervical cancer is preparing for brachytherapy, she meets with her primary care nurse and will be given more specific information about preparation for brachytherapy, also known as HDR (High Dose Radiation) treatment. She will also be provided with information about the treatment process and the nurse or doctor will discuss the possible side effects and symptoms. The information given by the nurse is reinforced through the provision of a brachytherapy pamphlet that outlines the treatment purpose,

method, side effects, and precautions. Once treatment begins, the radiation therapists provide more information about the treatment itself.

According to the brochure, in the treatment room a woman will lie on her back on the treatment table and her legs will be spread and positioned in stirrups. The typical brachytherapy treatment begins with placement of a catheter containing a balloon of radio-opaque dye into the bladder so that the location of the bladder is visible on x-ray and the dose of radiation to the bladder can be determined. Once the catheter is in place, the oncologist inserts a speculum into the vagina. The placement of the internal radiation applicator into the cervix follows; several attempts may be made before the proper sized applicator is determined and placed. The applicator is then secured in place with a table mounting brace. With the applicator firmly in place, a small amount of barium is put into the rectum to allow for the rectum to be visible on x-ray. The woman is then required to stay in this position for an hour or more while x-rays are taken and analyzed, dosage calculations are made, and the actual radiation dose is administered.

Women are routinely given Ativan (Lorazepam)³ before this procedure to help with anxiety. Women are told they will feel pressure and cramping similar to menstrual cramps and that they will be in the treatment room alone once the treatment begins. Brachytherapy may be repeated six to eight times over the course of three to four weeks. Each treatment adds to the vaginal sensitivity and pain so that when the applicator is positioned on subsequent visits, there is a potential for increased discomfort and pain.

The nurse tells women to expect some vaginal bleeding and cramping after treatment and burning with urination because of the catheter. They are sometimes given a

³ Ativan (Lorazepam) is a benzodiazepine that slows down the central nervous system to relieve anxiety and seizures.

vaginal dilator to use one to two weeks after treatment to minimize the radiation induced narrowing of the vagina. The nurse also advises women to resume sexual activity as soon as it is comfortable. Women are provided with a short list of possible symptoms that require follow-up with the primary care nurse or oncologist, or the hospital emergency room after hours. These include a fever over 101degrees Fahrenheit, severe abdominal pain, bleeding more than a normal menstrual period, and burning on urination that lasts more than 24 hours.

There is one additional step that some but not all women require before brachytherapy treatment begins. This is a dilation of the cervix. If this is deemed to be necessary, it is done under a general anaesthetic in the hospital and requires time in the recovery room before discharge.

Much of the information discussed in this treatment section was provided by the nurse who works closely with cervical cancer patients in the radiation treatment program. I spoke with her a number of times to understand the detail provided here and to verify this information. During one of our conversations she mentioned that many women will have apparent bleeding for months before they even start treatment and they are already having difficulty maintaining their normal sexual activity. Others have already experienced a long period of abstinence as a result of their cancer, its symptoms, and any preliminary treatments or procedures that they have already experienced before coming to the cancer centre.

For women who are postmenopausal there may be hormone therapies that sometimes improve treatment-related symptoms. For the others there is very little to offer beyond the use of dilators and lubricants.

Literature review

This literature review explores sexuality from several perspectives that are important to understanding the experience of women with cervical cancer. This disease and its treatments have the potential to alter a woman's body so dramatically that it puts limits on her sexual activity and her experience of sexual pleasures. This review is divided into three sections. The first deals with the nature or meanings of sex and sexuality historically and in contemporary society. The next section reviews the research literature on women's physical changes and resulting sexuality changes after cervical cancer treatment. The third section discusses the health professionals' perspectives and their approach to dealing with sexuality within a treatment setting. Finally, the work of three sociologists is presented to offer a sociological context. In this literature review I first explore the question of what counts as having had sex.

Sex, what is it?

A mutual understanding of the meaning of what constitutes sex needs to be established when discussing sexual behaviour in a study interview or in a counselling room. In "Are we having sex now or what?" Greta Christina (1992) provides a humorous account of how she struggled with defining what counts as 'having sex'. She describes a variety of activities that open the door to a wide range of definitions. This is a serious question for many women who have their abilities to have intercourse, be sexually aroused, or experience orgasm altered by treatments for cervical cancer.

Christina aptly points out that what constitutes sex can be defined rigidly, loosely, or anywhere along this continuum. The influence of Freud and psychoanalysis during the

first half of the twentieth century focused on the vagina as the centre of women's sexuality and constructed the notion that vaginal orgasm was necessary for women to be considered sexually healthy. The latter half of the twentieth century saw sexologists as experts who moved the site of the orgasm from the vagina and located it in the clitoris. Feminists then liberalized, politicized, and normalized the clitoral orgasm, thus redefining what could be considered as 'having sex' and sexual pleasure. The sexually open-minded woman could consider a variety of genital contacts with her partner or partners (or indeed without anyone else at all) as sex. The loosened boundaries for defining 'having sex', has allowed the inclusion of any activity where there is a deep emotional bond regardless of whether any physical contact takes place (Gerhard, 2004).

At present the dominant understanding of sex is as an intercourse focused activity. The development, promotion, and popularity of remedies, such as Viagra for men and Eros for women, both reflect and reinforce the dominant norms and understandings of sex that include intercourse as the most desired sexual activity (Fishman & Mamo, 2001). Peggy Kleinplatz (2001), an Ottawa-based sex therapist, researcher and university professor, also describes more conventional models of sex as focused on heterosexual intercourse and she sees this as "fairly narrow, constricted, heterosexist, phallogentric and procreative" (p. 123). She perceives this as problematic and an issue that arises from looking at women's sexuality from the outside, without asking women about their own sexual experience, and instead imposing male sexual norms.

The contemporary view of heterosexual sex as centred on intercourse has implications for women with cervical cancer and how they construct their sexuality. Tiefer (1986) points out that we also live in a time when sexual satisfaction in

relationships is emphasised, as traditional social reasons for being in relationships, such as raising families and economic needs, are less important. At the same time, popular culture both reinforces this shift and advises women to take more responsibility for sexual knowledge and pleasure. Women with cervical cancer receiving these messages face challenges in adjusting their sexual behaviour to meet dominant expectations and their changed bodies.

For the purpose of this study I use the term sex, which is commonly used to describe the physical characteristics that define a person as male or female (Pan American Health Organization & World Health Organization, 2000, p. 120), to denote sexual behaviour or sexual activity. Thus 'having sex' is a personal definition that women have that is informed by a particular set of sexual behaviours or other experiences. It may or may not conform to the contemporary view described above. Along with other problems already discussed, most scientific research in this area measures sexual dysfunction and sexual health in terms of resumption of sexual intercourse. (Burns, Costello, Ryan-Woolley, & Davidson, 2007, p. 365; Takahashi & Kai, 2005).

I have used the term 'sexuality' in a variety of ways throughout this thesis. In their 2000 document *Promotion of Sexual Health, Recommendations for Action*, the Pan American Health Organization and the World Health Organization defined sexuality as follows:

Sexuality refers to a core dimension of being human which includes sex, gender, sexual and gender identity, sexual orientation, eroticism, emotional attachment/love, and reproduction. It is experienced or expressed in thoughts, fantasies, desires, beliefs, attitudes, values, activities, practices, roles, relationships. Sexuality is a result of the interplay of biological, psychological, socio-economic, cultural, ethical and religious/spiritual factors. While sexuality can include all of these aspects, not all of these dimensions need to be experienced or expressed.

However, in sum, our sexuality is experienced and expressed in all that we are, what we feel, think and do.

This definition illustrates the breadth of experience and ideas that 'sexuality' can be used to express. I use it in its broadest meaning in discussions of communication between health care providers and staff and when appropriate I use it in discussions of the impact of cervical cancer and its treatment. One of the methods I used for drawing women into discussion of sexuality related to the physical changes they may have experienced as an outcome of their cervical cancer treatment was to ask them if they have changed the way that they see themselves as women. This question provided an opportunity for women to focus on aspects of sexuality that were relevant to them rather than prescribing for them a particular aspect of sexuality that might be less meaningful.

Effects on Sexuality

There are two areas of literature that will be addressed in this section. Although they overlap in that they discuss some of the same basic concerns, they are distinct approaches to the study of women with cervical cancer. First, there is the quantitative literature that focuses on physical changes, symptoms, and quality of life issues and is most often referenced by the medical community to describe what we know about these areas. Many of these quantitative studies essentially equate adequate sexual functioning with the ability to have sexual intercourse. Secondly, there is qualitative research literature, which is sparse. The qualitative research presented here explores women's subjective experience to discover how sexual changes due to cervical cancer impact their everyday lives, self perceptions and relationships. This section will end by describing what has been learned about women's need for counselling and information, drawing on the combined literature.

Quantitative Literature Review

Cervical cancer has provided a rich arena for quantitative research that effectively explores physical changes and symptoms associated with the treatment of cervical cancer through the lens of scientific inquiry, but the actual subjective experiences of women are largely lost or ignored. However, the studies presented here merit review as they form an understanding of the types of challenges faced by women and provide a starting place for further inquiry. The more recent articles (Donovan et al., 2006; Frunovitz et al., 2005; Lindau, Gavrilova, & Anderson, 2005; Park et al., 2007; Wenzel et al., 2005) that explore quality of life issues and sexual health deliberately examine women's issues of sexuality post treatment.

Women treated for cervical cancer with local treatments such as surgery, external beam radiation, and brachytherapy are at risk for a long list of physical changes and accompanying symptoms. Troubling vaginal changes may result from treatment induced hormone deficiency, fibrosis, and damage to blood and nerve supply to the vagina (Bergmark, Avall-Lundovist, Dickman, Henningsohn, & Steineck, 1999). These include loss of elasticity, reduction or perceived reduction in vaginal length, dyspareunia⁴, reduction in vaginal lubrication, reduced swelling during intercourse and, for some, vaginal bleeding, and these changes persist over time (Bergmark et al., 1999; Frunovitz et al., 2005; Jensen et al., 2003; Paavonen, 1999). Additionally, Jensen et al. (2003) noted only minimal improvement during the first two years, which was the time period studied.

Other symptoms that are common after surgery, radiation treatment, or chemotherapy that are usually associated with menopause include hot flushes (flashes),

⁴ Pain during sexual intercourse

sweating and loss of libido (Park et al., 2007). There are mixed findings reported in the literature about the benefits of hormone replacement therapy for women after treatment for cervical cancer. Women who were on hormonal therapy had considerably more interest in sex than those who were not (Donovan et al., 2006) but still experienced discomfort and pain with intercourse as well as hot flashes and vaginal dryness (Wenzel et al., 2005). Bergmark et al.'s 1999 study also found that about a third of women of childbearing age were distressed by the infertility caused by their treatment.

Some researchers conclude that women with a history of cervical cancer are less interested in sex and have lower sexual satisfaction (Donovan et al., 2006; Jensen et al., 2003). Not unexpectedly, women who experience vaginal changes also experience increased sexual dysfunction and a large number of women experience distress as a result of their physical changes and the subsequent effect on sexual intercourse. Vaginal changes that involve pain or bleeding during intercourse interfere with the experience of sexual pleasure (Bergmark et al., 1999). These physical changes are sometimes temporary, but often permanent and have the potential to affect a woman's ability to experience sexual pleasure in the same way that she may have prior to her cancer (Bergmark et al., 1999; Mckee & Schover, 2001; Paavonen, 1999).

Several studies indicate that patients who undergo radiation therapy on its own or in combination with other treatment can expect more severe symptoms and sexual dysfunction (Donovan et al., 2006; Frumovitz et al., 2005; Jensen et al., 2003; Park et al., 2007). These women also experience significantly more menopausal symptoms and find it harder to become sexually aroused, lubricated, and satisfied, and have more difficulty achieving orgasm (Frumovitz et al., 2005). This more recent information contradicts an

earlier study by Bergmark et al. (1999) that found no difference in prevalence of vaginal changes across different types of treatment. Findings of Frumovitz et al.'s 2005 study indicate that surgical interventions result in far less sexual dysfunction than radiological interventions at seven year follow-up, with no difference other than arousal when these women are compared to the non-cancer patient control group.

A large quality of life study (Park et al., 2007) of 860 cervical cancer survivors with an average survivorship of 5.86 years found body image, lymphedema⁵, sexual functioning, sexual worry and anxiety about sexual performance to be problems for all women and dyspareunia a particular problem for women who had had radiation treatments. A study of long-term survivors of cervical cancer with a mean survivorship of 26.8 years found that women's physical health hampered having sex all or most of the time and their multiple sexual problems included pain and lack of sexual pleasure (Lindau et al., 2007). Despite these poor outcomes these women continued to value sexual activity and participated in sexual relationships and activities similar to those in the non-cancer population control group.

Qualitative Literature Review

Two qualitative studies (Burns et al., 2007; Juraskova, Butow, Robertson, Sharpe & McLeod, 2003) of sexuality after cervical cancer were reviewed; they offer a rich representation of women's experience. Hordern & Street's (2007) study of sexuality and intimacy after cancer, although it does not address cervical cancer specifically, will also be discussed as it provides an excellent reflection of the cancer patient's experiences that has implications for women with cervical cancer. All three of these studies identified

⁵ compromised lymphatic system, in this case due to cancer treatment, that results in fluid build up.

many of the same issues discussed in the quantitative literature; this section will focus on the subjective experience of women that can only be found through qualitative studies.

Burns et al. (2007) conducted their study to acquire detailed insight on the subjective experience of women who had been treated with radical radiotherapy⁶ focusing on the long-term psychosocial effects, especially those that impact sexuality. Their initial study group included 28 women who were two to three years post treatment. Of the 28, 15 declined and the remaining 13 participated in semi-structured interviews. These women talked about how bladder and bowel problems interfered with their ability to be sexual with their husbands and found the diarrhoea to be “terrible” (p. 386). Some women expressed anxiety about resuming sexual activity because they thought it might hurt and others were concerned that bleeding would start again. Some women discussed how their reduced interest in sex put a strain on their marriage because their husbands still wanted to be sexually active. Weight gain after treatment had a negative effect on self image for many women. One woman talked about wearing baggy clothes to conceal her weight gain which she saw as her worst outcome of treatment. This study found that women who could not adjust to their additional weight accommodated by becoming depressed.

Juraskova et al.’s 2003 study of 20 heterosexual women who had either surgery alone or some combination of surgery, external beam radiation, and brachytherapy, several themes emerged. Most evident in younger women who had not yet completed their family, was the loss of fertility. These women felt that their infertility would compromise their current and future relationships. Some saw their lost reproductive organs as “symbols of their womanhood” and some felt that they would have to face the

⁶ Radical radiotherapy was left undefined in this article

“whole thing” again with a future husband. One woman talked about feeling dirty and scrubbing herself so hard that she left scars (p. 271). In this study a woman’s sense of being feminine only changed when she equated femininity with fertility.

Women in the Juraskova et al. study who just completed surgery did not see sexual functioning as a priority but reported fear about re-initiating sexual interaction. Later, women described both physical and emotional pain during their earliest sexual experiences after treatment with some women reporting that their “mind wasn’t there” and “I just blanked myself out” (p.272). Some women did not emphasize intercourse as necessary for sexual expression but expressed their belief that it was the main source of sexual satisfaction for men. These women participated in intercourse to fulfill their partner’s desire as they felt they would otherwise need to allow him to ‘go elsewhere’ for sex. When men did not initiate resumption of sexual intercourse, women often interpreted it as their partner’s fear of hurting them or their difficulty accepting the diagnosis. Most partners did not speak about these concerns unless prompted and some women believed that their partner felt “lost and helpless”, or they “just wouldn’t talk about it”, and one woman stated “it was a lot harder on him than really me” (p. 273). Not surprisingly, couples that openly communicated and had a “broader sexual repertoire” before cervical cancer had fewer problems about issues of penetration (p. 272).

Hordern and Street’s 2007 study of 50 cancer patients and 32 health care professionals found less reflexive patients were more likely to define sexuality in terms of intercourse, see survival as more important than sexuality, and ultimately put their trust in the experts. This group felt that they needed to “just get on with life”, “manage without intercourse”, and felt “lucky to be alive” (p. 1710). Cancer patients that were described as

moderately reflexive searched for the “right” professional to help them with issues of sexuality and intimacy as well as more practical concerns such as prosthetics and wigs. The highly reflexive group of patients sought to normalize their experience by actively seeking out professionals who would talk to them about their issues of sexuality and intimacy. Highly reflexive individuals also felt themselves to be active participants in their treatment and identified that sexuality, intimacy, and relationships were the most important aspects of their lives.

Women’s Informational and Supportive Care Needs

Lindau et al.’s 2007 study found that although women were very satisfied with their overall quality of care, they were less satisfied with their care related to sexual health. Most survivors (74%) thought that their doctor should initiate conversations about sex and 70% of women said they would be comfortable talking about sexuality with their doctor although only 55% of women reported that they had initiated this discussion. It is disturbing that 62% of survivors said that their doctor never initiated discussions of sexuality with them as the same study reports that discussion of the side effects of cancer and its treatment reduces sexual morbidity.

Women of all ages require information about their disease and treatment-related vaginal changes before and after treatment for cervical cancer (Bergmark et al., 1999). In addition, Juraskova et al. (2003) suggest sexual issues should be discussed beginning at consultation and be repeated at follow-up visits when sexual activity may be resumed. They also indicate that a patient may require psychological and medical counselling long after treatment has finished.

An important finding of Juraskova et al. (2003) was that women dealt with the treatment and side effects of treatment much better when they had been explained and identified as a possibility, even when the treatment was traumatic. Another interesting finding of this study was that women felt that their health care providers over-estimated their understanding of their own physiology and anatomy; they believed that this assumption impacted their understanding of the treatment effects on their body and its functions. These women also identified peer support as important, especially six months after treatment.

Women in the Burns et al. (2007) study also identified a need for more information on the treatment effects on sexuality and although women differed somewhat on when this information should be given, most women in relationships identified follow-up visits as the most appropriate time. In this study, 85 percent of women said that sexuality was never discussed during follow-up visits with their oncologist.

Anderson, Woods, and Copeland (1997) suggest that women with a negative self-schema would benefit from learning strategies for improved sexual arousal, increasing 'sexual behaviour repertoire', and decreasing problematic effects such as embarrassment. They suggest that traditional counselling that focused on behavioural change techniques might also be employed to support women with sexual dysfunction. Counselling may be employed prior to treatment for prevention of problems and post-treatment if sexual problems arise.

Sex, Cervical Cancer, and the Health Care Professional

The research literature appears to lay blame at the feet of health providers for not attending to the sexual information and counselling needs of women with cervical cancer.

The study by Hordern and Street (2007) provides insight into how health care professionals experience their roles in communicating with patients about sex. My own observations regarding the reluctance of health care providers at the cancer centre to enter into discussions of sex are supported by this research. Hordern and Street explore the dominant structures that create an atmosphere where sex is a taboo topic for discussion in a health care setting. They challenge the assumption that simply telling health care providers to talk about sex with their patients will result in them doing it.

Exploring the health professional's experience, Hordern and Street identify a range of conceptualizations along a "reflexive cluster continuum" (p. 1710). The article discusses how many health care providers in their study were less reflexive than patients, believing that patients share their focus on treatment and cure. Sex not being a life or death issue, it is not a topic for discussion. Other health professionals discussed sexuality primarily within the context of medical functional issues, such as erections and fertility, and discussed sexual issues only superficially because of their own discomfort with the topic. These health care providers identified insufficient time and lack of privacy as reasons for not discussing sex with patients. They also made assumptions that others would talk to patients about sex. A smaller, more reflexive group of health care providers recognized that environmental factors could be seen as an excuse to avoid discussions that made them personally uncomfortable, inadequate, and embarrassed. Even though the most reflexive health care professionals were able to articulate a holistic definition of sexuality and intimacy, their clinical practice belied any integration of these concepts; they were most comfortable with an 'asexual' patient.

Theoretical Perspective

Although sociology does not focus on particular diseases, disease and illness can be examined from a sociological perspective. The work of three sociologists is of particular interest to the discussion of the experiences of women with cervical cancer. The first sociologist, Arthur Frank (1991), analyses his own experiences with heart disease and cancer from both micro and macro theoretical perspectives. The micro perspective encompasses his personal reflection of his experience along with those of his wife and his health care providers within their respective roles of patient, wife, and professional. Frank also discusses the macro perspective to explore how cancer is handled within the health care system in the 20th century (when he was writing), including how the work of health care is performed, and how cancer is dealt with in the workplace.

As we have seen, there is ample quantitative evidence (Bermark et al., 1999; Donovan et al., 2006; Frunovitz et al., 2005; Lindau et al., 2005; Mckee & Schover, 2001; Paavonen, 1999; Park et al., 2007; Wenzel et al., 2005) that women with cervical cancer experience a variety of symptoms that indicate a need for information and support to assist them with sexuality issues that are part of their illness experience. So why is it that these needs remain unmet?

Frank found the health care setting and health care professionals unresponsive to his needs beyond the treatment of his disease. When talking with doctors he became conscious about what he was 'not' to say. The talk that was acceptable was "disease talk" which encompassed information about his condition that was objective and could be measured, and did not extend to how it impacted his life. Frank describes "illness" as a

person's experience of their disease within the context of their life. It includes their subjective experience such as hopes and sorrows which cannot be measured. Medical staff focus on curing and controlling disease and avoid non-disease issues that would require open discussion and an understanding of patients' stories.

Frank proposes that the separation of disease and illness experiences is useful for treating cancer but gets in the way of 'care' which can only begin when the difference between the two is recognized. Although physical symptoms that could be objectively observed were discussed, the experience of them within the illness framework was largely ignored.

To assist with understanding why health workers within health care systems fail in providing adequate care, Frank takes a broader view and discusses how cancer as a disease creates a great deal of discomfort and fear in our society. This is evidenced by pervasive beliefs in unsubstantiated personality theories which blame patients for their illness, metaphors that reflect the idea that cancer is an evil to be battled, and the denial that causes friends and family to disappear when they are most needed. In a society where control of the body is highly valued, disease is viewed as body out of control. Thus cancer is a moral failure and patients are stigmatized and forced to turn inward. The desire to control bodies along with the social isolation of people with cancer gives the health care system permission to focus exclusively on disease and disregard the challenges of illness. Within this system people with cancer become cancer patients that are seen as passive recipients of cancer treatment, bodies to be "colonized as medical territories" (p. 56). Similar to Hordern and Street, Frank believes that the system as it is cannot accommodate the whole illness experience of cancer.

Once a disease has been successfully treated and in remission, Frank suggests that one is expected to return to normal. To be valued in society one needs to be productive, so return to previous worker roles is expected. Frank found this difficult as, although his disease was in remission, he was still recovering from illness. He writes briefly about relationship stress during illness and role expectation within this relationship. Although he does not discuss sex within this context, it is certainly a component of the role of partner that may be affected during serious illness. As Tiefer has suggested, currently women in general feel pressure to perform well sexually. For women with cervical cancer who experience physical changes that affect their sexuality, returning to this role has painful consequences, yet many women return to their role as sexual partner even though they receive no pleasure from these interactions (Lindau et al., 2007). The need to deny cancer as an illness and perform as normal appears difficult to resist.

A review of literature for this study located few qualitative studies and this is problematic since this type of research takes us into the experience of illness that Frank says is vital to share. It provides the opportunity for women to experience catharsis but as importantly, Frank believes there is a reciprocal responsibility for the ill person to express their suffering and society to witness it (p. 122). Without these stories the social context of cancer is missing.

The second sociologist, Kathy Charmaz (1991), undertakes the study of people with chronic illness through a micro perspective. This thesis utilizes her understanding of how patients and health care professionals interact, paying particular attention to her understandings of the doctor / patient relationships.

Similar to Frank, Charmaz identifies concerns regarding the positions of doctors and patients within the health care system. She found that while the prevalent assumption that doctors are active and patients are passive supports compliance to treatment, it also fosters an expectation of cure and return to a pre-illness normal that may not be possible. Physicians themselves often directly encourage this perception by being vague or incomplete in their information and communication with patients.

Unfortunately, this expectation of recovery results in a lack of recognition that illness often creates lasting changes for patients. This has serious implications for patients as they do not adjust their self-concept to incorporate continued illness and are left unsupported at the end of treatment. This might explain the findings of Lindau et al. (2007) on sexual morbidity in cervical cancer patients discussed earlier. If care is centred on treating cervical cancer with no recognition of its implication for future sexuality, women find themselves unprepared to deal with unexpected sexual problems.

The studies of Bergmark et al. (1999) and Juraskova et al. (2003) suggested that more education, support, and counselling should be available to women with cervical cancer before, during, and after treatment. Charmaz and Frank would concur with Hordern and Street who emphasize that this cannot happen in our current health care system with its emphasis on disease management. Like Frank, Charmaz believes that a broader focus in health care is necessary to support persons with illnesses beyond treatment of their disease. This must include a variety of support services that assist with educational, physical, emotional, and social problems that are part of the illness experience and extend well beyond treatment.

Both Frank and Charmaz came to similar conclusions about the health care system's inability to support the whole person during their illness experience. What makes this interesting is that Frank's experience took place within the Canadian System of socialized medicine while Charmaz's research involved patients in the US where no universal government sponsored health care is available. One might conclude that shared societal beliefs regarding disease and illness create systems that fail to recognize the need to support people with illness beyond the treatment of their disease.

What makes both Frank and Charmaz's work important is that they bring out the voices of people with illness as a way to educate and promote change. They exemplify the kind of qualitative study that is vital to understanding the illness experience and tailoring care to meet these needs.

The work of the third sociologist, Steven Epstein (2007), takes a broad look at research, capturing an historical view of who and what is included as research subjects. His work can help us understand why qualitative research into the sexual experience of women with cervical cancer is lacking.

Epstein outlines the history of inclusion and difference in biomedical research within the United States up to the present day. He discusses the change of primary objects of study from 35 year old white males, known as a 'standardized human' (who was seen as representative of all people) to the current emphasis on the study of groups based on identities such as sex, age, and race. As Epstein points out, the study of groups, although in many ways an improved approach, fails to recognize individual differences and needs. Thus qualitative research, especially study into the individual experience of illness, does not have a place within this paradigm.

Additionally, the study of women's sexuality that includes the study of sexual behaviour is largely absent. First, the focus of biomedical research that is limited to how different bodies react to medications and how they experience symptoms does not easily lend itself to research on individual experience of sexuality or sexual practices. Secondly, Epstein identifies problems that political conditions in the US create, specifically a discomfort with the study of sexuality and sexual behaviour. This has translated into a lack of approval and funding by federal agencies and research review boards. This might partially explain how research on sexual behaviours and practices became the domain of drug companies who, as Tiefer points out, view sexuality from the perspective of male performance making assumptions about women's experience and desires. Thus Epstein's historical review helps us understand why research on cervical cancer has been focused on symptoms and quality of life data, and holds intercourse as the goal of sexual rehabilitation after cervical cancer treatment, a perspective that does not serve women with cervical cancer.

In summary, the works of Frank, Charmaz, and Epstein assist us in contextualizing the problems experienced by women with cervical cancer. Society cannot recognize their subjective experience because of a widespread discomfort with both cancer and sexuality. The health care system institutionalizes the discomfort and work is geared towards avoidance of issues beyond treatment and management of disease. Qualitative research into women's lived experience is stifled and their voices rarely heard.

Conclusions

As we have seen, few qualitative studies that focus on the subjective experiences of sexuality after cervical cancer have been done to date. Understanding of cervical cancer treatment and sexuality after treatment can only be captured by listening to the stories of women who have lived these experiences. Although the quantitative research seems to be becoming broader in its inquiry and including issues of sexuality, it continues to lack the voices of women who own the experience. As a society, it is our privilege and our obligation to listen to these stories.

In the present study, I asked questions that provided a framework for the articulation of women's experiences and I listened closely as women told me their stories. The details about how this was accomplished are reported in the Methods chapter which follows this introduction. What I heard from women is reported in a chapter for health care providers and a chapter for patients; it is my hope that their stories will guide health care professionals through increased understanding of women's experience and support other women diagnosed with cervical cancer. The final chapter will review conclusions within the context of the analytical frameworks provided by Frank (1991), Charmaz (1991) and Epstein (2007).

Chapter 2

METHODOLOGY

This research explores experiences of sexuality after cervical cancer and responds to a call for greater understanding of the needs of women affected by this form of cancer. Although an existing body of quantitative research explores issues of sexuality, only recently has the subjective experience of women been heard in two qualitative studies (Burns et al., 2007; Juraskova et al., 2003). This thesis focuses on women who have been treated for cervical cancer at the Windsor Regional Cancer Centre and hopes to add to the meager body of qualitative literature and to encourage conversation among and between health care professionals and the women that they treat.

Research Design: In-Depth Interviews

This study used a qualitative research design, gathering data through in-depth interviews with women who had received treatment for cervical cancer at the Windsor Regional Cancer Centre. This methodology allows for more comprehensive recording of the lived experiences of the women. Using qualitative research techniques permits the researcher to share in the awareness of others, thereby encouraging an understanding of how others bring meaning to events in their lives. This methodology produces richness in research data that is not quantifiable (Berg, 2004).

Women diagnosed with cervical cancer come into treatment with their own unique experiences of their disease that may be influenced by their sexual history, how they see themselves as sexual beings, how they define sex, their journey to diagnosis, symptoms pre and post diagnosis, and their understanding of the cause of their cancer. All aspects of one's life have the potential to impact the experience of cancer treatment.

The in-depth interview offered an opportunity to encourage women to give voice to their experience while providing me, as the researcher, the flexibility of pursuing issues of interest that arose during the interviewing process (Babbie & Benquisto, 2002).

Both the University of Windsor and Windsor Regional Hospital reviewed the study protocol and provided ethical clearance.

Sampling

Initially sixteen women were identified as possible participants by the radiation therapy nurse who served as a gatekeeper for this study. She approached women who were up to five years post treatment and spoke to them briefly about the study when they attended follow-up visits at the cancer centre. She obtained consent for me to call them to provide additional information and to request their participation in the study. Of the initial sixteen, fourteen agreed to meet with me for an interview and two did not return my calls. Eleven of the initial fourteen were eventually interviewed. Of the remaining three, two changed their minds and did not attend scheduled interviews. The deeply personal nature of the topic seemed to be a deterrent for some women. A total of eleven women were interviewed.

All eleven women in this study were current patients of the cancer centre. The women ranged in age from 33 to 71. Women interviewed were diagnosed at various stages of their cancer and were treated with external beam radiation and brachytherapy and one or both of surgery and chemotherapy. The study sample included only those women who had completed treatment between 2003 and 2008 and were being seen for follow-up appointments with a radiation oncologist.

An attempt was made to include women in long-term relationships, new relationships, relationships that had ended since treatment, and women who had not been in relationships since their treatment. The intent was to include women of different sexual orientations, ages, and ethnicities, as much as possible. The sample does include women that represent each of these descriptions, although all of the women spoke exclusively about heterosexual relationships.

Data Collection

An interview guide was developed and used as a tool to guide discussion and ensure that key areas of interest were discussed. The interview guide consisted of opened ended questions to elicit information on each of the following topics:

- How women first understood that something was wrong
- Treatment experience
- To whom women spoke about their sexuality concerns
- How women coped with sexual problems
- How partners coped
- How women and their partners worked out issues about their sexuality
- Women's ideas about what sexual behaviours need to be included for them to feel had they had 'had sex'
- Advice for women newly diagnosed with cervical cancer and advice for their partners
- Perception of causes of cervical cancer
- Recommendations for health care professionals

The women in this study chose the location for their interview. Three interviews took place in a private office at the cancer centre and eight took place in women's homes. The length of the interviews ranged from 15⁷ to 60 minutes. All of the interviews were recorded and transcribed. Prior to each interview I reviewed the purpose of the interview, the goals of the study, the potential benefit and risks, and confidentiality. Each woman

⁷ This short interview was an outlier. One woman could not be drawn into a conversation about sexuality making the interview very brief.

signed a consent form that detailed these items; they also signed a consent form for the audio-recording of the interview.

Women were also given a copy of the study information and my business card and informed that they could call if they had anything that they wanted to add. One woman called the next day but did not offer any new information.

Data Analysis

The interview transcripts were analyzed with the assistance of QSR N6 software. The interview data were coded initially using clustering based on the interview guide questions. Through repeatedly reviewing the interview transcripts, the deeper personal and unique meanings of the experience became apparent. Subsets of clusters emerged and similarities and differences between women's experiences were identified.

Reported findings of this study satisfied at least one of three criteria. First, ideas or experiences that were discussed by multiple women in the study were included. Second, thoughts, experiences, and perspectives that were strongly stated or emotionally charged, even if only by one woman, are reported in the findings and are especially important given the small sample size of this study. Third, elements that had previously been discussed in the literature or were linked to my prior knowledge based on my professional experience at the cancer centre are also included among the findings.

Very little of the data has been quantified and this document purposefully contains a profusion of direct quotes from the women interviewed so that their stories are not lost during the reporting of findings.

Difficulties/Lessons Learned

The number of women identified as meeting the criteria for this study was smaller than expected. Additionally, many of the initial eighteen women were ambivalent about talking about sex and sexuality and it was difficult to gain their trust over the phone. Ultimately eleven women participated in the study.

In retrospect, it may have been beneficial to have reviewed charts and developed a list of women who met the study criteria.⁸ Using this list, introductions through the nurse gatekeeper could have been scheduled at the time of the next clinic visit. This may have helped in two ways. First, the number of women identified as meeting the criteria may have been larger than those identified by the nurse. Second, most women seemed very comfortable talking about sex and sexuality once I was actually sitting across from them. It is possible that face to face introductions would have increased the number of women who agreed to participate in this study.

There were additional unexpected challenges with this sample. Four of the women interviewed were not in a relationship or sexually active at the time of their diagnoses and had not resumed any sexual relationships. This limited discussions of the impact of cervical cancer and treatment on sexual activity to conjecture. Additionally, one of these women was a widow who did not speak English and used her daughter as an interpreter; the daughter actually served more as an information gatekeeper, often choosing to answer the questions herself. This interview was also limited because the daughter did not think it was appropriate to ask her mother questions about her sexuality. Another of these four could not be drawn into any conversation about sex or sexuality which made their

⁸ Patients of the cancer centre sign a release allowing for chart review for the purpose of identifying study patients.

interview very short. Seven of the interviews were very good. These women were engaged in the conversation and answered questions thoughtfully.

Although partners were not intended to be part of the interview, one husband decided to stay and participate. This was actually valuable in that the partner's perspective was available first hand and also because he supported his wife during the interview. The drawback was that he sometimes spoke on her behalf.

The semi-structured interview worked very well for this study. Women often talked for long periods of time without interruption. This allowed them to develop and express a train of thought that lead them to what was important to them about their experience. It was as if they were reviewing their experience and discovering insights as they went along. Not only was this beneficial to the study but it also benefited them. Emotional responses to questions and to their own expression of their experiences were common during these interviews. The flexibility that the open-ended interview offered created an atmosphere where both the study requirements and the needs of women were achieved.

Summary

The women interviewed were drawn from the approximately 12 patients per year treated at this small regional cancer centre. Privacy was maintained through the use of pseudonyms. In total 18 patients were recruited and 11 ultimately participated in the study. Four of the women interviewed were not in relationships at the time of their diagnosis and had not been sexually active since. Although they could only speculate about experiences of sexuality, they offered a great deal of information related to other

study questions. Seven of the women interviewed discussed their experience of sexuality in detail, sharing deep insight and emotion.

A number of women who participated in this study were very articulate and had well thought out responses to my questions. Other women had some difficulty talking about the subject matter and for a couple of women there were language barriers. In dealing with the topics in this and the following chapters I draw more from the articulate women; however their experiences were also reflected in the experiences of the other women in the study. Thus, it should not be assumed that the quotations represent the views of just one particular woman, but rather that the experiences and feelings spoken of were common to many women in the sample.

Chapter 3

INFORMATION FOR WOMEN

The information used to develop this resource reflects the stories of women who have been diagnosed with cervical cancer and treated at a regional cancer centre. Eleven women agreed to talk about their experience and share what they learned to help guide other women. These women ranged in age from 33 to 71. They included women who were single, married, divorced, and widowed. Some were in sexual relationships at the time of diagnosis and treatment and others were not. All of these women had completed their treatment during the five years immediately preceding their interview. Each one of their experiences was unique and all of them had insight and wisdom that contributed to this resource.

The recommendations that follow are based on the experience of these eleven women. These women hoped that by telling their stories they would improve the experience of women who undergo treatment for cervical cancer, particularly as it relates to sexuality. Their stories are supplemented with information gathered from previous studies to provide a more complete picture of women's cervical cancer experience.

Journey to Diagnosis

Women learned about their diagnosis in a variety of ways and their journeys were very individual. Some were diagnosed as a result of routine screening through a PAP test and others had symptoms that caught their attention and sent them to a doctor for help. Some experienced challenges and they offer what they learned from their experience as suggestions to other women.

Recommendations

- **Make your annual PAP test a priority.**

Christine knew that early abnormalities identified and treated as a result of a PAP test can sometimes prevent cancer from developing. She explained how she believes she ended up with cervical cancer.

By me not taking care of myself. By me not going to see a doctor to get a PAP smear test...

For some women, a PAP will lead to an actual diagnosis of cancer. Women in this study whose PAP test eventually led to their diagnosis moved more quickly through the system.

December was the PAP smear and January was [consultation in another city]; I finished treatment in May, so it happened pretty quickly.

- **If you have symptoms such as abnormal bleeding and discharge, get yourself checked out by a doctor. If you are not satisfied with the explanation you receive or your symptoms continue, be persistent in your efforts to find an appropriate explanation.**

Diane was initially told that her symptoms were menopausal but knew in her heart that it was something more.

... if you're not getting the answer you want to hear then go see somebody else. Because, if I hadn't gone to see somebody else, I wouldn't be here today.

Diane experienced a great deal of anger because she felt she was not diagnosed as early as she could have been. One of the ways she dealt with this anger was by telling her doctor about his mistake, hoping to prevent a repeat of her situation.

I went back and updated what happened to me, and he was quite shocked. Hopefully now he's more cautious with his patients, and if he thinks something is wrong, have it tested and make sure that what he thinks is wrong is wrong.

- **Make sure you understand your diagnosis. Receiving the news that you have cervical cancer can be such a shock that it becomes difficult to hear and understand anything that is said after the word ‘cancer’.**

Freda had this experience and took care to ensure that she got the information that she needed.

So, as [my doctor is] talking to me I was very calm. And he said you know what? You have cancer. And that was the only thing I heard. I don't know what he is saying and I remember he said [the name of another cancer centre] and some stuff. And I went out, and then I went back to his office and said, "Excuse me can I see the doctor?" And the secretary is like, "Why?" And I said, "He talked to me but I don't understand what he say." And I went back in and he explained to me [about] cervical cancer.

A Word about HPV and Cervical Cancer

Several women who told their stories about cervical cancer talked about how they became distressed when they learned that HPV was sexually transmitted and was also strongly linked to cervical cancer. These women thought that this meant that they had been promiscuous and it did not make sense to them because they had had few or only one sex partner. Here are some of the things that these women did not know:

- HPV is very common; about 75 percent of men and women who have had sex will have been exposed to the virus. (Cancer Care Ontario, 2008)
- While it is true that the risk of acquiring HPV increases with the number of sex partners, it only takes one sexual encounter with one partner to acquire HPV.
- HPV can remain present in a person for many years before the virus can even be detected and it is not usually possible to determine when HPV was contracted. This means that women with cervical cancer may have contracted it from a partner who

was faithful to them throughout a very long term relationship (American Social Health Association, November, 2008).

- More information is available on internet websites. Cancer Care Ontario is a reliable online source of information:

(<http://www.cancercare.on.ca/english/home/pcs/screening/cervscreening/hpvfaq>)

Treatment

Several studies that look at women and cervical cancer find that the more information a woman has before starting treatment, the better she will be able to cope with the side-effects of treatment (Burns et al., 2007; Corney, Crowther, Everett, Howells, & Shepherd, 1993; Juraskova et al., 2002) and most women in this study felt the same way. The experiences of women in this study do not represent all situations for all women; therefore, it is vital that the information presented here is supplemented by information from your doctor who will tell you more specifically what you might expect. The recommendations are based on the experiences of the women in this study.

Treatment Recommendations – Making Informed Decisions

You may meet with a number of specialists who will talk with you and make recommendations about treatment. The common treatments for cervical cancer are surgery, external beam radiation treatment, brachytherapy (internal radiation treatment), and chemotherapy. Any or all of these treatments may be suggested. Ensure that you are properly informed about what will happen during treatment and how your body will be different afterwards.

- **Make sure you understand the language that is used.**

There are no 'stupid' questions and you will not be expected to know as much as your doctor. This is especially true about parts of your body that you may know by different names.

(a diagram of female genitalia could be included here)

- **Take your time.**

If you feel you need it, ask for more time or another appointment.

- **Make sure you understand why the treatment is necessary.**

It may be helpful to ask two types of questions. First: How will this treatment help me? Second: What will happen if I do not choose this treatment?

- **Ask about how the treatment might change your body and how it functions.**

Example: Might I have problems with bladder or bowel function?

- **Ensure that you have enough information about how the treatment could affect how you experience sex and sexuality in the future.**

Examples:

Might I have pain or other difficulties during sexual intercourse or other sexual activities after I have this treatment?

What kinds of sexual problems might I have?

Will I look different than I do now?

Do you have resources that may help me better understand what might occur?

- **If any of the responses to your questions are unclear to you in any way, ask the question again.**

It is sometimes helpful to ask the same question in a different way to ensure your health care provider understands.

- **Take some time to review all of the information you have been given by the doctor.**

You will often have days or weeks to make treatment decisions without hurting yourself in any way. Check with your doctor about how much time you reasonably and safely have before you need to make a decision.

Experiences of Treatment

When making treatment decisions or preparing for treatment, it can be helpful to learn what other women experienced during their treatment. Treatment descriptions follow, along with a summary of women's comments about what they experienced during different treatments. Only two women in this study had surgery as part of their treatment and they did not speak specifically about the experience of surgery. This section focuses on external beam radiation, brachytherapy (internal radiation), and chemotherapy treatment.

External Beam Radiation Treatments

When external beam radiation is administered, you will be required to come to the cancer centre for a series of outpatient treatments. You will have an initial appointment to set up the treatment. You will receive a few tiny tattoos that help the radiation therapist ensure the radiation is directed exactly where you need it.

The actual experience of treatment is much like having an x-ray. Each treatment, which aims the radiation directly at the area to be treated, takes from 15 – 30 minutes. General radiation treatment education is usually provided at the cancer centre and additional information related to your specific treatment plan will be given to you by the oncologist, primary care nurse, and the radiation therapists.

Women's experiences. Overall, women in our study felt that the external beam radiation treatments were not too difficult. Although some women experienced side effects that they associated with these treatments such as weight loss, fatigue, and bowel and bladder irritation, most women thought they were simply an inconvenience and tiring because of the daily appointments.

.. the [external beam] radiation was totally painless, just a lot of going and trying to work at the same time. I gave up the work for almost three weeks.

- Iris

At least one woman found these treatments to be a time of introspection and adjusting to the diagnosis.

And, the radiation, the first two or three weeks I thought if this is cancer treatment I can handle it. But after the symptoms started setting in from the radiation I wasn't feeling too good. I lost a lot of weight, lost 20 lbs, and I was, how can I say, I was more worried about me. I was constantly thinking about me, anything else could happen out there and I could not care.

-Diane

Brachytherapy Treatments

After deciding to have brachytherapy treatment you will meet with your nurse and will be given more specific information about preparing for brachytherapy, also known as HDR (High Dose Radiation) treatment. Once treatment begins, the radiation therapists provide more information about the treatment itself. Some cancer centres provide the option of sedation while others do not. Explore this possibility with your oncologist.

In the treatment room you will lay on her back on the treatment table with your legs spread and positioned in stirrups. The typical brachytherapy treatment begins with placement of a catheter containing a balloon of radio-opaque dye into your bladder which identifies the location of the bladder on the x-ray to help determine the dose of radiation to the bladder. Once the catheter is in place, the oncologist will insert a speculum into your

vagina. The placement of the internal applicator into the cervix follows. Several attempts may be made before the proper sized applicator is determined and placed. The applicator is then secured with a table mounting brace. With the applicator firmly in place, a small amount of barium is put into your rectum to allow for the rectum to be visible on x-ray. You may be required to stay in this position for an hour or more while x-rays are taken and analyzed, dosage calculations are made, and the actual radiation dose is administered. While the treatment is being set up radiation therapists, your nurse, and an oncologist will be in and out of the room and you will be in the room alone once the treatment begins.

You may be given Ativan (Lorazepam), before this procedure to help with anxiety. You will feel pressure and cramping similar to menstrual cramps. Brachytherapy may be repeated several times over the course of a few weeks. Each treatment adds to previous vaginal sensitivity and pain so that when the applicator is positioned on subsequent visits, there is a potential for increased discomfort and pain.

You may experience some vaginal bleeding and cramping after treatment and burning with urination because of the catheter. You may also be given a vaginal dilator to use one to two weeks after treatment to minimize the radiation induced narrowing of your vagina. You will also be advised that you can resume sexual activity as soon as it is comfortable.

There is a short list of possible symptoms that require follow-up with the primary care nurse or oncologist, or the hospital emergency room after hours. These include a fever over 101degrees Fahrenheit, severe abdominal pain, bleeding more than a normal menstrual period, and burning on urination that lasts more than 24 hours.

Women's experiences. Women found brachytherapy the most challenging of all treatments. They talked about a variety of side effects that they experienced during and after treatments. Some women said that the treatment was not easy but that it was not that difficult.

Not painful, the [treatment] wasn't painful, it was just getting ready for the [treatment], a lot of manipulation, and a lot of things going on... Well, you know, the internals aren't very funny. There's a lot of preparation. It's a three minute [treatment] that takes 45 minutes of preparation. It takes a long time for me to get set up.

-Iris

Others found it very challenging and experienced extreme discomfort.

When I started, like I said with the first round of internal, it was ok, definitely wasn't pleasant but, it was ok. Second one was a little bit uncomfortable, third one I was just in tears, because I was just so sore at that point...

- Kayla

Going through that is the toughest part, the internal radiation, was setting up with the equipment. At one time Dr. [oncologist] had to stop and give me a break, because of the radiation, because there are six of the internal treatments were near the end, the last six of them, and I think, one a week. By then the side effects of the radiation, was awful. You're hurting when you pee, your vagina is all red, and everything feels like its just raw, and here he is probing with stuff in you. At one point I told him I can't expand any more, don't even try to pry one more thing into me it won't fit. And [the nurse] is the best. She helped me, she helped me through this. If it weren't for her, I remember telling her 'I'll never go through this again'.

-Diane

Yeah at the beginning was ok but when the last treatment I have, that was very painful.

-Brenda

The radiation [external] treatments were pretty basic but the internal [brachytherapy] was pretty devastating.

- Elaine

Chemotherapy Treatments

If chemotherapy is a component of your treatment plan, you will visit the cancer centre and will probably receive Cisplatin through intravenous infusion. The chemotherapy nurse will provide you with specific information about the treatment protocol and more general information is available through attendance at an introductory chemo class.

Women's experiences. Chemotherapy can create some initial anxiety but most women find it more manageable than they feared.

And, I was scared of getting chemotherapy. I thought, 'It's going to kill me'. Because you hear of people going through chemotherapy who get so sick they end up dying.
- Diane

Some women experience some symptoms but many take these in stride.

Chemotherapy, it [was] ok. I take the medication I come home I throw up, I'm dizzy, I'm nauseas.
- Freda

Coordination of treatment can be a concern since chemotherapy and radiation treatments are scheduled on the same day. Diane gives her perspective.

I would have to get my chemo therapy and my radiation on the same day, and I would have to have blood work done before I went home in order to know if I had to have chemo the next week. And coordinating those three things would sometimes be awful. They would be waiting for me downstairs while I was upstairs doing chemo. I went for my chemo one time and my blood work wasn't in, that kind of stuff. That is the only thing and really those are minor things.

Complications that result in hospitalization can occur. To minimize the risk of complications it is important to provide a full medical history and let your doctor know about any medications and over-the-counter products such as herbs and vitamins you are taking as they might interact with your chemotherapy drugs.

Coping with Treatment

There are a number of approaches that women have used to cope with treatment.

- **Decide how much information you want and let your medical team know.**

For many women, understanding what to expect from treatment is key to preparing for treatment. Other women prefer to know less.

- **For brachytherapy treatments, discuss conscious sedation with your doctor.**

Conscious sedation may be available at your local cancer centre or you may obtain a referral to another cancer centre. Women in this study did not receive conscious sedation.

- **Many women feel that they receive excellent support from their health care team and that coping mechanisms are built right into their treatment.**

I have a wonderful oncologist and if it wasn't for him I don't think I would have tolerated what I tolerated.

- Gail

The nurses are good, they are very good in supporting you. There was even music put on. There were different topics brought up during the set up so that you could kind of keep your mind off it, or talking about these topics or the weather whatever...

- Diane

- **Having a relative or friend support you through treatment can be an excellent way of coping.**

Many women find that confiding in someone they know and trust is very soothing. This person can also help with communicating treatment progress with others if you find that helpful.

I had a good friend, a very good friend that I talked to all the time, and she was very amazed that I got through it so easily. I seemed to get through it so easily but I hid my feelings a little bit. But she helped me...My son, he was very good to talk to.

-Gail

When asked if there was anyone besides her sister who supported this woman she responded:

Not to the degree that I talked to my sister. I didn't want to get all the theatrics when you get too many people involved how you have to go back and make sure they are up to speed. I would rather have one person that could take care of all that. And she did that, it's very hard to keep everyone on the same page. It's just a circus and that's the last thing I want to worry about.

- Iris

- **Finding ways to focus your attention off the treatment onto something that you enjoy may be helpful.**

This may be especially helpful when you are having your brachytherapy treatments. Women found they enjoyed their favourite music during their treatment. Prayer was helpful for many women as was meditation.

- **One of the ways some women get through the treatment is to focus on the purpose of the treatment; to get well.**

If you are unclear about how a particular treatment will help or what might happen if you do not have the treatment, ask your doctor. This could be very important to how you view and cope with your treatment. Interestingly, women who did not believe their treatment was necessary experienced more distress about their treatment than women who felt it was necessary.

I blocked everything out; I did what I was supposed to do. I had no memory of what I was doing, because it had to be done. And it's just ok I'm strong I can do it.

- Christine

[Brachytherapy] was uncomfortable, but I knew I would have to do it, so I did it, because I didn't want to have cancer I wanted to get rid of it, and if that's what it took, that's what I needed to do...

- Gail

- **If you are experiencing pain, discomfort, or other symptoms make sure you report them to your health care professionals and ask them if there are medications available to help you cope with these symptoms.**

You may be prescribed Ativan to relax you before brachytherapy. Let your doctor know if the medication does not work; this information is helpful for regulating the dose. Medications for nausea are available and the doctor may try a variety of techniques to relieve pain.

- **Connect with women who have completed treatment.**

Ask your doctor for the names of women who have completed treatment and might be willing to talk about their experience. You may also connect by phone with another woman who has been through cervical cancer treatment by calling Cancer Connection at 1-888-939-3333. Knowing that you are not alone can be very helpful.

Experiences of Sexuality after Cervical Cancer Treatment

If you are at the point of making treatment decisions this may be an important section to read. As this resource has indicated elsewhere, information about what to expect is key to dealing with treatment and its symptoms. Learning how treatment might affect your sexuality in advance of making a decision will help you to make an informed decision.

Learning how treatment may affect sexuality is also important when reintroducing sexual activity after treatment. You may refer back to this section once treatment is complete and you feel ready to resume sexual activities.

Some women encounter very few problems with sexuality after treatment while others face a variety of challenges. Some women experience symptoms briefly, then

sexual activity returns to their pre-cancer normal. Many women, however, experience symptoms including pain and discomfort that never entirely go away.

Sexual Problems Associated with Cervical Cancer Treatment

Women who have had treatment for cervical cancer may have some or all of the following physical changes that can impact on how they experience sex and sexuality.

- Treatment induced menopause
- Infertility
- Loss of sexual desire
- Shortening of the vagina and loss of elasticity
- Reduced or absent lubrication and swelling during intercourse
- Pain and vaginal bleeding during intercourse
- Irritable bowel and bladder

How you experience physical changes sexually is very unique. Your age and how important sex is in your life are among the lifestage situations that may also have an impact on how you experience your sexuality. The following are passages selected from stories women told about how they experienced the physical changes in their body after treatment for cervical cancer.

Diane, who had a hysterectomy as part of her treatment, talks about how she actually welcomed this.

When I went through this I was 49. And to be honest with you I was relieved, I wasn't going to have my period anymore. So I didn't feel any less of a woman. If I would have been younger and wanting children, I would have been devastated. But, at that point in my life I was welcoming the fact that I needed a hysterectomy...

Elaine, however, did not feel ready for the surgery and treatment that resulted in early menopause.

You don't feel so feminine you know you feel like, and plus I went right into menopause...

Elaine described intercourse as impossible because surgery and brachytherapy had shortened and shrunk her vagina. This had a profound impact on her life. She felt this loss both emotionally and physically and wondered about the possibility of future relationships.

I have no desire I feel like I've lost something.

It's like, I mean I probably could handle it if I was 15 years older, you know. But, being at my age and you know, and being divorced and you know would like to have another relationship in my life. It kind of makes me feel like I don't know if I ever will because of it.

Kayla spoke about her earliest experiences of sex with her partner after cervical cancer. Kayla considered sex to be an important part of her life and found her initial attempts at intercourse disappointing.

It probably would have been about eight or nine months when we first tried and it was too, it was just too much.

...and I asked [my oncologist], and he said it was probably a little bit too soon.

Sexuality wise, yes it's on my mind. It was very, very painful it was just like being a virgin again. Like you were just, because the radiation had tightened everything up. ...it's just very, very uncomfortable. It's to the point where the pain surpassed the pleasure; it's like oh forget this!

Freda found that although sex with her husband improved over time, her body was not yet able to accommodate what was normal for her before her treatment.

I don't know how many months after that I have no sex, nothing. I can't even like, I don't want anyone to touch me. I'm scared. And my husband is very understanding... So the day I married him I'm the only woman in his life, so we are very like, how to call it, close. That's why I think he was patient with me, and

certain things, even today I will not allow him to do it because I'm scared. I don't know how. To be honest my life is different.

Diane shared a similar experience.

There [are] certain positions that I cannot do that I used to be able to do before. There's always that fear of him going in a little bit too far... But like I said, I have the positions I know that I'm comfortable with, and we just stick to those.

Not all women have negative stories. Christine found that when she and her partner got past the initial pain and discomfort that she experienced when she resumed sex, sex was actually more pleasurable for her than before her cervical cancer.

It's just more sensitive. I can feel, I feel like it's amazing because when we make love... it's because I can really feel him inside me and it's just, I have orgasms.

Recommendations for Resuming Sexual Activity

Women who have had treatment for cervical cancer and have dealt with resuming sexual activity offer a few suggestions.

- **Take it slow.**

Women in relationships who most successfully adjusted to limitations that resulted from cervical cancer treatment were those who were in relationships with caring partners. These women felt safe, that their partners would take a slow approach to resuming sex, especially intercourse, and would be willing to stop if sex became too uncomfortable.

Well, whenever we got intimate he would ask if I was comfortable with having sex. And I would cry, and he would just be very slow, and asked if it hurts. So, like I said he was understanding and patient, so that really helps. And at first, yeah, it did hurt. And he'd have to stop.

- Diane

I'm with a guy who is very, very understanding... he's ok with it, whatever makes me happy he's ok with it you know? But I'm trying my best.

- Freda

- **Take care of pain and discomfort as much as possible ahead of time.**

Your desire for sex can be greatly reduced by worry about possible pain. Ask your doctor about a vaginal dilator and begin using it as recommended. Ask for gels or creams that can numb the vagina and labia so that there may be less discomfort and pain. Use a lubricant such as K Y Gel to make sexual contact more comfortable.

You just have to realize that, if you have gone through the cervical cancer and you have gone through the radiation, your body has changed a little bit. So do yourself a big favour, and when like the doctors give you one of these dilators to use, use the dilator. Worse comes to worse get a bigger dilator. Do what you have to do. Don't lose that part of your life because that really is a human quality. Don't lose it.

- Kayla

- **Explore your own body to discover what activity creates pleasure and what increases pain.**

If you are comfortable exploring your own body you can discover areas that are very sensitive to pleasure or pain and you will be able to advise your partner(s). This can reduce anxiety because you will know what to expect.

Good sex makes you a happy person.... But [masturbation] is a very, very good way to explore your own sexuality so you know what to expect and you know how to speak to somebody, your significant other to let them know that ok, can't do this because it hurts.

- Kayla

- **Talk with your partner about the changes to sexual activity you are both experiencing.**

For Freda, coping with issues of sexuality involved talking about the limitations of the sexual aspects of their relationship. She described a conversation that she had with her partner.

Oh yeah, like one time I said I break his heart and he said, 'No. I love you too much and love is not only sex; believe me in my eyes love is not only sex. You can

have sex anywhere but you cannot have love and I love you too much.' And I said, 'I can't give you more than what I have now.' And he said, 'Its ok honey I know. It's ok.'

- **Explore different ways to be sexual.**

Most people have a set of sexual activities that are comfortable and they have not explored beyond their comfort zone. If you are having difficulty with your usual activities, this might be a good time to discover other ways of being sexual that might minimize physical discomfort and maximize pleasure.

Ask if your doctor or cancer centre has a sexuality library or books that they might recommend. If not, libraries and bookstores will offer a variety of resources that may be helpful. If you are feeling more adventurous, there are adult sex shops and websites that may offer new ideas. If you are embarrassed about going to a sex shop on your own, bring a friend with you.

- **Ask for support or counselling.**

Talking about sex and sexual problems can be important to how you adjust to a 'new normal' sexuality. Do not be afraid to reach out for support. There will be a professional you can speak with at your cancer centre or in your community. Ask your health care provider for a referral.

- **If you have not done so already, connect with other women who have completed treatment and have resumed sexual activity.**

Ask your doctor for names of women who have completed treatment and resumed sexual activity. Talking to others who have had a similar experience can provide additional coping information and a sense that you are not alone.

I would have liked to have had me to listen to when I was going through it, to know that I wasn't the only one going through it because half the time I thought I was.

- Diane

Without treatment cervical cancer is a life-threatening condition. This resource is intended to help prepare you for treatment and the possibility of changes to your experiences of sexuality that may follow. We hope that you will use the wisdom of other women shared in this resource to help you through your treatment and sexuality after treatment. Remember, you are not alone.

Chapter 4

INFORMATION FOR HEALTH CARE PROVIDERS

This qualitative study explores the experience of women with cervical cancer from a phenomenological perspective. Although there are a number of excellent quantitative studies that investigate symptoms and quality of life concerns caused by cervical cancer and its treatment, there are few that are guided by the experience of women and focus on the impact this disease and its treatment have on the everyday lives of women and their partners.

Two primary philosophies are taken up when studying human experience. The first is positivist scientific enquiry that employs methods that are based on the examination of phenomena that are observable, measurable, and verifiable. This empirical form of inquiry seeks to understand cause and affect relationships between variable. The second philosophy is that of phenomenology. Phenomenological research is interested in subjective meanings in their natural contexts. It seeks to understand experience and its meaning rather than predict or control, thus it seeks to answer the question, 'how is this experienced?' (Knaack, 1984).

Phenomenology is focused on understanding a person's experience of their world from their own perspective through observation or listening to their stories (Wilson, 2002). This approach was selected for this study in order to increase knowledge of women's subjective experience of cervical cancer. Women interviewed were given an opportunity to talk and be heard. Several women in the study indicated that this was their first opportunity to tell their story and to give detailed accounts of what happened and

how it affected them and their partners. Several of the women commented that they found the interviews cathartic.

This study used semi-structured interviews to elicit women's descriptions of their experiences of cervical cancer. Women answered open-ended questions however they chose. Women were specifically asked about their treatment and the impact of cancer and treatment on their sexuality. The interviews lasted from about 15 minutes to one hour.

Seventeen women who had been treated for cervical cancer and one treated for uterine cancer who had the same treatments were approached to participate in the study and 11 were interviewed. One of these women had a previous diagnosis of Hodgkin's Lymphoma for which she had been successfully treated and also had a diagnosis and treatment for breast cancer one year following her cervical cancer treatment. For the purposes of this study, she was asked to limit her discussion to the experience of cervical cancer.

Women in this study ranged in age from 33 to 71 at the time of the interview and all had completed treatment within the last five years. Four women were not in relationships at the time of diagnosis and of the seven who were, one relationship ended within one year of diagnosis. All seven women in relationships had male partners.

A number of women who participated in this study were very articulate and had well thought out responses to my questions. In dealing with the topics in this resource I draw more from the articulate women; however their experiences were also reflected in the experiences of the other women in the study. Thus, it should not be assumed that the quotations represent the views of just one particular woman, but rather that the

experiences and feelings spoken of were common to many women in the sample. The names used here are pseudonyms and not the real names of women in the study.

Diagnosis

The path to diagnosis was quite varied for the women in this study. For some women the diagnosis was made as a result of routine screening while other women sought care when they experienced unusual symptoms such as bleeding, discharge, and discomfort. For some of the women that I spoke with the diagnosis was made quickly and easily. Iris told me about how quickly she moved through the diagnosis and treatment phase process.

Well the PAP smear was done by [doctor] and he got the results and did a biopsy. And he referred the case to [a cancer centre in another city] and they saw me almost right away and they checked me and ordered CAT scan and an MRI here, blood work and then I waited.

Q: So how long was that process?

I found out in January, last January. December was the Pap smear and January was [a consultation at a cancer centre in another city], I finished treatment in May, so it happened pretty quickly.

Other women with symptoms needed to be persistent in order to receive care that looked beyond a simple answer. Diane initially had her symptoms attributed to early menopause and her doctor recommended Hormone Replacement Therapy (HRT). She had to seek further consultation before receiving tests that ultimately led to a diagnosis of cancer. This process took two years. She continued to be angry that she was not diagnosed sooner when she believed her treatment may have been less involved.

I started having, noticed that something was wrong when I was 48 years old and my periods started getting irregular and I was having some type of discharge either prior or during mid cycle and that would go away. And when I was visiting my doctor he would blame it on menopause, pre-menopause. [He wanted me] to wait out the symptoms and see if they got any worse. And of course they did get

worse. It was a consistent discharge that I had. And when I went back to the doctor, he told me to go on hormones, and I thought I'm not going to take this till I get further testing done first. So I visited my family doctor and she sent me for an ultra sound and sure enough there was a mass there. So at first it was thought of as being fibroid and so the removal of the fibroid or a hysterectomy was indicated. But when a biopsy was done it was shown to be atypical. So that's when I figured out that it was cancer and that those symptoms I had been having the last couple of years, were probably that growth causing it.

Elaine, who was about one year post treatment, used a walk-in clinic for her medical care. She told me that she believed strongly in alternative medicine and that she came into this experience with distrust of the Canadian medical system and its doctors. She talked about dissatisfaction with the health care system throughout her entire cancer journey but was especially disappointed with the diagnosis phase.

I did a PAP smear, and I went to the [walk-in] clinic, and I had a woman there, and I was going there because, I'm a Canadian, and I was going there because I don't have a doctor out here. And the doctors there really scared me because every one of them [at the walk-in clinic] wanted to put me on HRT. They thought that you were going through partial menopause and everything else and you're going to go through a depression and they wanted to put me on depression pills and everything else and I was like this is absolutely nuts. You guys are nuts. Well I kept every prescription they have given me because I never filled any. I had a woman doctor, and I thought ok this was the only woman doctor that was there so... but when I had my PAP smear it was the most painful thing I have ever experienced and I thought something's not right. So I was suggested to go to this other doctor who was a gynaecologist out here and it took me about three months to get in to him. And when I got into him he was like I want to do a biopsy. You know he didn't even do a PAP smear he did a biopsy right away.

Freda had been having regular annual PAP tests with abnormal results and subsequent D and Cs for several years before she eventually was diagnosed with cervical cancer. At the time of the interview she continued to have difficulty trusting her diagnosis, because she had no symptoms.

You know the PAP smear test showed abnormal cells. For me I have no knowledge about abnormal cell or normal. But every time I check the PAP smear test every year, it show the abnormal cell. The doctor, my family doctor and the specialist they fight for D and C. I had like maybe three or four D and C. And

after last visit with my specialist he says, "Go home. You have nothing. You are ok." I was with my daughter and I was like oh my gosh. I waited all this time for you to tell me there is nothing? It was my son's wedding in 2003. I have the PAP smear. But my doctor when she was doing my yearly check up she sees something she can see it's outside of my womb you know and she told me you know I see something but you know its ok. You go have your son's wedding and we'll talk about it. We'll check it later. And I said no I want to check it; I don't want to wait. What is that? She said ok and sent me for a check up, for I think the biopsy, I think. And I had my son's wedding. And after that they sent for me. And I was by myself. I had no idea. I had no symptoms like I don't have bleeding, or rash or itchy. All this woman problem I have no problems all my life. I was by myself. I drive to the doctor and my son and my husband I remember that day they were at home and I'm going to see the doctor. I was like [have] fun. I'm going to see the doctor. So, as he's talking to me I was very calm. And he said you know what? You have cancer. And that was the only thing I heard. I don't know what he is saying and I remember he said [the name of another cancer centre] and some stuff. And I went out, and then I went back to his office and said excuse me can I see the doctor? And the secretary is like why? And I said he talked to me but I don't understand what he say. And I went back in and he explained to me that cervical cancer.

Perceptions of Causes of Cervical Cancer

Women identified the cause of their cervical cancer in a few different ways. Some attributed it to not taking care of themselves, not having regular PAP tests, stress, depression, or bad genes. One woman, Anna, who made the link between cervical cancer and HPV, used the internet to find more information. Because she had only four sexual relationships in her lifetime she could not understand why she had cervical cancer. She understood HPV as a disease of promiscuous women.

Freda, who was 18 and a virgin when she got married, continued to struggle with what she knows about the association between cervical cancer and HPV five years after her treatment was completed.

Really I don't know and I like to if they can explain because I read about cervical cancer. It's from multiple relations. The HPV virus, you know the many partners or something, but all my life, I was 18. I was a virgin. I was married to my husband. He was the only man in my life. I have been married for 34 years now and never ever NEVER have another man in my life so how I? I don't have it in

the family, and I try to say that, I want to say that maybe they can research something else about this I want to help some other people because I don't want the... because when I did the research on this about this, even my friend tell me, but when I read about this, all whatever they say about this it's not me.

Neither Freda nor Anna was prepared to associate the knowledge that HPV causes cervical cancer with the possibility that they could have been infected by their partners.

Gail, a widowed woman in her early seventies, spoke tearfully of the information she received from the gynecologist who diagnosed her with cervical cancer. She came back to this several times over the course of our interview.

This other doctor told me that I got it through some sort of sexual activity or something. Unless... you know I knew my husband was home every night. I didn't believe he was ever unfaithful, but that's what this doctor told me was the only way to get it. It was very upsetting because I was already a widow for seven years so I was kind of afraid...

Well, from that one doctor he made me feel ashamed. Like I doubted my husband and what he had done and I didn't want do that after being with him, and I trusted him. He was home every night; I don't believe he could have done anything like that. But that doctor told me that was the only way I could get it. I think he's wrong.

...[this doctor] made me feel like some kind of street walker. I didn't like that. I just thought it was wrong for somebody to say that to another person when they know nothing about them.

Treatment Experiences

Only two women had surgery as a component of their treatment. All women had external beam radiation and brachytherapy and seven women also had chemotherapy.

Surgery

One of the two women had a hysterectomy after treatment but did not talk much about it and did not mention any concerns. The second woman, Elaine, who was in a long distance relationship at the time of her diagnosis, had surgery prior to radiation and said

that she was very upset by the experience. She indicated that she had not been sufficiently prepared for the surgery or the change in her genitals.

Elaine had been referred to a tertiary centre for consultation for surgery. When she arrived she was told that the surgeon only had five minutes to talk so she re-scheduled the appointment. She describes her experience when she arrived for the second time.

So when I came back they had me into a room with four different people, with a counsellor telling me I'm in denial. I said I'm in denial because I'm telling you, you're only giving me five minutes and you're telling me you're going to operate on me next? And first they were like first keep your ovaries and then don't keep your ovaries. I'm like, "This is absolutely crazy. You guys don't even have a clue."

After surgery, Elaine's distress increased when she began to understand the impact of the surgery on her body.

[examining my genitals] that was the first thing I did after my catheter was gone and everything else and I was like wow, like I looked totally, like I looked like a little kid then.

Basically my, how do I put it, like my lips, the whole part was like half the size. I looked like a little kid you know.

It was several months before she discovered additional consequences of her surgery.

I found out probably a few months later, and even from my doctor, and he was like from your surgery, they must have had to because of where it was and everything else they made you much shorter. I'm like, don't you think I was entitled to know this before I was operated on?

External Beam Radiation

Some women were initially encouraged by their lack of symptoms while they were treated with external beam radiation. They saw it more as an inconvenience as they needed to be at the cancer centre daily over a number of weeks. The women in this study spent very little time in the interview discussing their external beam radiation treatment.

When they did discuss it they spoke mostly about this treatment being the beginning of bladder and bowel difficulties and a time of adjusting to their diagnosis.

I had a very active bladder, and very tired later on but that could have been from traveling back and forth [to daily treatment]. The [external beam] radiation was totally painless, just a lot of going and trying to work at the same time. I gave up the work for almost three weeks.

-Iris

And, the radiation, the first two or three weeks I thought if this is cancer treatment I can handle it. But after the symptoms started setting in from the radiation I wasn't feeling too good. I lost a lot of weight, lost 20 lbs, and I was, how can I say, I was more worried about me. I was constantly thinking about me, anything else could happen out there and I could not care.

-Diane

Brachytherapy

Women in this study talked about a great difference in experience between external beam radiation and brachytherapy. It was clear from the conversations in the study interviews that women experienced brachytherapy as a particularly challenging, and for most, a difficult treatment to endure.

Well, you know, the internals aren't very funny. There's a lot of preparation. It's a three minute process that takes 45 minutes of preparation. It takes a long time for me to get set up.

- Iris

The radiation [external] treatments were pretty basic but the internal [brachytherapy] was pretty devastating.

- Elaine

The [external radiation] one was fine. The [brachytherapy] was something else.

- Gail

Although there was consensus about brachytherapy being the most difficult treatment there was some variation in experience. Iris said that "It wasn't easy, but it wasn't the end of the world" and when asked if it was painful she said "not painful, the

[treatment] wasn't painful, it was just getting ready for the [treatment], a lot of manipulation, and a lot of things going on".

Most of the women talked about the brachytherapy experience as being more intense and painful.

When I started, like I said with the first round of internal, it was ok, definitely wasn't pleasant but, it was ok. Second one was a little bit uncomfortable, third one I was just in tears, because I was just so sore at that point...The [brachytherapy] has to be the most painful that I have ever had to endure. It's the worst thing I probably medically had to go through in my life.

-Kayla

It was like, I used to scream in the room by myself because you know it like metal and cold and they put something inside me and they have to. And just to put that thing inside me it was like metal and wires and it's not easy. And to start this electricity work, I don't know what they call it. I used to say like 'Oh god, please stop'.

-Freda

Yeah at the beginning was ok but when the last treatment I have, that was very painful.

-Brenda

The internal radiation [treatments] were very hard. The best term I can think of for it is barbaric...But that experience is rough. I thought that it was traumatizing...It's painful and you have to try and relax and cooperate, and once that's all set up in there everyone leaves the room, and this machine zaps the inside of you for like five minutes. I forget how long, I never thought I would forget how long. It felt like a long time.

-Diane

And it was very painful. The one time I actually felt that they touched something they shouldn't have touched, and it made me jump and I screamed. And I think they might have touched my bowel with the radiation and after that I have had diarrhea. And I've had it ever since.

-Gail

During the interviews each woman had the opportunity to describe the brachytherapy process and many recounted it in great detail, their experience etched in

their memory. The following is an excerpt from a very detailed description of Diane's experience.

Going through that is, the toughest part, the internal radiation, was setting up with the equipment. At one time Dr. [oncologist] had to stop and give me a break, because of the radiation, because there are six of the internal treatments were near the end, the last six of them, and I think one a week. By then the side effects of the radiation, was awful. You're hurting when you pee, your vagina is all red, and everything feels like its just raw, and here he is probing with stuff in you. At one point I told him I can't expand any more, don't even try to pry one more thing into me it won't fit. And [the nurse] is the best. She helped me, she helped me through this. If it weren't for her, I remember telling her 'I'll never go through this again'.

Two of the women found the experience so uncomfortable that they asked for a general anesthetic.

They tried like I said they tried a couple of different things. The ativan and it didn't really, it didn't keep me relaxed enough, and you know you have to be awake for that procedure. You know it's like can you just knock me out for a couple of hours? I don't really care. But, they couldn't do that.
- Kayla

I don't know what other women say about it but, I asked to be put to sleep for them; I asked to be put halfway out of the world for them, and that could not be done. I had to participate in all six of them and that was very hard. Very hard.
- Diane

Most women were given Ativan prior to their treatment but did not find it helpful.

Well, ok, you're put into a harness with your legs up and everything else, they give you like a little pill to calm you down, then they come in and then they have like there had to be three different people that come in and you know you're like up there and they're looking ...
- Elaine

They would prescribe me some ativan, or something but that wasn't working because you're so worked up that the mellowing effect of that drug really doesn't take effect.
- Diane

They tried to make me as comfortable as possible. They tried to give me, a couple of different things at this point. I think it was ativan. It really didn't do anything for me.

- Kayla

Most women talked about feelings of fear each time they had to undergo a brachytherapy treatment. As soon as one treatment was finished this woman began to worry about her next one.

I said, 'I'm not coming back next week'. And [the oncologist] said, Gail, I'm going to see you back next week'. I said, 'No [I'm] not' and he said, 'Oh I'll see you next week' and that was it. And I kept going back and I would tell him the same thing every week. 'Well I'm not coming back again'. 'Yes you are'... so I went back again and I finished my treatments. It was very difficult.

- Gail

Fear of the radiation was part of the overall scary feeling of the brachytherapy treatments for this woman.

... it was painful and a bit scary to me, because you know there is radiation being blasted into you and you're left alone in that room while that is going on

- Diane

Some found that their fear did not go away when their treatments ended but extended to their follow-up exams and to their sex lives. Freda, who was five years post diagnosis at the time of this interview, tells about how the tattoos on her abdomen that were actually used to guide her external beam radiation treatments serve as a frightening reminder of her brachytherapy treatments as well, and a reminder of her disease.

You know when you are going to watch a scary movie? It's like this but you have to, but it's maybe better for me but I have to go for this but I'm scared to go for it. Sometimes some stuff you can't describe. You feel it but you can't describe. It's scary something scary but for me until now, my scary, is here where they put the tattoo because they have, before they start radiation they give you tattoo to mark the area. So I have four dots; one, two, three, four. So this area for me is like scary.

And because it was in this place, maybe not if it were somewhere else. But I think also, having these things makes me not enjoy anything [sexually]. Maybe in time.

Q: Like the place in your body where those little tattoos are?

Yes, you know. Like every time, how many time I use the washcloth. Every time it take me back, and I like to forget, I like to forget that. Like I believe I'm not sick anymore.

Elaine explained that she never expects to recover from the fear and observes that other women appear to be afraid as well.

But I don't think that there is a woman who goes through this that will ever feel the same, and I noticed that through this that there [are] so many women who are so afraid...

Chemotherapy

Of the 11 women interviewed, three did not have chemotherapy as a component of their treatment; one of these was offered chemotherapy but refused. Most women who had chemotherapy spoke little about it and it was apparent that they found it less difficult than brachytherapy. Diane said she found that although she was initially quite afraid, chemotherapy was not that difficult.

And, I was scared of getting chemotherapy. I thought, 'It's going to kill me'; because you hear of people going through chemotherapy who get so sick they end up dying.

I would have to get my chemo therapy and my radiation on the same day, and I would have to have blood work done before I went home in order to know if I had to have chemo the next week. And coordinating those three things would sometimes be awful. They would be waiting for me downstairs while I was upstairs doing chemo, I went for my chemo one time and my blood work wasn't in, that kind of stuff. That is the only thing and really those are minor things.

Even though Freda had a number of symptoms, she still compares her chemotherapy experience favourably to brachytherapy.

[My oncologist] decided to go first for external radiation, and after I have internal radiation and that was the worst. The worst thing I ever have to do, worse than the chemo chemotherapy. It was ok. I take the medication, I come home, I throw up, I'm dizzy, I'm nauseas. But not like the internal radiation.

Two women had more challenging experiences with chemotherapy treatment and were hospitalized. One had continued to take medication that she was directed to stop during the chemo and had a reaction. The other woman was hospitalized when she became very ill because of an infection.

Coping with Treatment

When women in this study spoke about coping they talked primarily about coping with brachytherapy. Women called on their own resources and those of others to help them deal with the fear, pain, and embarrassment that they associated with this treatment.

Many women identified their health care team as helping them cope with treatment.

I was like ok just do what you got to do. You hear me yipping and yapping and cursing and swearing, I'm going to apologize now, and they totally understood. They're like, you know cry, you do what you want. Just give me a pillow and I'll squeeze the pillow (laugh) and we kept trying everything. So, I made it through.
- Kayla

I have a wonderful oncologist and if it wasn't for him I don't think I would have tolerated what I tolerated.
- Gail

The nurses are good; they are very good in supporting you. There was even music put on. There were different topics brought up during the set up so that you could kind of keep your mind off it, or talking about these topics or the weather whatever...
- Diane

Talking to friends and family was a method of coping that several women used to get through their treatment.

I had a good friend, a very good friend that I talked to all the time, and she was very amazed that I got through it so easily. I seemed to get through it so easily but I hid my feelings a little bit. But she helped me...My son, he was very good to talk to.
-Gail

When asked if there was anyone besides her sister who supported her this woman responded:

Not to the degree that I talked to my sister. I didn't want to get all the theatrics when you get too many people involved how you have to go back and make sure they are up to speed. I would rather have one person that could take care of all that. And she did that. It's very hard to keep everyone on the same page. It's just a circus and that's the last thing I want to worry about.

- Iris

Most women chose to enter into treatment because of their determination to recover their health and stay alive. For several women, focusing on the cure was a primary method of coping with their cancer treatments.

And the doctor told me that if I got the chemotherapy that I can not have kids anymore because I not have any more blood, menstruation. I would be like in menopause. So I say that I rather [have] chemo than I will be dead and I said that I still got a son to take care of.

- Brenda

You just cope with it. It's an easy choice, do you want to live or do you want to die? It's not that hard; it's not rocket science.

- Elaine

I blocked everything out; I did what I was supposed to do. I had no memory of what I was doing, because it had to be done. And it's just, ok I'm strong I can do it.

- Christine

[brachytherapy] was uncomfortable, but I knew I would have to do it, so I did it. Because I didn't want to have cancer. I wanted to get rid of it, and if that's what it took, that's what I needed to do...

- Gail

Four women talked about using prayer as a way of coping with their pain and anxiety.

I just pray. I keep praying. Pray to God all the time for almost six weeks. What I do is just pray and pray and pray.

- Freda

...there is nothing that you can say except to relax and pray

- Gail

Experiences of Sexuality

What is Sex?

Women were asked what sexual behaviors they think are necessary for them to consider that they have had sex. This is an important question for understanding how women who have had their genitals altered due to cancer treatment approach sexual activity. Overall, most women indicated that intercourse was either important to them or important to their partners. When they spoke about their partners, they indicated that intercourse was a 'need' rather than something that men desired or found pleasurable.

It's ok. Give me hug, kiss me I'm fine, but I'm sure for him he needs more than that.

Q: So you think he needs intercourse?

Oh yeah.
- Freda

I think if you have a partner and you don't have any sex. That's why your partner will find some other woman because you know some... I don't know, but for me I'm not really aggressive for that.
- Brenda

Sometimes I wonder if maybe my husband misses my enthusiasm during sex because of certain positions we can't do, whatever. But for myself, no I'm ok with it. You know us girls we can go without sex; we're not like the guys. But, no I was ok with it; no I'm ok with it.
- Diane

Although some women said that intercourse was not necessary for them to feel that they had had sex, how they spoke about sex with their partners belied this assertion. One woman, for example, spoke about how the human emotional connection was the defining factor for her to consider that she had had sex and that intercourse was not necessary. Later in the interview, however, she recommended that women use a vaginal

dilator to prepare themselves for eventual resumption of sex, implying that intercourse was an essential activity.

Femininity

Two of the women interviewed were able to articulate how they found that the experience of cervical cancer changed how they saw themselves as women. Christine found that she felt less feminine during her treatment experience.

But now in the beginning it was slow because I thought I wasn't a woman, I felt neglected... I didn't feel the way a woman should feel... The reason why I didn't feel like a woman was because I went through the cancer and the treatment. And with [oncologist] and having, I'm sorry I don't mean to be rude, but having your legs up and to let him do what he needs to do down there, and I'm a very private person when it comes to that...

- Christine

For Elaine the loss of the sense of femininity was a lasting experience that was not lessened by the knowledge that the treatment was necessary for survival.

You don't feel so feminine you know you feel like, and plus I went right into menopause... I don't know I guess, you know, I guess in a weird way I feel like... I said to this one doctor. I said, because he was like well you know you should just do what you're supposed to do and everything else, and I said, 'Can I sit back and ask you what would happen if they ended up taking your balls?' You know what he said to me? 'Nobody would castrate me.' And I said then you have no damn sympathy for anybody else. And I feel that at least the doctors that I have come across, they have no sympathy for women that way. It's just like its better than having cancer isn't it?

- Elaine

Entering menopause caused by cancer treatment was actually a welcome change for one woman.

When I went through this I was 49. And to be honest with you I was relieved, I wasn't going to have my period anymore. So I didn't feel any less of a woman. If I would have been younger and wanting children, I would have been devastated. But, at that point in my life I was welcoming the fact that I needed a hysterectomy...

- Diane

Kayla, who underwent a double mastectomy less than a year after her treatment for cervical cancer, did not identify the source of her femininity with either her body or her ability to have sex. This allowed her to maintain her feminine identity even under these physically and sexually challenging circumstances.

Q: Some women that I have talked to expressed how they felt as a woman changes, did you feel any of that?

No, I don't even have breasts anymore, and you know I just put my tank top on and it's just like I don't really care how people view me.

Q: And the way you view yourself hasn't changed?

No, I was always taught that it was the inside person. If you can't bring the inside person out, your beauty always comes from the inside and I guess that's just the way I was taught. But like I said it's a lot of times the way my common sense leads me.

Challenges and Changes in Sexual Experiences

Most of the women interviewed who were in relationships spoke candidly about how cervical cancer and its treatment affected their sexual experiences, including how this experience impacted their own sexual desire. Elaine found that intercourse was impossible; it was too painful. This had a profound impact on her life. She felt this loss both emotionally and physically and wondered about the possibility of future relationships.

I have no desire I feel like I've lost something.

...well you know, you basically, it's not the same kind of connection and for me too, you know. Like I keep thinking in my mind well you know, if it's really the right person and dadadada and everything else but there's something missing from me. You know...

I think both, yeah. I think both [no sexual feeling, emotionally or physically]. It's like I mean I probably could handle it if I was 15 years older, you know. But, being at my age and you know, and being divorced and you know would like to

have another relationship in my life. It kind of makes me feel like I don't know of I ever will because of it.

One woman, Kayla, talked about her earliest experiences of sex with her partner after cervical cancer.

It probably would have been about eight or nine months when we first tried and it was too, it was just too much.

There was a little bit of contact a couple of times but it was very, very painful and it just shut me right down because it was just so painful. And I asked [oncologist], and he said it was probably a little bit too soon.

Sexuality wise, yes it's on my mind. It was very, very painful; it was just like being a virgin again, like you were just, because the radiation had tightened everything up. You didn't have that... it's just very, very uncomfortable. It's to the point where the pain surpassed the pleasure; it's like oh forget this!

Kayla described her experience when she resumed self-pleasuring after treatment. Kayla was the only woman who mentioned masturbation and said she resumed self-pleasuring after her sexual desire returned. She also found that masturbation was a good way to discover what kinds of touch were pleasurable what produced pain after her treatment.

Q: One of the things you have talked about it is the pleasuring yourself, and as a way of kind of exploring and figuring out what feels good. At what point did you feel able to do that?

It was well over probably, I think it was about six months and I try a little bit and I'm like 'oh no that's not going to work, [I'm] going to wait a while'. I still have to basically insert [the dilator] to keep me stretched and I think I kind of got away from that. And so I think the second time around it was a little bit harder for me to get back into the swing of things. So I think I might have hurt myself.

Another woman, Freda, five years post diagnosis talked about her sexual experiences post treatment.

I don't know how many months after that I have no sex, nothing. I can't even like, I don't want anyone to touch me, I'm scared. And my husband is very understanding. And I give him credit for that. He's young you know. He's the only

man I have ever known in my life. I married [when I was] really young. He was the first and he's the last. So the day I married him I'm the only woman in his life, so we are very like, how to call it, "close". That's why I think he was patient with me, and certain things, even today I will not allow him to do it because I'm scared. I don't know how. To be honest my life is different.

Like when I say I don't want and I'm scared, he will be very gentle, checking with me. I'm ok I'm fine don't worry, you know? He tries, and the first time it was the worst. I was very scared and I was so tight, and so like alert, you know? But now I'm trying my best but it's not like how I was. Like honestly I don't feel it [desire] and just I want it to happen and be done.

[I feel] empty, nothing. The problem is there is no feeling. And as I told you, every time I have pain. Like he, to be honest he's very, very gentle, he's trying his best but I sometimes, he's like 'Am I hurting' and I'm like 'I'm not'. I'm lying to myself. You're sort of pretending so he doesn't feel bad because he doesn't like to feel like he's hurting me and he doesn't want that and so that's why I'm like, 'It's ok I'm fine, don't worry', you know? If it's up to me I don't want sex, serious.

When asked how sex had changed from before cervical cancer this woman responded:

I don't want to. If it's up to me I don't want to, but because I have a husband, and he has his needs... but I don't enjoy it.

Diane talks about her long journey back to being comfortable during intercourse.

After my radiation was done, I was given a dilator and I used it. You know how men are. And my husband's still quite active and I thought if I want to be able to keep up with him I better make sure I do everything that I can do. So I used it every day, ten minutes like it says on the box. So I don't know if that helped? But, at first, like during radiation, I didn't have intercourse for about two years, all my treatments and everything, [then waiting] 12 weeks after my surgery. And then I was allowed to for the first time. And it was very hard at first because everything was narrow, even my belly button was narrowed, and I think it was from the radiation. Thank God I had an understanding patient man, because we were able to work through that. Still to this day it's not like it was. But, it's much better, as far as the, once I can be comfortable while we are having sex. Before it was 'I hurt, I hurt'. Now I'm starting to ease up. There hasn't been pain down there for a while now. So, I'm ok.

When asked if there were changes from her pre-cervical cancer experience she responded:

Yep, there's certain positions that I cannot do that I used to be able to do before. There's always that fear of him going in a little bit too far... But like I said I have the positions I know that I'm comfortable with, and we just stick to those.

And again, like I said, because of the sensitivity, sometimes I find I reach orgasm sooner than I did before. So, I don't want to sound like this has been a good thing for me, because it really hasn't. But, I'm lucky that we, my husband and I can work this out. Some men couldn't or wouldn't have the patience.

Brenda, who indicated that sex was not important to her before cervical cancer, said that there were no changes to her sexual experience as a result of cervical cancer or its treatment. Christine found that when she and her partner got past the initial pain and discomfort when they re-initiated sex, it was actually more pleasurable than before her experience of cervical cancer.

It's just more sensitive. I can feel..., I feel like it's amazing because when we make love... it's because I can really feel him inside me and it's just, I have orgasms.

Cervical Cancer's Impact on Relationships

Most of the women in this study who were in relationships at the time of diagnosis had partners whom they described as supportive and patient. Partners who were said to be very sexually active were seen to be just as supportive as those that did not see sex as all that important to their relationships. Most women in this study described their partners as focused on them getting well rather than their own sexual losses.

Oh, he was devastated for me, because of what was happening with me. I don't think he felt deprived, or like "poor me". No, because of my illness he was very compassionate. He was hoping I would pull through. He was afraid when I was first diagnosed too...

- Diane

Kayla had not yet been physically able to resume her normal sexual relationship with her partner before she was diagnosed with breast cancer a year later. Her partner began an affair which ended their relationship.

We separated May of this year, and yes it had everything to do with the sexual side of things. But, you know, it's kind of, in one aspect, yes it was the sexual things, but because...going through the cervical cancer, for a year afterwards I had no, like that was the last thing on my mind. Now before this started we did have a very good sex life. I rather enjoyed sex. The thoughts are coming back and wants and the needs, but unfortunately it's been his loss because that's when it was coming back and he ended up cheating on me because I guess he had to satisfy that need of his.

Elaine talked about changes and confusion in her long distance relationship and wonders about future relationships.

Like at [work] there are several different people that have asked me out. And I used to be the type of person that you know like oh, you know, even if I wasn't you know and even if this long distance relationship. It's like, I don't even know where it's at because I feel totally different than I did prior with myself, with[my] relationship... just everything. I don't really know where I'm at. Which is, you know, I don't really know where he's at, ok? Because I've withdrawn and he sees that. You know what I mean and to him maybe it's baggage you know. But to me, it's gone on with me. I can't act like it didn't happen, you know it? And I'm not one to dwell you know, I'm not a dweller. I'm usually really positive, but it happened. It's gone on with me I mean you know. I don't know maybe in three years my whole vagina will close.

The women who were not in a relationship at the time of treatment either said that they were not interested in having a relationship or did not wish to speculate about how cervical cancer and its treatments might impact future partners or their potential to have a relationship.

Resuming Sexual Activity

Most women in this study were not prepared to resume sexual intercourse for many months and for some up to two years after being diagnosed with cervical cancer. Key to how couples resumed sexual activity was a partner who was sensitive to the pain and fear that many of the women in this study described. Two women described how their partners would check in on their comfort level and were willing to stop if they were uncomfortable.

Well, whenever we got intimate he would ask if I was comfortable with having sex. And I would cry, and he would just be very slow, and asked if it hurts. So, like I said he was understanding and patient, so that really helps. And at first, yeah, it did hurt. And he'd have to stop.

- Diane

I'm with a guy who is very, very understanding, for he's ok with it, whatever makes me happy he's ok with it you know? But I'm trying my best.

- Freda

Kayla found that when she resumed pleasuring herself she had to be careful to not injure herself.

I find that it has to... I have to be very slow and very easy.

She explored her own body while masturbating which she said would help her understand what she would want a sexual partner to do and not do. She said that this would keep her safe and help her obtain the most from a sexual encounter. When asked whether she felt this was important to future sexual encounters she responds,

Yeah, because I know at that point how far I can push my body. So it's going to, I mean in the long run it's going to be able to tell me to tell somebody, you know that you gotta go slow or don't do this. And like I said I'm a very boisterous person when it comes to like that. I don't have a problem speaking my mind and I will...

For Freda, coping with issues of sexuality involved talking with her partner about the limitations of the sexual aspects of their relationship. She described a conversation that she had with her partner.

Oh yeah, like one time I said I break his heart and he said, 'No. I love you too much and love is not only sex; believe me in my eyes love is not only sex. You can have sex anywhere but you cannot have love and I love you too much.' And I said, 'I can't give you more than what I have now.' And he said, 'Its ok honey I know. It's ok.' And I'm trying my best.

While several of the women in this study spoke about using friends and family as support through their treatment, few of them confided in anyone about sexuality issues

besides their partners or their doctor. Three of the women specifically said they would not confide their sexual concerns with family members, even if they were a primary source of support through their cervical cancer experience.

While Elaine found her conversations about her sexual issues with family very unsupportive, she found female friends were a great source of support in all aspects of her cervical cancer experience. She was able to talk to them about her fear of never having another relationship because her body could no longer accommodate intercourse.

Oh, you know my girlfriends are great support. I think that people who go through this, honestly I think the greatest support could be good friends, more than family, because I feel family is more, they want to give their opinion when they have no opinion, because they haven't gone through it, you know. And family... they say things that [are] just nonsense, you know. And I think friends are more cautious. But my women friends have given me great support in it. And you know its like, 'Oh maybe you'll meet some guy who his sex life is over'. And I'm like, 'Oh great. Then we can just hang out together'. (laughs) But at least you know there is some laughter there, you know.

During the interview Diane thought of someone who would have been a valuable support person for her.

I would have liked to have had me to listen to when I was going through it, to know what I wasn't the only one going through it because half the time I thought I was.

The women in this study were asked what they would recommend to women newly diagnosed with cervical cancer that would help them cope with sexuality issues.

Diane made this recommendation to women about sex.

To take their time. [Try] not to get frustrated with themselves and give up because they haven't been able to do what they used to be able to do. Like not be hard on themselves because they're not performing as well. Take their time and gradually work towards where you were before. It's not going to take a month; it's going to take a while and it's going to take a husband that understands.

Kayla talked about recognizing and calling on the strength that she believed women who have gone through cervical cancer treatment possess.

Don't be afraid of it. Don't let it rule the person that you are, both the cancer and the sex. A lot of people in this world, the easiest thing, the nicest thing I could say to somebody is if you're strong enough to get through the cancer, there's nothing in life you should be afraid of. If you don't understand something, ask your questions, ask your doctors, go on the internet, look it up. You're not the only person this has happened to. There is nothing to be embarrassed about. If it's a matter of you're with somebody for the first time, and they're getting flippy or freaky or whatever, you know it's got nothing to do with you. It's them. So don't let that bring you down. Life is only going to be what you make of it.

Kayla also believes that you need to prepare your body physically for sex after treatment.

You just have to realize that, if you have gone through the cervical cancer and you have gone through the radiation, your body has changed a little bit. So do yourself a big favour, and when like the doctors give you one of these dilators to use, use the dilator. Worse comes to worse get a bigger dilator. Do what you have to do. Don't lose that part of your life because that really is a human quality. Don't lose it.

You should know your body better than anybody, better than anybody on the face of this earth. Common sense will tell you if you're doing something. There's nothing wrong with playing with yourself. There's nothing wrong with buying a dildo. Those things are out there. If that's what you have to do to figure out when the time is right. If those thoughts are coming, don't lose it. Don't push it under the rug because you know what, it's going to make you a miserable person. Good sex makes you a happy person.... But [masturbation] is a very, very good way to explore your own sexuality so you know what to expect and you know how to speak to somebody, your significant other to let them know that ok, can't do this because it hurts.

Most of the women I spoke with struggled with describing how they coped with changes in the way they experienced sex. Although a couple of women had been able to resume sex in the manner that they had before cervical cancer, and one spoke of an enriched experience, most of the women in relationships continued to struggle. Elaine

suggested jokingly that a good Margarita and women friends could help one cope but she said honestly, "I haven't dealt with it all myself."

Information Needs

All of the women in this study said they liked their oncologist and nurse and most of the women felt that they could ask them their questions.

...I had already asked those questions of [oncologist]. Actually he kind of explained things, 'This is probably what's going to happen, so don't be alarmed' so going in to the whole thing I wasn't worried because I knew why. I knew what to expect in the change in my, like my mental status and my physical. I knew those changes were coming.

- Kayla

It wasn't an issue. I would have asked questions if I had had any. But I didn't.

- Iris

Gail indicated that even though she did not feel that she had been given enough information about brachytherapy, she would not have wanted to know any more. Freda on the other hand, found she could actively pursue information on her own but would have preferred to receive it from her medical team. When asked if she had enough information, she responded:

Not really, no. Just that I know I'm going to have radiation and chemo...I tried myself to read about it [brachytherapy], from the internet, but [it was] not very like clear.

[I wished] that they would have explained more. That I'm going to be in pain or they explained this is where we're going to put it you know. And they closed the room, there is nobody only me and this is a very scary part.

When Kayla was asked if she would have liked to have more information about what to expect when she resumed sexual activity she said that she had had several candid discussions with her oncologist that were very helpful. These discussions were primarily initiated by Kayla. She talked about her concern that not all women would feel

comfortable asking the kinds of questions she asked or would have an oncologist who would openly discuss the answers.

I really honestly think that if there was something that would just kind of lay things out. And not necessarily say this is what's going to happen to you because it [might not] happen. Something that would explain the possibilities...I truly honestly think that if women who are going through or diagnosed with cervical cancer, if they have that kind of knowledge [it] will be a little bit easier on the sexual side of things after they come out of it.

Elaine mistrusted the medical system and her health care providers in Canada.

She felt that she was not sufficiently informed about the consequences of her surgery.

Well, when I went to [a cancer centre in another city], I was like you know like I wanted more feedback, you're not giving me enough information to sit there and want to take a knife and cut me open. You know it? And when I came here and they sent me here [local cancer centre] I said I don't really know if I want to do this. And that's exactly what they told me, 'Well you're just in denial. You make the decision'. I was just like... so then it haunts you, eh? And if I had to do it over again I would have never done it. I would have never done it.

Later while Elaine was having treatment, she said that she did not feel free to ask questions.

And [oncologist], and don't get me wrong I liked him but I felt he was intimidated because I asked too many question and you know I was like, this is nuts. I should be able to ask you as many questions as I want without feeling uncomfortable.

Women in this study had divergent information needs and expectations. They also had differing levels of comfort with exploring external sources of information on their own and asking questions of the medical team.

Summary

The findings from this study indicate a wide range of experience related to the path to diagnosis, understanding of the cause of cervical cancer, information needs, tolerance of treatment, and sexual morbidity. Women in this study found brachytherapy the most difficult treatment and used a variety of techniques to cope with treatment.

Focusing on becoming well was a primary motivation for entering treatment and the impetus for continuing when treatment was difficult. It appears that along with the physical changes from brachytherapy that challenge sexual function, there is an emotional component that linked future sexual experiences with brachytherapy treatment. This would be an interesting area for further study.

Most women in this study, some several years post treatment, continued to experience symptoms that limited their ability to experience sexual pleasure. While one woman spoke about enhanced sexual experience, the others in relationships continued to struggle with lack of desire, pain and discomfort during intercourse. Women in relationships with partners who were supportive and patient resumed their sexual activity, but in a limited fashion. The list of coping strategies identified by these women was short; possibly indicating that they are not coping as well as they could be and would benefit from some additional information and/or professional guidance.

Recommendations

The recommendations outlined here reflect the experience and views of the women interviewed for this study. These women offered insight into what helped them cope with treatment and how they dealt with sexuality after treatment. Even in this small study the divergent experiences and needs of women with cervical cancer are evident. The recommendations also reflect the ideas presented in the literature based on earlier studies.

Much of what women valued and wanted more of was information. Although the amount of information that each woman wants will vary, assuring that the information is available and offered is very important. The first four

recommendations deal with approaches to providing women with information that will support them through their treatment experience and living with its side-effects.

1. ***Discuss causes of cervical cancer in a manner that is sensitive and minimizes embarrassment and shame.*** Women whose cervical cancer is linked with the HPV, a sexually transmitted disease, may make an association that they find shameful. A candid discussion about the prevalence of HPV, its latency period, and the ease with which it is shared, may help women see it with appropriate perspective. Care must be taken to ensure women do not unnecessarily suffer damage to their self-concept or lose trust in their relationships.
2. ***Provide comprehensive information about treatment and its possible impact on future sexual experience and other quality of life issues.*** This information should map out treatment details including possible challenges women may face such as pain and discomfort. Printed resources that illustrate and label the anatomy affected by treatment would minimize opportunities for misunderstanding. Earlier studies noted that women had less distress and coped better with the side effects of treatment when they were well prepared and understood what might occur (Burns et al., 2007; Corney et al., 1993; Juraskova et al., 2002).
3. ***Provide information and support about coping with sexual side effects.*** The most appropriate time for these discussions would be at follow-up visits after treatment is completed (Burns et al., 2007).
4. ***Develop a library of materials about sexuality.*** These materials should contain information about sex that ranges from very basic to more adventurous. As the current study found, many women believed that vaginal intercourse was necessary

for them or their partner to feel that they have 'had sex'. Not all couples have adequate knowledge of sex and sexuality and the diverse possibilities for sexual expression, pleasuring, and orgasm (Blank, 2000 as cited in De Lamater and Sill, 2005, p. 141).

Since desire is directly related to the avoidance of pain and seeking of pleasure (Kaplan 1977, 1979 as cited in DeLamater and Sill, 2005, p. 139), it is not surprising that the women in the present study reported a lack of desire after treatment. Pain during intercourse and fear of pain during intercourse was a significant problem for several of the women in this study. All methods of minimizing pain should be presented as options. Additionally, almost all women focused attention on vaginal intercourse. Many would benefit from learning alternative ways to experience sexual pleasure and should have the opportunity to be referred to a sex therapist or other professionals who could offer teaching and support.

5. *Offer vaginal dilators to women who wish to use them.* Along with possibly stretching the vagina to more easily accommodate intercourse, they also provide women with an opportunity to explore their own body and discover what types of activities produce pain and what types produce pleasure.
6. *Offer anesthetic gels, even for a short time, to minimize the pain* (McKee & Schover, 2001). When women first begin to engage in sexual activity after treatment, anesthetic gel may offer physical relief from pain and assist with minimizing the anticipation of the discomfort of early experiences.

Some women in this study used words like ‘barbaric’, ‘traumatizing’ and ‘devastating’ to describe their experience of brachytherapy. Some women several years post treatment cried while they discussed their brachytherapy experience. There is little doubt that the experience of brachytherapy is traumatic for many women and that both the immediate experience and the memory cause women pain and fear.

- 7. Explore the possibility of conscious sedation for women who require brachytherapy.* If this is not practical in all cancer treatment centres, offer the option of referral to other centres that can provide sedation.

Most of the women interviewed for this study were very glad to have someone to talk to that had a working knowledge and an interest in discussing their cervical cancer experience. Most found it difficult to talk to family and friends about it and some relied exclusively on their encounters with their medical professionals. One woman specifically mentioned that she would have liked to have been able to talk to another woman who had been through the experience of treatment for cervical cancer.

- 8. Develop a list of women who would be willing to speak with and support women who are entering treatment for cervical cancer.* Offer each newly diagnosed woman the opportunity to meet or speak with someone who had completed her treatment and was open to sharing her experience.

Women look to their health care providers to answer questions about living with their physical changes that result from cervical cancer treatment. They may not ask questions about sexuality directly because of their own discomfort or their perception that

their health care workers are uncomfortable (Hordern & Street, 2007). Frequent conversation initiated by health care professionals that specifically encompass issues of sexuality and sexual activity changes that arise as a result of cancer and its treatment can normalize these discussions and ensure that all women have access to appropriate information and support.

Chapter 5

CONCLUSIONS/DISCUSSION

We rarely consider Canada as a place where sexual health and the right to sexual pleasure would be an issue. Women with cervical cancer are the forgotten group in our own back yard. Through a review of this study and other research this chapter will address why cervical cancer is a particularly difficult disease for women.

HPV and Cervical Cancer

With increased public awareness of the link between sexual activity, HPV, and cervical cancer there needs to be an understanding of how easily HPV is transmitted and its prevalence in both men and women. While the increased understanding has positive implications for the prevention of cervical cancer, it is clear from this study that some women are experiencing embarrassment and shame when they make the connection between HPV and their own diagnosis of cervical cancer.

Most of the eleven women interviewed for the current study spoke about the causes of their cervical cancer in a way that was consistent with Costanzo et al.'s (2005) findings. Many of these women identified stress and hereditary factors as the cause of their cervical cancer and they did not appear to be distressed about these causes. However, three of four women who identified HPV as the cause of their cancer spoke of being distressed by this connection. Two women identified a link between their cancer and HPV on their own and explored the internet to learn more. Neither felt that their sexual history matched what they understood as necessary for acquiring HPV, specifically multiple sexual partners. Another woman was very distressed because she said that her doctor indicated that HPV was caused by promiscuity. The increased distress

level of women who believed that their cervical cancer was a result of acquiring HPV through sexual contact tended to support Constanzo et al.'s conclusion that women experienced more distress when they believed that their cancer was a result of activity under their control. Interestingly, even women who had only one sex partner tried to make sense of HPV within the context of their own behaviour, rather than their partner's. One of these women did not even consider that her husband may have had other sex partners while yet another considered and dismissed the idea. In addition, clearly neither of them considered partners that their husbands may have had before they had initiated their relationships.

Although women in this study identified the link between HPV and cancer, they did not identify media as the source of their understanding of this link. This may be because the media attention related to the introduction of the HPV vaccine began after most of the women in this study were diagnosed. It will be interesting to see if the media attention will educate and normalize HPV eventually leading to a better, less judgmental understanding of HPV, thus decreasing the distress of women diagnosed with cervical cancer, or simply call more attention to HPV as a sexually transmitted disease, which may increase distress.

Low Incidence

Thankfully, cervical cancer is a disease that affects relatively few women in western society. Although overall a positive situation, this poses several problems for women who do have cervical cancer. First, low numbers make it difficult for women to gather and support one another or for partners of women with cervical cancer to find someone to talk to who has had a similar experience. Largely alone with their diagnosis,

treatment, and concerns, the primary sources of support for women in this study were family, who did not have a thorough understanding of cervical cancer and its emotional, social, and sexual implications, and their busy health care team.

Women in the current study were among the approximately 12 women treated for cervical cancer in this relatively small cancer centre per year. Although one woman had an acquaintance that had been treated for cervical cancer years ago, she found that their experiences were very different because of the changes to treatment protocols over time. Another woman sought out and spoke with a few other women who were being treated around the same time as she was but expressed a need to speak with more women. Another woman said she felt very alone and would have felt less so had she known someone else who had gone through the cervical cancer experience.

Second, the low number of women with cervical cancer may mask the need for less traumatizing methods of treatment and contribute to the lack of understanding of the cervical cancer experience among health providers, especially the impact on sexual lives of women and their partners. With cervical cancer making up only 1.5% (Canadian Cancer Society, 2008b) of all cancer diagnoses each year in Canada, consistent with Epstein's (2007) observations these women would have difficulty making their voices heard and mobilizing health care providers to make system changes that would more comprehensively meet their needs. The lived experience of cervical cancer and its treatment is still a mystery for most health care professionals, making it difficult for them to develop appropriate supportive care programs and resources.

Third, as Epstein observes, low numbers may be a factor in the discrepancies in the amount of research, especially research that seeks to improve women's experience, between cervical cancer and other cancers that affect larger populations.

Complex Treatment Information

Many people are still in shock and will be trying to assimilate new and sometimes complex information about their diagnosis when they enter the cancer treatment system. As they begin cancer treatment they are expected to rapidly adjust to accommodate the cancer system, a system that focuses almost entirely on their disease and not their experience of illness. Patients learn quickly and early what questions and conversations are acceptable in the medical environment. Doctors talk about diseases while patients experience illness, making it difficult for women to access the 'care' that they require. (Frank, 1991).

Women with cervical cancer have the additional challenge of treatment information that is very complex because of the combination and sophistication of treatment modalities involved. Surgery, external beam radiation, brachytherapy, and chemotherapy are all possible treatments, with most common protocols utilizing a combination of several of these. This challenging information is presented by several different medical specialists involved in planning for and treating women with cervical cancer. To complicate this situation further, women may encounter difficulty in obtaining the facts of their diagnosis, treatment, prognosis, and expected treatment outcomes because of complex factors in the doctor/patient relationship.

As Charmaz (1991) discussed in her study of people with chronic illness, doctors are good at presenting a diagnosis but are likely to leave it to the patients to discover the

various meanings of the diagnosis. For a more esoteric diagnosis, such as cervical cancer, the situation becomes even more problematic.

The information that women with cervical cancer receive may be simplified to make it manageable for the average patient without a medical background, yet it was clear that some women in this study were asked to make decisions before they fully understood what was involved and all of the implications for their future. When asked, several women responded that they would have liked more information, particularly an honest, comprehensive treatment plan that explained what difficulties each treatment might present and the symptoms that they might expect. The level of detail of treatment information desired by women in this study was not consistent and although some were satisfied with the amount of information received, others were not. It is clearly a challenge for health care professionals to assess the detail of information each patient requires and to provide information that closely matches that need. What is less clear is how much information doctors choose to withhold to create conditions for a compliant patient. Charmaz indicates that doctors, who are the active players in the doctor/patient relationship, often encourage the perception that full recovery from disease and treatment is possible. This may be responsible for the distress women experienced when they re-initiated their sexual relationships and discovered the limitations to sexual activity and pleasure imposed by the effects of their treatment.

It is worth noting here that one of the women in this study, Elaine, who required surgery, external radiation, brachytherapy, and chemotherapy reported being told repeatedly by health care professionals that she was in denial when she asked questions. Elaine found it difficult to obtain information about her treatments and the implications

of the treatment for her sexuality. When she asked for more information, alternative treatments, or was resistant to the prescribed treatments, she was labelled as being in denial.

Charmaz (1991) points out that denial is an “elastic” label that stretches to fit the judgement of professionals who hold the power in the patient/doctor relationship. Often related to “patient management and compliance” (p. 17), a label of denial can have an impact on this relationship that has profound implications for a patients’ understanding of their illness and how it affects their lives. Elaine, for example, was physically and emotionally devastated by her treatment by her medical team and felt her mistrust of the Canadian medical system was validated.

Some women felt comfortable asking questions and this assisted them in acquiring more information. However, there seems to be an inherent risk in asking the wrong or possibly too many questions, as both Frank (1991) and Charmaz (1991) illustrate in their work. Elaine’s story exemplifies what can happen to the doctor/ patient relationship when patients push for information.

Treatment Experience

The treatment experience for women with cervical cancer is more challenging than most other treatments involving other cancer disease sites for a few reasons. First, it can involve several different treatment modalities, all of which can produce their own treatment complications, symptoms, and difficult outcomes. Second, both surgery and brachytherapy are highly invasive in nature. And third, cervical cancer treatment is directed to an area of women’s bodies that many consider private and that is inextricably linked to sexuality.

The experience of treatment for cervical cancer, although varied among the women, had some common elements. Overall, external beam radiation, chemotherapy, and surgery were better tolerated than brachytherapy. Women in this study who did not have pre-existing risk issues⁹ found these treatments manageable and reported few lingering symptoms. One notable exception was discussed by Elaine. She did not expect that her genital area would be so altered and compared her post surgery body to male castration.

This section focuses on the brachytherapy experience as it was identified by the women in this study as the most challenging treatment. Brachytherapy was difficult for all of the women although pain and discomfort were reported in varying degrees. Several women found the pain and overall experience of brachytherapy “barbaric” and “traumatizing”. Several women found the exposure of their genitalia to a number of professionals in the treatment room a source of embarrassment. Some women required a great deal of encouragement to continue with the brachytherapy treatment. Although women prayed, focused on getting well, and used a variety of methods to distract themselves from the experience of brachytherapy treatment, they were unable to offer much hopeful advice for supportive measures to women who might be about to begin brachytherapy treatment. Women found the health care professionals involved in providing the brachytherapy to be very kind and supportive but their support did not mitigate the pain and trauma that these women experienced.

Overall, the level of trust in the health care team and the treatment is worth noting. Although many women indicated that they found brachytherapy painful and

⁹ One woman in the study continued to take a medication that she had been told to discontinue during her chemotherapy treatments and had an interaction reaction. Another woman treated previously for a different type of cancer had to be hospitalized for a period during her chemotherapy treatment.

challenging, only two said that they had asked to be put to sleep for their treatment. These two women were told sedation was not possible and they appeared to accept this as universally true¹⁰. All women in this study completed all of their brachytherapy treatments in spite of the pain, embarrassment, and discomfort. In essence, all women accepted that brachytherapy treatment in the prescribed manner was necessary.

Several women indicated that they got through it by focusing on getting well which was consistent with the perspective of health care providers in a 2007 study by Hordern and Street. The desire to get well does not fully explain this phenomenon. Why did they so easily accept that this difficult treatment had to be administered while they were awake? An obvious reason is that they never understood that there was an alternative, but why did they not look for alternative methods of treatment? Several had searched the internet to look for causes of cervical cancer yet none talked about checking out ways of reducing the pain and discomfort of brachytherapy treatment.

The probable explanation is that women who have reached the point of their first brachytherapy treatment have already been involved in the health care system for long enough to have experienced loss of self. In her review of her research on chronically ill patients, Charmaz (p. 257) discusses how a number of physical, social, economic and mental losses that can accompany illness serve to break down boundaries of self-concept, changing how a person sees themselves. They look to others to reflect who they are, and what they see is illness. They lose their former self, at least temporarily, and become resigned and passive. It may be from this place of loss that they accept that the illness must be treated in the manner presented by their doctor, no matter how difficult.

¹⁰ Sedation for brachytherapy for cervical cancer treatment is available at other cancer centres.

For some women the trauma of the experience of brachytherapy is relived in future physical examinations and also while being sexually intimate. The pain and fear associated with brachytherapy make them anxious about being touched and some women have reported that this fear has never gone away. The brachytherapy-related damage to tissue can cause pain and bleeding during intercourse or medical exams which sparks new fears of cancer recurrence. The following section explores the sexuality concern.

Sexuality

Women in this study learned very little in advance of their treatment about the possible sexual problems that result from treatment; they focused on getting well and said that they never thought about sex as they entered treatment. Although women remember being told of a potential loss of lubrication, vaginal burning, and pain during intercourse, much like their brachytherapy treatment, many women did not completely understand the full implications of their treatment for their sexuality. This may well reflect Charmaz' observation (1991) that doctors will sometimes be vague with information to ensure compliance to treatment protocols. In fact, the example of Elaine who said she would have refused treatment had she known the consequences for her sexuality is an example of the potential noncompliance that doctors fear.

Although women in this study felt well supported by their health care team during their actual treatments, most women would have liked more information about treatment-related sexual activity changes and methods for coping with these changes. Women's experience in this study supports findings by Hordern and Street (2007) where health care workers, even those professionals that were the most reflexive, rarely addressed issues of sexuality. One woman in the current study said that she was comfortable bringing

questions about sexual activity to her oncologist and she was satisfied with the responses that she received. She did, however, point out that a less assertive woman with a less responsive oncologist might not get the information about sexual activity that they required, indicating that the treatment process was not designed in a manner that supported women in learning about sexual activity changes. Charmaz (1991) and Frank (1991) similarly found that health care workers were not apt to discuss issues that did not involve the treatment of disease.

Women in this study who were in relationships resumed sexual activity several months to two years after treatment. All women experienced some discomfort and pain when re-initiating sexual activity and for some women pain during intercourse persisted and has never resolved. Findings in earlier studies (Juraskova et al., 2003; Lindau et al., 2007) suggest that sexual morbidity was reduced when women were told what side effects to expect, indicating that the sexual problems women in the current study experienced may have been minimized had they been informed of their possibility.

That all women in this study who were in relationships resumed sexual activity despite pain, fear of pain, and discomfort is consistent with Lindau et al.'s (2007) findings that survivors of genital tract cancer engage in sexual activities at a similar rate as the general population even though the activity may not be pleasurable and may involve pain.

Lindau et al. found that the need to engage in sexual activity among women with pronounced problems with sexual function "is significantly related to health and quality of life" (p. 417) and believes that the answer to how and why this occurs is important to better understanding of the role of sexual relationships. The current study confirmed the

findings of an earlier study (Juraskova et al., 2003) and suggests that women felt compelled to accommodate their partners with sex, even when they had no desire or found it painful. Women in this study strongly suggested that men needed sex and that men might look elsewhere if it were not provided, indicating that they had sex in order to meet their partners needs and maintain their relationships.

Information gathered from discussions with women in this study regarding what constitutes sex did not support an open, individualized definition such as that discussed by Christina (1992). Women in this study held the belief that sex was completed or defined by the act of sexual intercourse, which aligns with the current understanding of sexuality as a phallus or intercourse-centred activity (Fishman & Mamo, 2001; Kleinplatz, 2001; Tiefer, 1986). It was also evident that some of the women had given consideration to what behaviour would be involved for themselves personally to feel that sex was complete. Although some women seemed to challenge the idea that intercourse was necessary by describing other activities in which they and their partners engaged or proposing that a deep spiritual connection was all that was needed, most of these women could not entirely refute the idea that intercourse was integral to their sexual relationships. It was the pressure to fulfill what some women described as “a male need” for intercourse that guided their actual activity rather than their own desires.

Women in this study described a range of experiences regarding the impact of cervical cancer and its treatment on how they experienced themselves as women. Most women did not feel a lasting loss of femininity although two extremes were present in this study group. One woman welcomed menopause, which was a natural outcome of treatment, and another experienced profound loss of femininity that she felt was way too

early for a woman of 45. Although several women were of childbearing age, none seemed to have their sexuality identified with their ability to have children, an identification which one would expect to result in a sense of loss (Frumovitz et al., 2005)

Although one woman in this study described an enhanced sexual experience after her treatment and another described the return of sexual feelings, the most important losses described by most women were sexual desire and sexual pleasure. Some women said that if it were up to them they would not have sex at all. Although almost all women in relationships at the time of treatment said their spouses were supportive and more concerned with their partner's health than their sexual need, clearly these women felt pressured to resume their roles in sexual relations. As Frank points out, our society does not recognize the illness experience; therefore patients are expected to resume roles, in this case sexual roles, as soon as treatment is completed.

Frank indicates that there are losses that accompany disease that are unavoidable and these need to be mourned. It is possible that there is no way to change the sexual morbidity of women with cervical cancer, but the system needs to provide an opportunity for women to mourn their loss not to pretend that it doesn't exist.

Research

It was projected that in 2008, 1,350 Canadian women would be diagnosed with cervical cancer while 22,600 women would be diagnosed with breast cancer (Canadian Cancer Society, 2008b). Women with breast cancer have been able to organize and advocate for their own interests. In some areas of the US, women with breast cancer have found success in challenging the biomedical approach by successfully advocating for

research that takes a broad look at their struggles beyond screening and the clinical setting (Klawiter, 1999).

Cervical cancer is one of a very limited number of diseases that can so directly and profoundly affect sexual expression, desire, pleasure, and sexual satisfaction. Research focused on the actual lived experience of women while they undergo cervical cancer treatment and the impact of the resulting sexual morbidity after treatment has been minimal. The problems in expanding this research can be viewed from the paradigm presented by Epstein (2007) in his work on inclusion and difference in medical research.

First, although the current trend of inclusionary reform in health research brings women, along with other formerly under-represented groups, into health research as subjects with distinct identities (Epstein, 2007), this does not necessarily benefit all women, particularly minorities such as women with cervical cancer.

Women have, within biomedical research, been excluded on the basis of their sex, included on the basis of their sex, or standardized as their own biomedical group at different points in history. Epstein (2007) talks about the latter of these as “niche standardization” (p. 135) which places people in groups on the basis of their sex, race, etc. and where members then become standardized objects to study. From a political perspective, this model makes it easy to assign research resources and other benefits to different groups in society. Epstein describes how competition among these groups for resources seems to rest in funds being assigned to the largest and most politically powerful groups. Historically, larger groups, powerful because of their numbers, have been instrumental in forging medical and political alliances to move forward what Epstein calls the “inclusion and difference” paradigm. Women with breast cancer have

placed women's health issues on the research agenda in the US and, as stated earlier, have been successful in promoting research that focuses on the lived experience of women with breast cancer. This has not however, translated into the same resources or attention for women with cervical cancer who continue to be under-represented.

Although not specifically discussed by Epstein, there seems to be the same competition for resources within each of these groups. Cervical cancer being a disease of few women, it has not gained the same access to resources as larger and more powerful groups of women.

An additional difficulty of niche standardization is the focus on the group rather than the individual. The ability to study women as individuals having a unique experience is not available under this model. This poses challenges for women and for physicians who wish to understand the variety of possible experiences in order to treat patients from the perspective of each individual (Epstein, 1991, p. 138). I have already discussed the difficulties that arise because health care professionals lack information about the individual informational and support needs of women.

Secondly, most cervical cancer research focuses on bio-medical issues that include physical changes after treatment but not the impact of these changes on sexuality. The study of sexual desire, sexual behaviour, and sexual health is itself problematic. Although work within the inclusion and difference paradigm has progressed toward recognizing different sexualities, the focus remains on sexual identities such as Lesbian, Gay, Bisexual, and Transexual groups. This reform shies away from research on sexuality that discusses sexual behaviour (Epstein, 2007). Epstein cites several political and advocacy groups and federal agencies that view sexual research through lenses that

range from a lack of interest to “hostile scrutiny” (p. 271). What research there is tends to cover familiar territory.

An additional problem is that when sexuality is studied, the focus is on sexual intercourse. This not only perpetuates the normative idea of intercourse as the defining activity of sex, but this kind of thinking imposes limits on research that may help us better understand the full impact of physical changes resulting from cervical cancer treatment. It is women’s understandings of their own needs and desires that requires further exploration.

The subjective experience of women that encompasses the full spectrum of women’s sexual expression and sexuality is required to develop new sexual paradigms (Kleinplatz, 2001). Women with cervical cancer may provide an excellent resource for exploring subjective experience given their experience of altered genitalia and the accompanying intercourse-related sexual problems. They might also benefit from a shift away from contemporary notions of sexuality and the development of more open sexual paradigms.

Research that might bring about a shift that improves the condition of women with cervical cancer needs to break through existing barriers to explore both the sexual experience of these women and the broader context of social sexual beliefs and norms. It needs to hold the same regard for the lived experience of women as it does for the diseases that create difficulty. To make this happen, methods of promoting and funding research to improve the conditions of minority groups, such as women with cervical cancer, that are not dependent on the power of large numbers need to be developed.

Study Limitation

This study represents the experience of eleven women all from the Windsor and Essex County area. Although an attempt was made to include women in relationships with women, it was not possible. Women from several ethnic minority groups were included but not all ethnic groups were represented.

Although these women had a wide range of experience, it cannot represent the full spectrum of experience of cervical cancer. Some women were reluctant to be specific about their sexual experience and were more comfortable speaking generally, which limited the detail they shared. Four women were not in relationships at the time of their diagnosis or at the time of the study; they reported no sexual activity.

Since treatment protocols vary depending on the location and size of the cancer centre, women in this study's experience will be different than where the brachytherapy treatment involves sedation, for example. Other centres may also have more or less access to trained supportive care professionals.

Final Thoughts

As Frank (1991) pointed out, stigma is attached to disease that is related to the level of societal discomfort attached, cancer being highly stigmatized. Even within cancer there is a hierarchy. Cancers that are caused by sexually transmitted diseases, such as HPV and HIV, and cancers that affect taboo parts of the body such as the genitals or anus are also high on the list. Cervical cancer is difficult as it contains this triad of factors. Women with cervical cancer suffer because of difficult treatment, lack of adequate support, and emotionally and physically painful sexuality. That these conditions prevail speaks to the intensity of blame and shame attached to this disease.

The women who participated in this study were eager to talk about their treatment experience and the impact of cervical cancer on their lives. All of them pushed through feelings of fear and discomfort to remember aloud their treatment experiences. Many overcame their initial embarrassment about sharing their sexual experiences that most had previously considered private. Although it was clear that these women appreciated the opportunity to tell their stories, they cited their desire to improve the experience of other women who are yet to be diagnosed with cervical cancer as their motivator. Their words have been recorded in this document so that their voices will demonstrate the need to make time and space to listen to the experience of women as they journey through their cervical cancer treatment and recovery, and to make changes and provide support when they most need it. Listening to women is the key to timely diagnosis, pain and symptom management during treatment, assessing information needs, and medical and psychosocial support for relationship issues and concerns. Women are ready to talk to those who are willing to listen.

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APPENDIX A

Interview Guide

Please tell me about yourself. (looking for demographic information; check out further at the end of the interview.)

Tell me about how you first understood that something was wrong?

- What prompted you to get a diagnosis?
- Tell me about that process (the process of getting a diagnosis)?
- What kind of treatment(s) did you have?
- What was that like?

We know that women often have sexual problems after they have had cervical cancer, can you tell me about your experience?

- What was that like for you?
- Tell me about the changes in your body. What were these like for you?
- Did these have an effect on your sexuality? On how you feel as a woman?
- What about your partner how did s/he respond?

Who did you talk to about these things? Who did you talk to about what was happening in your sex life or with your own sexuality?

What about partner, where did s/he get support?

How have you worked out any concerns that either of you had?

Every one has their own ideas about what “having sex” means. What does this mean to you?

What advice do you have for women who have just been diagnosed with cervical cancer? I'm thinking especially advice about sexual issues.

How about advice for their partners?

What do you think caused your cervical cancer?

What recommendations would you have for your health care team to help women to cope with sexuality concerns?

Is there anything that you want to share that we haven't talked about yet?

If there are other things that you want to tell me, please give me a call. (leave card and interview questions.)

APPENDIX B

Office of the Research Ethics Board

University
of Windsor
thinking forward

Today's Date: April 14, 2008
Principal Investigator: Ms. Maureen Reynolds
Department/School: Sociology & Anthropology
REB Number: 08-070
Research Project Title: Experiences of Sexuality after Cervical Cancer
Clearance Date: April 14, 2008
Project End Date: December 31, 2008

Progress Report Due:
Final Report Due: December 31, 2008

This is to inform you that the University of Windsor Research Ethics Board (REB), which is organized and operated according to the *Tri-Council Policy Statement* and the University of Windsor *Guidelines for Research Involving Human Subjects*, has granted approval to your research project on the date noted above. This approval is valid only until the Project End Date.

A Progress Report or Final Report is due by the date noted above. The REB may ask for monitoring information at some time during the project's approval period.

During the course of the research, no deviations from, or changes to, the protocol or consent form may be initiated without prior written approval from the REB. Minor change(s) in ongoing studies will be considered when submitted on the Request to Revise form.

Investigators must also report promptly to the REB:

- a) changes increasing the risk to the participant(s) and/or affecting significantly the conduct of the study;
- b) all adverse and unexpected experiences or events that are both serious and unexpected;
- c) new information that may adversely affect the safety of the subjects or the conduct of the study.

Forms for submissions, notifications, or changes are available on the REB website: www.uwindsor.ca/reb. If your data is going to be used for another project, it is necessary to submit another application to the REB.

We wish you every success in your research.

Dr. Maureen Muldoon

Maureen Muldoon, Ph.D.
Chair, Research Ethics Board

cc: Dr. Eleanor Maticka-Tyndale, Sociology & Anthropology
Mark Curran, Research Ethics Coordinator

This is an official document. Please retain the original in your files.

APPENDIX C



Research Ethics Board

Windsor Regional Hospital
1995 Lens Avenue
Windsor, Ontario
N8W 1L9

Date: April 1, 2008

Project Title: Experiences of Sexuality after Cervical Cancer

Student Investigator: Maureen Reynolds, Windsor Regional Cancer Centre

Faculty Advisor: Dr. E. Maticka-Tyndale, Department of Sociology and Anthropology,
University of Windsor

REB File Reference: CC 08-100

Submissions Submitted:

- Revised Sections 4b) and 4c) of Ethics Submission Form.
- Letter of Information Version date: March 30, 2008.
- Consent to Participate in Research Version date: March 30, 2008
- Consent for Audio Taping Version dated: March 30, 2008.

This Research Ethics Board is constituted and operated in accordance with the Tri-Council Policy Statement for Ethical Conduct of Research Involving Humans (TCPS), Canadian Food & Drug Regulations, Division 5 (Clinical Trials), ICH Good Clinical Practice Guidelines E6, U.S. Code of Federal Regulations Title 21 & 45. WRHREB also holds a Federal Wide Assurance Registration with the U.S. Office of Human Research Protection.

Only Research Ethics Board members who are independent of the investigator(s) conducting the study participated in decisions relating to this research.

All adverse events and any amendments to existing approved materials must be submitted for REB approval. Please use above REB reference number on all correspondence. This approval is for one year and expires on March 31, 2009. If you wish to continue the research beyond this, renewal application must be submitted. Applicable forms are available by email from karen_anderson@wrh.on.ca.

The revised documents have been reviewed and the project is approved to commence. Submit notification when your research is completed and provide a summary report.

John Strang, Ph.D., C. Psych.
Chair, Research Ethics Board
Windsor Regional Hospital

April 01/08

Date

VITA AUCTORIS

Maureen Reynolds was born in Windsor, Ontario in 1957. She graduated from the University of Windsor in 1981 with a B.A. in Psychology and in 1991 with a B. Ed. She has completed the requirement for a Master's degree in Sociology, also at the University of Windsor and hopes to graduate in June 2009. Maureen was employed at the Windsor Regional Cancer Centre's Supportive Care Program from 1994 until 2009.