

SEXUAL ADJUSTMENT OF WOMEN UNDERGOING
PELVIC EXENTERATION WITH
VAGINAL RECONSTRUCTION

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DEDICATION

"For there is no friend like a sister
In calm or stormy weather;
To cheer one on the tedious way,
To fetch one if one goes astray,
To lift one if one totters down,
To strengthen whilst one stands."

Christina Rossetti
English poet
(1830-1894)

I would like to dedicate this dissertation to my sister, Margaret, for all her love and support in completing this dissertation.

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ABSTRACT

A total pelvic exenteration is an aggressive attempt to surgically cure the patient with cervical cancer. A total pelvic exenteration includes removal of the bladder, lower portion of the bowel, and the female reproductive organs (including the uterus, ovaries, fallopian tubes, and vagina). The myocutaneous gracilis graft procedure is the preferred technique for neovaginal reconstruction. This study assesses the sexual adjustment of 40 women who have undergone pelvic exenteration at a 500-bed southwestern cancer center using a modified version of the Sexual Adjustment Questionnaire (SAQ) developed by Waterhouse and Metcalfe (1986), and a vaginal assessment form developed by the investigator. The Wilcoxon Signed Rank test was used to examine the difference in the mean ranks of the pre-exenteration and post-exenteration scores. The pre-exenteration score was 66.4 and the mean rank of post-exenteration score

was 48.7, showing a significant difference at $p < .0001$ between the pre- and post-exenteration scores. This finding means that the sexual adjustment of women following pelvic exenteration is less than before surgery. The Spearman rho was performed to examine the influence of time on sexual adjustment. The Spearman rho coefficient was $r = -.03$ showing no relationship between length of time following exenteration and sexual adjustment. With the vaginal assessment form, the physicians reported 31 patients (70.4%) with functional vaginas. Based on data collected the following conclusions were derived: women who undergo pelvic exenteration with vaginal reconstruction experience a decrease in sexual adjustment, time following pelvic exenteration does not influence resumption of sexual activity, and 31 patients (70.4%) had anatomical functional vaginas capable of penetration.

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CHAPTER I

INTRODUCTION

A total pelvic exenteration is an aggressive attempt to surgically cure the patient with cervical cancer. Pelvic exenteration is used when the primary cancer has not been cured by the initial treatment or when new cancer growth has developed locally. During the surgical procedure of pelvic exenteration, the perineum, pelvic floor, levator muscles, and all reproductive organs are removed. Additionally, the lymph nodes, rectum, distal sigmoid colon, bladder, and distal ureters are excised. A colostomy and urinary conduit are created and a vaginal reconstruction may or may not be performed (Gershenson, 1991).

Reconstruction of a functioning vagina is hopefully planned for most patients. The myocutaneous gracilis graft procedure is the preferred technique for neovaginal reconstruction (Rutledge, 1987). From a graft that is mobilized from the inner aspect of the thigh, a skin-lined tube is created and inverted into the pelvic cavity as a vagina.

The high mortality of the exenteration, 23% in Brunschwig's series more than 40 years ago, resulted in a major goal of gynecologic surgeons to improve operative

survival (Stanhope & Symmonds, 1985). More recently mortality rates have decreased. Rutledge (1987) reported a series of 152 exenterations from 1977 to 1984 for which postoperative mortality was 3.9%. In the past, concern for vaginal reconstruction has been secondary to surviving the surgery and a potential cure. As survival rates have improved, vaginal reconstruction has taken on a new significance.

Patient selection for exenteration is important, but the surgery offers a chance for cure. The five-year survival rate for patients undergoing pelvic exenteration ranges from 19% to 42% (Shingleton et al., 1989). For their study of 448 patients in the University of Texas M.D. Anderson study, 53.7% of patients will avoid death from recurrent cancer for 5 years and 41% will avoid death from all cancer-related treatment causes for 5 years (Rutledge, 1987).

Despite the improved survival rates with these gynecologic cancers, the quality of the patient's sexual life after therapy is often ignored by physicians and nurses (Jenkins, 1988). Genital cancers pose a threat to a woman's self-image and sexuality (Siebel, Freeman & Graves, 1980). The impact of the threat is compounded by actual physical interference with sexual functioning caused by the treatment.

Although there are no anatomical restrictions for sexual activity associated with the neovagina, psychological adjustments for recovery from the exenteration may indirectly delay rehabilitation. In addition, other physical changes such as the ostomies may require personal adjustment. The degree of sexual rehabilitation that may be achieved after exenteration using the myocutaneous gracilis graft procedure is unknown (Rutledge, 1987). Although the procedure has been performed at a 500-bed southwestern cancer center since 1977, there has been no published attempt to assess the impact of this surgery on sexuality.

Problem of Study

Pelvic exenteration with vaginal reconstruction impacts sexuality. The purpose of this study was to assess the sexual adjustment of women who have undergone pelvic exenteration at a 500-bed southwestern cancer center using a modified version of the Sexual Adjustment Questionnaire (SAQ) developed by Waterhouse and Metcalfe (1986).

Rationale for Study

Since described by Alexander Brunschwig in 1948, the role of pelvic exenteration in the management of recurrent or advanced carcinoma of the cervix has undergone constant reevaluation. In Brunschwig's series of 22 patients the indication for surgery was more for palliation than cure

(Brunschwig, 1948). Today 35% to 65% of these patients are cured (Osborne, Murphy, & DePetrillo, 1991). With the improved survival, emphasis should shift to quality of life issues. Research has shown that sexual function is the greatest disruption in the lives of these patients (Andersen & Hacker, 1983; Sewell & Edwards, 1980).

Two hundred ninety-six pelvic exenteration procedures have been performed at the large cancer center since 1977, when the myocutaneous gracilis graft vaginal reconstruction was first performed. From the surgeon's point of view, there are several advantages if the vagina is reconstructed using the myocutaneous gracilis graft. The risk of small bowel fixation to the pelvic floor will decrease and the neovagina permits pelvic examination for future follow-up examinations. The neovagina also assists in the revascularization of the pelvic floor. In addition, surgeons may go to great lengths to construct or reconstruct anatomical parts, because surgeons perceive patients desire reconstruction. Vaginal reconstruction is such an example (Gershenson, 1991; Thompson & DePetrillo, 1991).

According to Thompson and DePetrillo (1991) the mere presence of a vaginal receptacle and the patient's ability to have intercourse following this surgery constitute sexual rehabilitation for some physicians. Patient satisfaction, body image, and sexual pleasure are not addressed. In

reality, the sexual adjustment of these women is unknown (Rutledge, 1987).

At the time of diagnosis and proposed surgery, sexual function is not an issue of prime importance (Vera, 1981). However, as patients recover from surgery and the fear of persistent cancer lessens, hope for complete rehabilitation emerges. It is at this stage that concerns regarding sexual adjustment arise (Lamont, DePetrillo, & Sargent, 1978).

Two studies were undertaken to determine the extent of sexual rehabilitation achieved by women undergoing pelvic exenteration. Vera (1981) studied 19 patients and reported significant changes in sexual life. Lamont et al. (1978) used a multidisciplinary approach to provide rehabilitation to 12 patients undergoing pelvic exenteration. A sexual counselor was involved in preoperative assessment, during hospitalization, and during the postoperative period. Postoperatively, 8 patients resumed sexual activity. They found that loss of sexual functioning could be attributed to feelings of unattractiveness and lack of information and support from health team members (Lamont et al., 1978). They further showed that when sexual rehabilitation was incorporated in the management of exenteration patients, resumption of sexual activity and satisfaction were increased (Lamont et al., 1978).

Patients expect physicians and other health team members to bring up the subject of sexuality, thus giving permission to discuss these concerns (Bullard et al., 1980). Providing information outlines not only events that will occur but how the person may feel, and facilitates retention of that information. Identifying structural and functional changes that can be expected after surgery and letting the patient know what she can do to manage these changes can also help enhance sexual adjustment. Because of limited research regarding sexual adjustment following exenteration nurses have difficulty explaining to patients the sexual changes that will occur following vaginal reconstruction. Current literature on the myocutaneous gracilis graft vaginal reconstruction is limited to surgical construction and medical management of the graft.

Body image and quality of life are important issues with the increased survival rates of women undergoing pelvic exenteration. Problems may be assumed not to exist simply because they have not been discovered. However, patients report minimal information or an unrealistic impression of what to expect from the vaginal reconstruction (Bullard et al., 1980). Nurses need to be able to identify the aspects of sexuality which may be affected by the surgery to suggest specific ways for patients who have undergone pelvic exenteration to maintain sexual identity and to assist

future pelvic exenteration patients. The SAQ will facilitate research in this area and permit data collection that will assist patients undergoing pelvic exenteration with vaginal reconstruction in coping successfully with changes in sexuality.

Conceptual Framework

The conceptual framework used for this study was Sister Callista Roy's Adaptation Model. Adaptation refers to adjustment to constant changes which occur in and around us throughout our lives (Selye, 1952). Roy (1976) centers her nursing theory on this concept of adaptation.

Roy (1976) defined man as a biopsychosocial being in constant interaction with a changing environment. Man responds to a changing environment in an attempt to adapt. The ability to adapt depends upon the person coping with the change and the degree of change taking place. An adaptive response is behavior that maintains the integrity of the individual. Maladaptive responses do not maintain integrity and are disruptive to the individual.

The adaptive level is determined by three variables: a) stimuli confronting the person or focal stimuli, b) all other stimuli or contextual stimuli, c) residual stimuli such as beliefs, attitudes, or experiences which have an immeasurable effect on the present situation.

Roy has identified two major types of adaptive mechanisms, the regulator and the cognator. The regulator mechanism works through the autonomic nervous system to set up a reflex action which readies the person for coping with the stimulus. The cognator identifies, stores, and relates stimuli so that symbolic responses can be made. This mechanism acts consciously by means of thought and decision and unconsciously through the defense mechanisms (Roy, 1976).

Roy represents degrees of health or illness on a continuous line called the health-illness continuum. Adaptation problems are defined as situations resulting from inadequate responses to medical deficits or excesses (Roy, 1976).

The adaptation model depicts people as biopsychosocial beings required to adapt to environmental stimuli. In this study, the environmental stimuli is the surgical procedure of pelvic exenteration with vaginal reconstruction. According to Roy (1976), adaptation is considered to take place in one biological and three psychosocial modes. The biological mode of adaptation is concerned with basic needs to maintaining the physical and physiological integrity of the human being. In this study, the biological mode is the recovery of the patient from the surgical procedure. In Roy's model the psychosocial modes of adaptation include

self-concept, role function, and interdependence (Roy, 1976). The self-concept mode deals with people's conceptions of their physical and personal selves. Body image and self-esteem would be included here. The role function mode is concerned with people's performance of roles on the basis on positions within society. The role of wife and sexual partner might be included in role function. The interdependence mode deals with the development and maintenance of satisfying affectional relationships with others. Sexual adjustment might be included in the interdependence mode. However, the four modes are interrelated. Responses in any one mode may have an effect in one or all of the modes. For example, necrosis of the vaginal reconstruction in the biological mode will affect the self-concept of the patient, the role as sexual partner, and the maintenance of satisfying sexual relationships.

Environmental stimuli which are believed to influence adaptation are categorized as focal, contextual, and residual (Roy, 1984). The focal stimuli are those most immediately confronting the person, the contextual stimuli are the contributing factors in the situation, and the residual stimuli are unknown factors that may influence the situation. The focal or contextual stimuli can become the etiology component of the nursing diagnosis statement. An example might be knowledge deficit related to vaginal

reconstruction. Interventions could be aimed at assessing the knowledge deficit and providing educational interventions.

Roy's conceptual model helps to direct researchers to study problems in adaptation to constantly changing environmental stimuli. The purpose of Roy's research was to enhance understanding of how people adapt to environmental stimuli, how adaptive processes affect health, and how nursing can enhance adaptive life processes and functioning (Roy, 1988). The purpose of this study was to discover how women adjust to pelvic exenteration surgery. With this information nurses can design interventions to enhance pelvic exenteration patients' sexual adjustment and functioning.

Assumptions

For the purposes of this study, the following assumptions were identified:

1. Women who have undergone pelvic exenteration with vaginal reconstruction experience changes in sexuality that require an adaptive response.
2. Sexual adaptation of women who undergo pelvic exenteration with vaginal reconstruction is a function of the stimulus they are exposed to and their adaptation level.

3. Women will accurately remember and report their sexual experiences which occurred before and after the pelvic exenteration procedure.

Research Questions

The following research questions were addressed in this study:

1. Is there a difference in level of sexual adjustment as measured by the SAQ of women before and after pelvic exenteration with vaginal reconstruction?
2. Is there a relationship between sexual adjustment of women and the length of time since pelvic exenteration and vaginal reconstruction?
3. Do women who have undergone pelvic exenteration with vaginal reconstruction have anatomically functional vaginas as determined by the patient's physician?

Definition of Terms

The following definitions were identified for the study:

1. Pelvic exenteration with myocutaneous gracilis vaginal reconstruction - en bloc excision of the uterus, ovaries, fallopian tubes, cervix, vagina, bladder, and rectum with myocutaneous gracilis muscle flaps to reconstruct the vagina (Morrow & Townsend, 1981).

2. Sexual adjustment (sexual adaptation) - is defined as the women's sexual feelings and functioning after treatment for cancer, compared to sexual feelings and functioning before the diagnosis of cancer as measured by the SAQ (See Appendix A).
3. Sexual functioning - a component of sexual adjustment that includes desire, arousal, orgasm, and sexual satisfaction (Waterhouse & Metcalfe, 1986).
4. Functional vagina - a vagina which has no myocutaneous gracilis muscle flap loss or minimal as determined by the physician using the vaginal assessment form (See Appendix B).

Limitations

In this study, the following limitations were identified:

1. The use of a convenience sample from one institution limits the generalizability of the results to the target population.
2. There may be a sample bias since participation in this study is on a voluntary basis. Sexual adjustment may be higher or lower in those who agree to participate than in those who refuse.
3. Patients may have difficulty remembering their sexual adjustment before surgery.

Summary

Women who have undergone pelvic exenteration with vaginal reconstruction undergo many physical and psychological adjustments. This study assessed the sexual adjustment of women who had undergone pelvic exenteration to discover if there was a difference in level of sexual adjustment before and after this surgical procedure as indicated by the SAQ?

Roy (1976) states that becoming an integrated and whole person fulfills ones purpose in life. Studies suggest that women who undergo pelvic exenteration are not adjusting to changes in sexuality to become whole again (Andersen & Hacker, 1983; Sewell & Edwards, 1980). One assumption of this study was that women who have undergone pelvic exenteration with vaginal reconstruction experience changes in sexuality that require an adaptive response.

CHAPTER II

REVIEW OF THE LITERATURE

Locally recurrent cervical cancer may be treated by pelvic exenteration which involves removal of the bladder, rectum, vagina, uterus, adnexa, and pelvic lymph nodes. Frequently, vaginal reconstruction may be done at the same time as the exenterative surgery using a myocutaneous gracilis flap. Although pelvic exenteration with myocutaneous gracilis vaginal reconstruction has been performed at a large southwestern cancer center since 1977, the sexual adjustment of these women has never been formally assessed. The focus of this study was to assess the sexual adjustment of women who have undergone this surgical procedure.

In this chapter, literature related to sexuality and pelvic exenteration is reviewed. Because body image is closely linked to sexuality, body image is also discussed. Additionally, the effects of ostomies on sexuality is reviewed.

Body Image and Sexuality

Body image is the emotional view, attitudes, and feelings of one's physical being (Cohen, 1991). The dimensions of the concept of body image include self-

concept, body-concept, self-esteem, body scheme, self-connection, and body image boundary (Cohen, 1991). Self-concept is an objective summary of what one thinks about oneself. Body-concept is what one knows about one's body structure and functions. Self-esteem is the evaluation of one's worth. Body scheme is the perception of the body's self appearance based on proprioceptive experiences. Self-connection is the estimation of the probable effect of a specific disorder on one's self-esteem. Body image boundary is the limit of one's physical being.

An altered body image can result from congenital anomalies, trauma, and medical therapies (Cohen, 1991). The change in body image can occur rapidly, or gradually over time. Some changes that impact body image can be hidden from others such as a hysterectomy, but other changes are clearly visible such as an amputation.

Factors affecting body image include culture, race, education, genetics, socialization, and the media. Work is also an important component in establishing the feeling of self-esteem and the ability of the individual to be independent and care for himself.

Some people view their body as a base of support and have strong boundary perceptions. Others may perceive the body surface to be fragile and easily permeated (Goldberg, 1991). Body image disturbances can exist when the body wall

changes but the patient keeps the old boundary. For patients undergoing ostomy surgery, the body image must be extended to include the stoma. Individuals undergoing ostomy surgery enter the operating room as a whole person, and return minus body parts and with a new body part, the stoma.

The development of body image is a continuous process. Attitudes toward body parts are developed through early self-exploration and are expanded visually as the person grows and observes the changes that occur with the body. Social stimuli impinge on these attitudes, as the person relates his own feelings of himself in relation to others, adding another dimension to body image. The aging process continues with physical and emotional changes that require adjustment of body image (Goldberg, 1991).

The way a person feels about himself or herself also affects the person sexually. Sexuality is influenced by feelings of attractiveness and desirability. Each person needs to feel desirable and his or her body image influences the ability to be a lovable partner.

Sexuality is a comprehensive term that incorporates physical, psychological, and social factors (Woods, 1975). Body image, the way people perceive themselves, and self-concept, sense of identity, worth and capabilities, are closely related to sexuality. Sexuality forms the

biological basis for sexual pleasure and influences our relationships with each other.

Sexuality becomes a major part of the individual's body image during maturity and the exploration of maleness or femaleness. It deals with instincts, drives, and behaviors in relation to sexual activity. The individual's sexual identity is generally composed of attributes that are either predominantly male or female (Saunders, 1981).

Sexuality is usually seen as a force that encourages developing a relationship or seeking a mate to share aspects of ourselves. Sexuality includes such concepts as attractiveness, giving, openness, warmth, and nurturing. None of these concepts is an all or nothing idea. The messages individuals give themselves as well as those they receive from others will determine how fully they function as sexual beings (Saunders, 1981).

The acceptance and expression of sexuality is not confined to genital arousal and expression. The awareness, acceptance, appreciation, and expression of sexuality encompasses the total personality. What we think of our sexuality influences what we think and how we feel about our identity, self-worth, and self-esteem and how we relate to others (Nagata, 1982).

When feminine sexuality is considered alone, some of the concepts brought to mind are attractiveness,

shapeliness, warmth, and nurturing (Saunders, 1981). These concepts can be greatly altered when a woman finds herself confronted with a disease that cannot only threaten her life but her sexual desirability as well.

Attention to the sexuality needs of women with cancer has traditionally been considered an extra that can be easily omitted from the busy schedule of tests and treatments. Site of disease and the nature of the treatment contribute to the variability. Sexual dysfunction for early stage cervical cancer is in the range of 30% to 40%, whereas radical vulvectomy and pelvic exenteration is in the range of 70% to 90% (Andersen, 1987; Andersen & Hacker, 1983). Sexual disruption then is experienced by 30% to 90% of women treated for gynecologic cancer (Andersen & Turnquist, 1989). Women often claim that they receive little or no information to help them prepare or adjust to these problems (Vincent, Vincent, Greiss, & Linton, 1975). One of the challenges is balancing attention to the disease and its treatment with attention to the everchanging needs of the person who is living with that disease and the effects of its treatment.

To achieve sexual rehabilitation, the entire spectrum of human sexuality must be addressed. That means viewing the patient as being worthy of love and affection despite the devastations perceived--barriers of age, marital status, education, disease or prognosis (Woods, 1979). Sexual

adjustment goes beyond the intercourse of penis and vagina. It encompasses the needs of physical comfort, tenderness, affection, and love that exist within each of us from birth to death.

There have been few clinical studies of sexual therapy intervention for female cancer patients. Capone, Good, Westie, and Jacobson (1980) studied the effectiveness of individual counselling on the psychosocial adjustment of 41 patients with gynecologic malignancies. Return to employment and sexual activities were shown to be adversely affected by the diagnosis and treatment of genital cancer. For patients who received brief psychosexual counselling interventions, sexual functioning was twice the rate of return to pre-disease frequency of intercourse in comparison to the outcomes of untreated control patients (Capone, et al., 1980). These data suggest that interventions are necessary and that it can enhance the posttreatment outcomes for women. It is cost effective and of greater benefit to provide preventative rather than rehabilitative interventions to patients at high risk for sexual problems.

Sexual Adjustment in the Ostomy Patient

Ostomy surgery changes the physical image of the body, resulting in loss of bowel and bladder control. Because society places an emphasis on control of wastes, people

undergoing bowel or bladder diversion often suffer devastating effects on their sexuality and self-esteem (Shell, 1992).

The United Ostomy Association estimates that there are over 1.5 million people with ostomies in the United States and Canada. More than 100,000 were performed in 1981 (Hurny & Holland, 1985). Even with this incidence of occurrence, the stigma of something dirty and unacceptable is still attached to ostomies. Patients with the stigma associated with cancer, who also must face the additional problems of a stoma, are often fearful of the future.

The adjustments that the person who undergoes ostomy surgery faces are complex and multifaceted. Facilitating adaptation to the change of both body image and function is crucial for optimal rehabilitation (Goldberg, 1991). Radical surgery with threats to body image and self-esteem, as well as loss of bowel and bladder control, all combine to stress the individual's coping abilities. In addition, patients are expected to become proficient at stoma care while recovering from major surgery.

The biggest change since the early 1950s has not been in the psychological area, but in the improved ostomy equipment available today. In addition, stoma placement preoperatively takes into account abdominal skin folds, patient preference, and styles of dress. In earlier days

patients wore bulky dressings, clumsy belts, and leakage and odor were much more of a problem (Hurny & Holland, 1985).

The review of the literature found few studies concerning sexual adjustment of patients with ostomies. No instrument was found that specifically addressed the sexual adjustment of ostomy patients. Many of the studies were performed by physicians and looked solely at sexual functioning and often notes only the frequency of intercourse after ostomy surgery (Copeland, Hancock, Gershenson, Stringer, Atkinson & Edwards, 1989; Lawhead, Clark, Smith, Pierce, & Lewis, 1989). Copeland et al. (1989) only described the anatomic result of the vaginal construction. Several studies have been conducted by psychologists that document the psychological stress that individuals undergo when they experience a body image change from ostomy surgery (Hurny & Holland, 1985; Gloeckner & Starling, 1982). Areas of concern related to sexual attractiveness have been fears of appliance leakage during sexual activity, odor, and reactions of the sexual partner.

The first study of psychosocial problems of the cancer patient with an ostomy was done in the early 1950s at Memorial Hospital for Cancer and Allied Diseases in New York. Fifty-seven patients with colostomies were studied for colostomy adaptation. These patients had survived rectal cancer for more than 5 years, but had considerable

impairment in both social (work, community, and family) and sexual (neurologic and psychologic) functioning (Hurny & Holland, 1985). Depression, anxiety, and social isolation were frequently reported. Patients with poor family relationships did not cope as well as those patients with supportive families.

Studies investigating the psychosocial adaptation to an ostomy describe an array of problems. Some of them include: fears of sexual undesirability, impaired sexual function, fears about sexual function, even if function is unimpaired, and social isolation (Dempsey, Buchsbaum & Morrison, 1975; Gloeckner, 1991; Shell, 1992). Full adjustment has been reported to take up to 2 years or longer (Hurny & Holland, 1985).

Gloeckner (1984) interviewed 40 ostomy patients about their feelings of sexual attractiveness following ostomy surgery. Twenty-four (60%) reported a decrease in feelings of sexual attractiveness from before the surgery to the year following ostomy surgery. In contrast to their feelings during the first postoperative year, there was an increase in feelings of sexual attractiveness for 27 subjects (67.5%) by the time of interview (mean years since surgery = 4.6) (Gloeckner, 1984). Gloeckner and Starling's (1982) findings were in agreement with Dlin and Perlman (1971) who stated

that body image disturbance is worst during the first year following surgery.

The sexual behavior of ostomates in the older years should not be ignored. Gabriel (1989) stated that older ostomates can maintain an active and interested sex life after surgery, if they have a cooperative and understanding partner.

Cancer patients are mainly in the older age groups. Although there is evidence that human beings of every age have a need to express themselves sexually, there is a misconception by the health care team and the public that age limits interest in sex (Hurny & Holland, 1989).

Another misconception is that sex is not important if one has cancer. In the Memorial Sloan-Kettering Cancer Center Study of 80 patients with advanced colorectal or bladder cancer, many patients reported rewarding sexual experiences despite physical limitations (Hurny & Holland, 1985). Patients with advanced disease had a greater need to be held and touched.

Because sexuality is a basic need, the sexual impact of the ostomy surgery should be discussed with both patient and partner. Very little research has been conducted on female sexual dysfunction after ostomy surgery. Ruesgas (1989) surveyed 50 female ostomates to identify the effect of ostomies on sexual life. He found that 88% of the women had

a decrease in sexual desire and 56% reported painful intercourse. This pain with resulting decreased desire may be due to loss of the anterior or posterior vaginal wall, creation of a neovagina, altered position of the vagina, loss of cushioning behind the vagina, adhesions in the pelvis, impaired vasocongestion and lubrication, impaired vaginal sensitivity, and vaginal dryness and atrophy from ovarian failure (Ruesgas, 1989).

Individuals with stomas often have poor psychosocial outcomes that range from failure to return to work, withdrawal from social and intimate contact, to depression and anxiety. Klopp (1990) surveyed 155 ostomy patients. Using the Body Phenomenon Index she found individuals with fecal stomas have a poorer body image than individuals with urinary stomas.

Woods (1975) stated that the loss of control of body function generates anxieties about adult sex role identification and social interaction. This body image disturbance elicits feelings of unacceptability, which influences the person's self-perceptions as a sexual being and also affects sexual relationships.

Patients with ostomies may experience a range of concerns. These concerns can be broken into three categories. They are concerns related to self-concept, fears related to the stoma itself, and fears related to

recurrent disease (Goldberg, 1991). Nursing interventions should be designed to resolve and minimize fears and anxieties. Unresolved, these concerns can undermine the patient's self-concept, independence, and interfere with adjustments to altered body function and appearance. The changes in body image and function resulting from ostomies may alter the patient's perception of their self as a whole person.

A needs assessment by Bullard et al. (1980) revealed that 63% of the cancer patients that participated would have liked to have more information about sexual functioning after treatment and that 64% would participate in a specific counselling program on this topic. With the increase of consumerism, patients may soon require and expect interventions which will assist them in becoming psychosexually as well as physically rehabilitated. Perhaps, since little is known about sexuality after ostomy, it is not discussed with patients, but since it is not discussed with patients, little will be known. In spite of the trend in holistic patient care, many institutions do not have specific organized programs to deal with sexuality and the sexual rehabilitation of the patient.

Pelvic Exenteration

Of all patients treated for invasive cervical cancer, approximately one-third will develop recurrent disease (Gershenson, 1991). Central failure refers to recurrent disease in the vagina, cervix, uterus, bladder, rectum, or parametrial tissues. If the disease is confined to the central pelvis and does not extend to the pelvic side wall or has not disseminated to the lymph nodes, then pelvic exenteration surgery will be curative in greater than 50% of patients (Gershenson, 1991).

Alexander Brunschwig was the first to report the procedure of pelvic exenteration in the literature (Brunschwig, 1948). However, Appleby and Bricker and Modlin were actually the first physicians to perform exenterations (Appleby, 1950; Bricker & Modlin, 1951). Historically, Brunschwig is the one who is given credit for establishing the pelvic exenteration as a treatment for cervical cancer (Smith, 1989).

Pelvic exenteration for recurrent cervical cancer produces permanent sexual changes. Studies have shown the cessation of sexual activity for women to be 80% to 90% of those surveyed (Vera, 1981; Brown et al., 1972; Dempsey et al., 1975). Various techniques are available for vaginal reconstruction. Women without such surgery cannot resume intercourse because of vaginal closure. Andersen (1987)

states that women with reconstructed vaginas often do not resume sexual activity because of persistent vaginal discharge, reconstructive inadequacy, fears of pain or bleeding, or loss of sensation.

Several methods of vaginal reconstruction have been described in the literature. In 1976, McCraw, Massey, Shanklin, and Horton described the gracilis myocutaneous vaginal graft procedure. During this procedure, the patient is placed in the lithotomy position. The lower extremities are abducted and externally rotated to facilitate surgical access. Bilateral outlines of the flaps are drawn on the inner thighs. Incision of the skin and muscle is made, taking care not to sever the saphenous vein and the nerve that will supply the reconstructed flap. The gracilis muscle is transected and freed proximally. Both flaps are then rotated posteriorly through subcutaneous tunnels into the perineal defect. A vagina is created by suturing the flaps together and securing them within the pelvic cavity.

The neovagina has an approximate depth of 13 to 15 cm and a circumference of 12 to 14 cm. The neovagina consists of skin, muscle, and subcutaneous fat. It is a much softer vagina than the one composed of split-thickness grafts, is adequate in depth and width, and does not require the use of a dilator. A problem encountered during the early years was the size of the flaps and the tendency to prolapse.

Modifications were made making smaller flaps to achieve mobility (Smith, 1989). This method of immediate reconstruction has numerous advantages, including primary healing of the perineal defect, decreased fluid loss from the denuded pelvic cavity, revascularization of the remaining pelvic tissue (which is often irradiated), accessibility to the pelvic for follow-up examinations, and restoration of a functional vagina with minimal care by the patient (Gershenson, 1991).

The first documented discussion of the use of the gracilis myocutaneous flaps for pelvic exenteration patients was described by McCraw, Shanklin, and Horton (1976). They describe the use of the flap in 22 patients. The advantages of the flaps surgically was described. However, no mention was made to sexual adjustment of the patient. Surgical complications of the flaps included flap loss, hematoma, infection, pain in the thigh scars, prolapse, vaginal vault contraction, and flap sensitivity to touch. Twenty-seven percent of the patients had partial necrosis of the flaps with 9% having major necrosis of the flaps. Twenty-seven percent of the patients also had hematomas with resultant infections of the flaps. All 22 patients reported painful hypersensitivity of the scar. No patients prolapsed the flaps and one patient had neo-vaginal contraction. Flap sensitivity to touch was rated "fair" to "good."

Because of the benefits of the gracilis myocutaneous vaginal reconstruction, it was incorporated in the exenteration procedure at a large southwestern cancer center in 1977. From 1980 to 1987, 107 patients underwent gracilis myocutaneous reconstruction (Copeland et al., 1989). In a retrospective chart review the surgical results of this technique appear excellent, but the information regarding the sexual functioning of the reconstruction is unknown (Copeland et al., 1989).

The review of the literature on sexual adjustment of pelvic exenteration patients is limited, especially patients that have myocutaneous gracilis reconstruction. Highlights of the studies are presented. Brown, Haddox, Posada, and Rubio (1972) interviewed 15 patients to evaluate the social and psychological adjustment after pelvic exenteration. Twenty-seven percent of the patients reported sexual dreams. However, 73% indicated no present sexual interest. The authors made no reference to vaginal reconstruction and no questions about sexual activity were asked. Time since exenteration surgery was not mentioned.

Morley, Lindenauer, and Youngs (1973) reviewed the use of the split thickness graft for vaginal reconstruction in 30 pelvic exenteration patients. Four to eight weeks after the pelvic exenteration surgery the patients underwent the

vaginoplasty procedure. Fifteen of the 30 patients were able to experience sexual relations. However, most of the patients thought that the loss of the vagina should be described in more detail by the physician (Morley et al., 1973).

Dempsey, Buchsbaum, and Morrison (1975) interviewed 16 patients who underwent pelvic exenteration. They concluded that the quality of life after pelvic exenteration surgery is very satisfactory with only sexual function being compromised. Only 3 of the patients reported being sexually active postoperatively with only 1 of the patients having a vaginal reconstruction using a split-thickness graft. The other two patients did not have any vaginal reconstruction.

Lamont et al. (1978) examined the psychosexual rehabilitation of 12 exenterative patients that underwent vaginal reconstruction of multiple types but not using the gracilis myocutaneous reconstruction. Patients were interviewed by a sexual counselor preoperatively and postoperatively for sexual attitudes and adjustments. Eight women were found to have good sexual adjustment preoperatively with 7 of these patients having a good postoperative sexual adjustment (Lamont et al., 1978). They also found that sexual functioning was not a priority for patients at the time of exenterative surgery. However, 6 to 9 months after the surgery when the patient begins to hope

for complete rehabilitation, sexual functioning increased in importance (Lamont et al., 1978).

Vera (1981) surveyed 19 patients postoperatively to assess their social, sexual, and psychological adjustment after pelvic exenteration. Twelve (63.2%) of the patients who had been sexually active preoperatively responded that they had no sexual activity postoperatively. Only 3 patients had a neovagina created and these 3 patients found intercourse painful. As a result they did not engage in sexual intercourse. Vera (1981) also asked patients if they had to choose again would they opt for pelvic exenteration surgery. All patients said they would have the surgery. Vera's interviews were conducted 6 months to 9 years after the pelvic exenteration. However, the patients' memories of their preoperative reactions and feelings coincided with Brown et al. (1972), and Dempsey et al. (1975).

Andersen and Hacker (1983) surveyed 15 pelvic exenteration patients approximately 5 years after the surgery to assess psychosexual adjustment. Four of the patients did not have vaginal reconstructions. The type of vaginal reconstruction was varied. Only 4 of the patients had the gracilis myocutaneous graft reconstruction. Andersen and Hacker (1983) found that sexual functioning was the greatest area of disruption in these patients' lives and

that these women resembled severely sexual dysfunctional healthy women.

Berek, Hacker, and Lagasse (1984) studied 21 patients that underwent gracilis myocutaneous reconstruction simultaneously with pelvic exenteration. They found that 10 (48%) of patients were sexually active, 2 (9%) only rarely had sexual intercourse, and 9 (43%) never attempted intercourse. All patients noted moderate to heavy vaginal discharge. Four patients responded that the vaginal dimensions of the neovagina were too large and one patient responded that the neovagina was too small.

Sixty-five patients underwent pelvic exenteration from 1972-1981 at Memorial Sloan Kettering Cancer Center. Vaginal reconstruction was not performed at the time of exenteration and was performed as a secondary procedure in only 2 patients (Lawhead et al., 1989). Sexual adjustment of the patients was not assessed.

The number of studies assessing sexual adjustment in pelvic exenteration patients are limited. Of the studies that have been done, the investigators used self-made questionnaires in which there is no mention of the questionnaires being tested for reliability and validity. Although the myocutaneous gracilis reconstruction is performed the most often, no research study assessing sexual adjustment following this procedure has been conducted.

Exenterative surgery for pelvic malignancy involves loss of tissue which is sexually responsive. Traditional societal attitudes of "normal" sexuality, coitus, and reproduction present the exenterative couple with problems they may have never discussed. No previous discussions about nudity, cuddling, and general pleasurable stimuli make it difficult for the couple. Women, who lose their vagina and clitoris, can learn to have a complete sexual response with stimulation of other erogenous areas (Lamont et al., 1978). Thigh or breast stimulation may be heightened as well as mouth or hand stimulation. It is important for the patient to be educated so that she can respond to a wide variety of stimuli for a satisfactory response. However, in the series of reconstructions being performed at the large southwestern cancer center no structured sexual information is shared with the patients and no sexual counselling program exists.

The rehabilitation of the patient who has had a pelvic exenteration should be well structured. Patients who have survived for some time following pelvic exenteration can be well adjusted (Barber, 1987). There are many reasons for the patient to become well adjusted. After a period of time the patient realizes that the cancer is being controlled. The patient's partner can play a significant role in rehabilitating the patient. It is important to have a

sexual history in the preoperative period. It is important to explain to the patient that it is possible to make a psychosexual adjustment following pelvic exenteration.

Sexual functioning, especially under age 65, continues as the greatest area of disruption for these patients (Barber, 1987). Patients who have a strong sex drive before the pelvic exenteration fare better than those that have had a low sex drive (Barber, 1987). Patients should be encouraged to return to productive activity as soon as possible. The aim is to bring about total rehabilitation and an adjustment to their loss of bladder, rectum, and vagina. Having given these patients quantity of life, it is important to give them quality of life. These patients should be rehabilitated.

Patients must learn to accept not only a new physical body and different order of bodily functions, but also a new body image. Regardless of the woman's marital status or age, sexual body image assessment and explanations should be a routine part of care. The changes brought about by this surgery, which interferes with sexual activity, can be accepted by the person who sees the surgery as a chance to cure the cancer. A nurse who is comfortable with her own sexuality and educated in the primary aspects of sexual assessment can respond to the patient's concerns and anticipate needs. Schover and Fife (1985) suggest that

sexual counselling be undertaken by oncology nurse specialists who should understand how the surgery affects the physiologic aspects of sexual function, be able to respond to questions without moralizing and know when to refer to other health care specialists. If sexual rehabilitation is incorporated as a major component in the management of exenteration patients, resumption of sexual activity and satisfaction will be greatly increased postoperatively (McKenzie, 1988).

Summary

Pelvic exenteration is employed as a curative procedure in the treatment of recurrent carcinoma of the cervix. The medical and surgical aspects of this procedure has been well documented, but the postoperative sexual adjustment of these patients remains mainly ignored. The studies that have been done are with small sample sizes and a variety of vaginal reconstruction techniques are utilized. However, even with these limitations the studies show sexual adjustment to be a problem for these patients. Pelvic exenteration with myocutaneous gracilis vaginal reconstruction has been performed at a large southwestern cancer center since 1977, however, the sexual adjustment of these women has never been formally assessed. The focus of this study is to assess the sexual adjustment of women who have undergone this surgical procedure.

CHAPTER III

PROCEDURE FOR THE COLLECTION AND TREATMENT OF DATA

A nonexperimental descriptive research design was used to assess the sexual functioning of pelvic exenteration patients. Descriptive research aims to obtain accurate and meaningful descriptions of the phenomena under study (Abdellah & Levine, 1986). No attempt was made to control or manipulate the environment or to test interventions. A nonexperimental design was selected because there was no attempt made to manipulate the independent variable of sexual adjustment.

Setting

This study was conducted at a 500-bed comprehensive cancer center in a major medical center in the Southwestern United States. The questionnaires and the vaginal assessment forms were completed in the outpatient gynecology clinic. Approximately 70 patients were seen daily in the gynecology clinic. The gynecology clinic is staffed with 8 primary physicians, 6 fellows, 2 residents, and several medical students. There are 10 examinations rooms with 3 consultation rooms in the clinic.

Sample

The target population was patients who had undergone pelvic exenteration for treatment of a pelvic genital cancer. The sample was a convenience sample drawn from adult cancer patients who have undergone pelvic exenteration at a large cancer center where approximately 5 of these procedures are done each year. Two hundred ninety-six pelvic exenteration surgeries have been performed at the large southwestern cancer center since 1977. However, 161 of these patients have expired. Forty of the remaining 108 patients did not have vaginal reconstruction. Due to the size of the target population, 87 patients, a convenience sample was utilized. The convenience sample consisted of 40 patients that were entered in the study when they returned to the gynecology clinic for follow-up examinations.

Criteria for subject selection for the study included:

1. Be an adult female patient (18 years of age or older)
2. Be able to read and write English
3. Be willing to complete the questionnaire
4. Not be in the terminal stage of their disease process as documented in the medical record
5. Have a diagnosis of pelvic genital cancer
6. Have undergone pelvic exenteration with myocutaneous gracilis vaginal reconstruction

7. Surgery will have been performed at the large cancer center in the Southwest

There are three elements required to determine sample size: effect size, significance level, and desired power (Munro, Visintainer, & Page, 1986). The effect size indicates the strength of relationship between the independent and dependent variables. A medium effect size of 0.4 would indicate a moderate relationship between variables. The significance level will be 0.05 which determines the probability of making a Type I error. Power signifies the probability of correctly rejecting the null hypothesis. A power of .80 is the lowest acceptable power. Therefore, a sample size of at least 32 is needed for this study.

Protection of Human Subjects

Prior to the study, institutional review and approval for the use of human subjects was obtained. Patients were asked to fill out a questionnaire which asks about their general background, their dating or marriage relationship, and their sexual activity upon their regularly scheduled clinic visit. The patients were free to skip any question or to stop filling out the questionnaire at any time. The questionnaire was identified with the use of codes to protect subject privacy. Questionnaires were kept in a locked file cabinet. The investigator recorded information

about patients' disease and cancer treatments from their medical charts. Using the vaginal assessment form during the patients' routine gynecological exam, their physician also told the investigator and the patient whether the patients' vagina appeared healthy and of normal size.

This study was designed to discover how pelvic exenteration with vaginal reconstruction affects women's sexual relationships. In the future, the investigator may also be developing a program of counselling to help these patients maintain a satisfying sexual life. The information obtained from the questionnaire could be helpful in setting up such a program. The information obtained from the questionnaires may have benefited individual patients by increasing their awareness of their sexual concerns and allowing time by the investigator and the physician to address these concerns which might not be otherwise addressed. Also by participating in the study, individuals may have gained some satisfaction because they may be helping future pelvic exenteration patients maintain a satisfying sexual life.

Some of the questions may have been regarded as delicate. Other potential risks to the human subjects involved in this study included embarrassment about the topic of sexuality, embarrassment because participants did not understand a question, loss of confidentiality, and

improper release of data. The investigator had all participants sign a consent form highlighting the risks and benefits of the study (See Appendix D). The questionnaires were kept in a locked file cabinet. Only the research team connected with this research project was allowed to see the questionnaires as well as the vaginal assessment forms. The investigator also was available to answer any questions. Participants who chose not to participate in the study were informed that their cancer treatment and follow-up care would not be affected by this choice.

The participants of the study were also informed that if they should suffer any physical injury as a result of participation in this research activity that all of the necessary medical facilities are available for treatment, insofar as is reasonably possible. However, the study participants had explained to them that they could not expect to receive any payment for hospital expenses or any financial compensation for such injury.

Instruments

The instruments used for data collection were a modified version of the Sexual Adjustment Questionnaire (SAQ) developed by Waterhouse and Metcalfe (1986), and the vaginal assessment instrument developed by the investigator since no appropriate tool was found in the literature.

Permission was obtained by Waterhouse and Metcalfe to use and modify the instrument (See Appendix E).

Description of the SAQ

The Sexual Adjustment Questionnaire (SAQ) by Waterhouse and Metcalfe (1986) was developed to assess changes in sexual expression in the postoperative cancer patient. The questionnaire consists of 3 parts dealing with present sexuality and sexuality prior to diagnosis. Subsections of the SAQ test desire, activity level, relationship, arousal, satisfaction, techniques, and orgasm. The SAQ is a 16-page 108-item tool administered at 3 different points in time. Section A assesses sexual feelings 4 to 6 weeks after cancer treatment. Section B assesses sexual adjustment prior to the diagnosis of cancer. Section C assesses sexual feelings 16 to 20 weeks after cancer treatment. Questions on the 3 sections are very similar.

In addition to the subsections on the various components of sexual adjustment, each section of the SAQ contains several additional questions. These items ask whether the subject ever discusses sexual concerns with others, feelings about the effect of having cancer and having surgery on sexual relationships.

A background information sheet was also administered to collect demographic data such as age, race, sex, educational level, and general health. Questions on past and present

use of alcohol are also included because of the influence of alcohol use and abuse on sexual functioning. Information on the subject's medical diagnosis, surgical procedure, radiation therapy, and other pertinent information is recorded from the chart on a separate form.

Sexual adjustment was operationally defined as the patient's sexual feelings and functioning after treatment for cancer, relative to sexual feelings and functioning before the diagnosis of cancer. A high level of sexual adjustment exists when there is little change in sexual feelings and functioning between the pre-diagnosis and post-treatment periods, or when sexual feelings and functioning change in a positive direction (as defined by the patient or as indicated by score increments on the SAQ).

Content validity for the SAQ was established through a review panel of 6 experts in the fields of sexuality and head and neck cancer (Waterhouse & Metcalfe, 1986). Construct validity was established using a known groups technique by testing the SAQ on 84 healthy subjects and 8 subjects with head and neck cancer. Persons with cancer were found to have significantly ($p \leq .05$) lower scores on the subsections testing activity level, relationship, and techniques. Significant differences were in the predicted direction. Test-retest reliability was established for each

of the subsections of the SAQ. Values ranged from .5389 to .9374. The overall mean reliability was .6721.

Modified SAQ

The investigator modified the SAQ making the questions consistent with a true Likert-type scale so the items could be summated. The modified SAQ developed by the investigator consisted of 19 questions about sexual adjustment before pelvic exenteration surgery and the same 19 questions are repeated, to assess adjustment after pelvic exenteration. Patients were asked to respond to both sections after pelvic exenterative surgery. The responses were measured on a six-point Likert-type scale. The numerical values assigned for scoring were 6 - very often, 5 - often, 4 - sometimes, 3 - almost never, 2 - never, and 1 - no partner. The scores were summed to yield a total score for sexual adjustment before exenteration surgery and sexual adjustment after exenteration surgery.

Content validity of the modified SAQ was determined by a panel of experts which included the 8 gynecology staff physicians, 12 gynecology fellows and residents, and 2 nurses who are expert in the field of gynecology cancer. All agreed that the SAQ appeared to measure changes in sexual adjustment.

Cronbach's alpha was used to measure the internal consistency reliability of the SAQ. Internal consistency

measures the agreement of individual items with the total tool and results of .70 or greater are necessary to demonstrate good internal consistency of the tool (Roberts & Burke, 1989). In the pilot study of 10 cervical cancer patients, the total coefficient alpha level was .91.

Vaginal Assessment Tool

The vaginal assessment form to be filled out by the patient's physician was developed by the investigator since no instrument could be found in the literature. The instrument assesses the functional ability of the vagina. It is a 10-item tool which allows the physician to check items related to the neovagina. The items include health of the vaginal lining, the depth of the vagina, the condition of the skin flaps, the appearance of the thigh incisions, and the presence of edema. Based on the above assessment, the physician will then check whether or not the patient has a functional vagina. Interrater reliability of the items was established by the gynecology physicians having 2 physicians use the instrument on the same 10 patients. A high interrater reliability ($r=1.0$) was found on all the items except 2. Scores for these 2 items were .5 for vulva edema and .3 for thigh incisions. These 2 items, vulva edema present and noticeable thigh incisions, are subjective in nature and were compared with the patient's perceptions

during the study. Content validity was also established by the gynecology physicians.

Data Collection

Potential subjects for this study included all women who were treated with a pelvic exenteration and myocutaneous gracilis vaginal reconstruction for genital cancer at a large comprehensive cancer center. Approximately 40 patients were invited to participate in the study. Human subject criteria were met and agency approval was obtained. On the patient's next scheduled clinic visit potential study participants were asked to fill out the questionnaire by the investigator. The examining physician was asked to fill out the vaginal assessment form after the patient's pelvic examination.

Pilot study

A pilot study was completed with a sample of 10 patients with cervical cancer that had undergone radiotherapy for the treatment of the cancer. Due to the small sample of patients who have undergone pelvic exenteration which are available and the desire by the investigator not to eliminate any potential subjects from the dissertation sample, irradiated cervical cancer patients were used. The pilot included a nonexperimental, descriptive research design to survey irradiated cervical

cancer patients. Most women who have undergone pelvic exenteration also have a diagnosis of cervical cancer and have radiotherapy as part of the initial treatment. The pilot study sample, then, is similar in many of the characteristics to the dissertation sample.

The modified SAQ developed by the investigator consisted of 19 questions about sexual adjustment before radiotherapy and the same 19 questions were repeated, and the patient was asked to respond to both sections after radiotherapy. The responses were measured on a six-point Likert-type scale. The numerical values assigned for scoring were 6 - very often, 5 - often, 4 - sometimes, 3 - almost never, 2 - never, and 1 - no partner. Questions on sexual adjustment before irradiation were paired with the same questions on sexual adjustment after irradiation. The Wilcoxon Signed Rank test was used to examine the differences in the mean of the pre-irradiation and post-irradiation scores. The mean rank of the pre-irradiation score was 5.78 and the mean rank of post-irradiation score was 3.00, showing a significant difference at $p < .05$. This finding means that the sexual adjustment of women after radiation therapy is less than before the radiation therapy. In the pilot study, the coefficient alpha level for the SAQ was .91.

Treatment of Data

Descriptive statistics were used to summarize the data. These measures included percentages, frequency distributions, mean, and standard deviation. The internal consistency of the subscales was tested using the Cronbach's alpha statistic since all the items are supposed to measure the same concept, sexual adjustment.

The first research question, Is there a difference in level of sexual adjustment as measured by the SAQ of women who have undergone pelvic exenteration with vaginal reconstruction?, was examined using a Wilcoxon Signed Rank test. The Wilcoxon is a nonparametric test for two related samples, and may be used in either repeated measures or matched pairs designs. A high level of sexual adjustment existed when there was little change in sexual functioning between the pre-exenteration and post-exenteration periods, or when sexual functioning changes in a positive direction as indicated by score increments on the SAQ. The second research question, Is there a relationship between sexual adjustment of women and the length of time since pelvic exenteration and vaginal reconstruction?, was examined using a Spearman rho. In order to examine the third research question: Do women have anatomically functional vaginas?, the data were summarized using descriptive statistics.

CHAPTER IV

ANALYSIS OF DATA

In order to assess the impact of pelvic exenteration and vaginal reconstruction on the sexual adjustment of women, 44 subjects were asked to respond to a modified version of the Sexual Adjustment Questionnaire (SAQ). Additionally, a vaginal assessment of the participant's reconstructed vagina was completed by their physician.

This chapter reviews all the findings of the study and is divided into three major sections: description of sample, findings, and summary of findings. In the description of the sample, the demographic data form, the background information section of the SAQ, and the vaginal assessment tool are summarized using descriptive statistics. The findings of the study are presented for each of the three research questions. The summary of findings is a condensed review of all the findings of the study.

Description of Sample

The sample consisted of 40 pelvic exenteration patients who were being followed in the gynecology clinic. Forty-four demographic data forms and vaginal assessment tools were completed. However, only 40 SAQ's were completed. Two of the patients were unable to complete the questionnaire because of their inability to understand the questionnaire.

The other 2 questionnaires were so incomplete that they had to be discarded.

Demographic Data Form

Of the 44 patients, 31 (70.4%) patients were Caucasian, 8 (18.1%) were Hispanic, and 5 (11.3%) were Black. The age of the patients ranged from 30 to 79 years of age with a mean of 55.6 years (S.D. 13.3). Thirty-eight patients (86%) had a diagnosis of cervical cancer, 3 patients (6.8%) with rectal cancer, 1 patient (2.2%) with vaginal cancer, 1 patient (2.2%) with colon cancer, and 1 patient (2.2%) with cloacogenic cancer. Forty-three patients (98%) had received previous radiotherapy with only 1 patient (2%) not receiving previous radiotherapy. Years since pelvic exenteration surgery ranged from 1 to 14 years with a mean of 6 years (S.D. 4.1). Thirty-four patients (77.2%) underwent a total pelvic exenteration with 6 patients (13.6%) undergoing anterior pelvic exenteration and 4 patients (9%) undergoing posterior pelvic exenteration procedures. Nineteen patients (43%) had flap complications documented in the medical record with 25 patients (56.8%) that did not have complications documented. Necrosis and prolapse were the most common complication documented with 8 (18%) patients each (See Table 1).

Table 1
Postoperative Flap Complications of Women
Undergoing Pelvic Exenteration
(N = 44)

Complication	Frequency	%
Infection	1	2.2%
Necrosis	8	18.0%
Prolapse	8	18.0%
Other	2	5.0%
No Complication	<u>25</u>	<u>56.8%</u>
	44	100.0%

Background Information from SAQ

The background information from the SAQ was obtained for 40 patients. Twenty-six of the patients (65%) were married at the time of surgery with 19 patients (47.5%) presently married (See Table 2). Twenty-eight patients (70%) were not employed outside the home with 12 patients (30%) employed outside the home. The most common occupation for the patients was homemaker with 14 patients (35%) listing it as their occupation (See Table 3). Seventeen patients (42.5%) had completed less than a high school diploma while 12 patients (30%) completed high school and 11 patients (27.5%) had completed one or more years of college. Twenty-six patients (65%) did not have any medical problems

other than the pelvic cancer. Fourteen patients (35%) did have medical problems with hypertension being the most common, representing 42.8%. Twelve (85%) of the patients were taking medications for these problems. Thirty-one patients (77.5%) do not drink alcohol. However, of those patients that do drink, 6 patients (46%) listed beer as the most common alcoholic beverage. Five patients (45.4%) reported that they drink occasionally with 4 patients (36.3%) stating they drink socially. Seven patients (87.5%) had been drinking for 5 or more years.

Table 2

Presurgical and Present Marital Status
of Women Following Pelvic Exenteration

(N = 40)

Marital Status	Presurgical Frequency	%	Present Frequency	%
Single	1	2.5%	1	2.5%
Married	26	65.0%	19	47.5%
Widowed	4	10.0%	9	22.5%
Divorced	8	20.0%	9	22.5%
Separated	0	0.0%	1	2.5%
Living with Partner	1	2.5%	1	2.5%
	40	100.0%	40	100.0%

Table 3
Occupations of Women Undergoing
Pelvic Exenteration

(N = 40)

Occupation	Frequency	%
Professional	5	12.5%
Teacher	1	2.5%
Civil Service	1	2.5%
Micrographics	1	2.5%
Texas Instruments	1	2.5%
Computer Operator	1	2.5%
Clerical, Sales, Technical	14	35.0%
Store Clerk	3	7.5%
Bookkeeper	3	7.5%
Office Work	3	7.5%
Hospital Aide	1	2.5%
Apartment Locator	1	2.5%
Elevator Operator	1	2.5%
Factory Worker	1	2.5%
Cook	1	2.5%
Unskilled, Manual Labor	2	5.0%
Barmaid	1	2.5%
Waitress	1	2.5%
Homemaker	14	35.0%
Other	3	7.5%
No Comment	2	5.0%
	40	100.0%

Twenty-one patients (52.5%) stated that they did not resume sexual activities after surgery while 19 patients (47.5%) reported resuming sexual activity following 1½ months to 12 years post surgery. Of the patients who resumed sexual activity, most (16, 84%) had done so within 1 year (See Table 4).

Table 4
Time After Surgery Before
Sexual Activity Resumed
 (N = 40)

Time	Frequency	%
3 months or less	5	12.5%
4-6 months	8	20.0%
7-9 months	1	2.5%
10-12 months	2	5.0%
24 months	1	2.5%
144 months	1	2.5%
Resumption but no time	1	2.5%
No resumption	<u>21</u>	<u>52.5%</u>
	40	100.0%

The most common problems adjusting to sexual activity after surgery were feeling self-conscious about urostomy appliance and self-conscious about colostomy appliance. Sixteen patients (40%) rated each of these as being a problem of adjustment (See Table 5). These problems were followed by concern of being seen nude by partner (12, 30%), vaginal dryness and vaginal discharge were also common concerns (11, 27.5%). Fifteen patients (37.5%) had problems with thigh incisions. Of the 15 patients, 9 patients (60%) had difficulty walking, 5 patients (33.3%) had difficulty sitting, 3 patients (20%) reported swelling of the thigh incisions, and 1 patient (6.6%) reported tingling of thigh incisions.

Table 5
Problems Adjusting to Sexual Activity
After Surgery
(N = 40)

Complaint	Frequency	%
Vagina too dry	11	27.5%
Vagina too dry with lubricant	2	5.0%
Pain	7	17.5%
Vaginal discharge	11	27.5%
No pleasure when genitals touched	8	20.0%
No pleasure from penetration	7	17.5%
Sensations inside vagina as if thighs were touched	3	7.5%
Self-conscious about urostomy	16	40.0%
Self-conscious about colostomy	16	40.0%
Self-conscious about partner seeing me nude	12	30.0%
Vagina too small	8	20.0%
Vagina too large	2	5.0%
Self-conscious about thigh incisions	5	12.5%

When asked the question, if you had the chance to do it over again, would you have your vagina reconstructed as part of the surgery?, 27 patients (67.5%) said yes, 2 patients (5%) said no, and 11 patients (27.5%) were not sure.

Regarding the question, were you satisfied with the amount of information you received about emotional and sexual reactions to the surgery?, 33 patients (82.5%) said yes, and 7 patients (17.5%) said no. Comments about the most important thing health care team told patient included: "going to make some holes with bags," "body not the same but I would be same person," "I could have sex, just as before,"

"don't let your stomas rule your life," "told me what to expect," "normal person after surgery," "be brave," "exercise and how to care for stomas," and "time to get used to the idea." Meeting another patient that had already undergone the surgery also was cited as helpful to patients. Comments about dissatisfaction with information received from health care team included: "too much information too soon," "more information about possible complications," "feelings about after exenteration weren't discussed," and "physician said vagina was adequate for intercourse but it's never been satisfactory."

Findings

To analyze the research question, is there a difference in level of sexual adjustment as measured by the SAQ of women before and after pelvic exenteration with vaginal reconstruction?, the Wilcoxon Signed Rank test was used to examine the difference in the mean ranks of the pre-exenteration and post-exenteration scores. The mean rank of pre-exenteration score was 66.4 and the mean rank of post-exenteration score was 48.7, showing a significant difference at $p < .0001$ between the pre- and post-exenteration scores. This finding means that the sexual adjustment of women following pelvic exenteration is less than before the surgery.

Because 9 women no longer had sexual partners at the time of post testing, a Wilcoxon Signed Rank test was also completed eliminating those 9 women from the group. The mean rank pretest score for the remaining women ($n=31$) with partners was 72.6 and post test mean rank score was 57.3. This difference was significant at $p<.0001$, indicating women with sexual partners had lower levels of sexual adjustment following pelvic exenteration with vaginal reconstruction.

To analyze the research question, is there a relationship between sexual adjustment of women and the length of time since pelvic exenteration with vaginal reconstruction, the Spearman rho was performed to examine the influence of time. Two sets of ranks, the years since exenteration surgery and the post-exenteration scores were compared using the Spearman rho formula. The Spearman rho coefficient was $r=-.03$, which demonstrated no significant relationship between length of time following exenteration and sexual adjustment with $p=.84$. A summary of the Spearman rho results is presented in Table 6.

Because 9 women no longer had sexual partners at the time of post testing, a Spearman rho was also completed eliminating those 9 women from the group. The Spearman rho coefficient was $r=-.13$, showing no relationship between length of time following exenteration and sexual adjustment for women with sexual partners with $p=.46$.

Table 6

Spearman Rho Correlation on the Effects of Time on Sexual Adjustment Following Pelvic Exenteration (N=40)	
r Value	Level of Significance
-.03148	.84708

To analyze the research question, do women have anatomically functional vaginas?, the data were summarized using descriptive statistics. Forty-four vaginal assessments were completed. Thirty-four (77%) patients had bilateral flaps and 10 patients (23%) had unilateral flaps. Failure of the myocutaneous gracilis flap to take is defined as flap loss. Thirty-five patients (79.5%) had no flap loss while 6 patients (13.6%) had partial flap loss, and 3 patients (6.8%) had total flap loss. Thirty of the patients (68.1%) had no prolapse of the flaps, 9 patients (20.4%) had mild prolapse, 5 patients (11.3%) had moderate prolapse, with no patients having severe prolapse. Thirty-four patients (77.2%) had no granulation tissue associated with the flaps, 7 patients (15.9%) had mild granulation tissue present, 2 patients (4.5%) had moderate granulation tissue, no patients had severe granulation tissue. For one patient (2.2%), the response was missing. Forty-three patients (97.7%) had not had a flap revision while 1 patient (2.2%)

had a flap revision. Eight patients (18.1%) did not have noticeable thigh incisions, 17 patients (38.6%) had mildly noticeable thigh incisions, 10 patients (22.7%) had moderately noticeable thigh incisions, and 7 patients (15.9%) had very noticeable thigh incisions. For 2 patients (4.5%), the response was missing. Thirty-eight patients (86.3%) did not have contractures of thigh incisions, while 5 patients (83.3%) had mild contractures and 1 patient (16.6%) had a severe contracture with no patients having moderate contractures of the thigh incisions.

Forty patients (90.9%) did not have any vulvar edema present. Three patients (6.8%) patients did have vulvar edema present but it was mild in all 3 of the patients. For 1 patient (2.2%), the response was missing. Thirty-two of the patients (72.7%) had the flaps positioned vaginally and 8 patients (18.1%), the flaps were positioned posteriorly. Four patients (9.0%), the response was missing. Thirty patients (68.1%) the depth of the neovagina was appropriate and 14 patients (31.8%) the depth of the neovagina was too short. Based upon the vaginal assessment tool, the physicians reported 31 patients (70.4%) with functional vaginas and 13 patients (29.5%) with nonfunctional vaginas.

Other Findings

Cronbach's alpha was used to measure the internal consistency reliability of the SAQ. In the study of 40 pelvic exenteration patients, the total coefficient alpha level was .72, demonstrating good internal consistency of the SAQ with this sample of women.

Summary of Findings

To assess the impact of pelvic exenteration with vaginal reconstruction, 44 subjects were asked to respond to a modified version of the sexual adjustment questionnaire (SAQ). Of the 44 patients, 31 patients (70.4%) were Caucasian, 8 (18.1%) were Hispanic, and 5 (11.3%) were Black. The age of the patients ranged from 30 to 79 years of age with a mean of 55.6 years (S.D. 13.3). Thirty-eight patients (86%) had a diagnosis of cervical cancer. Years since pelvic exenteration surgery ranged from 1 to 14 years with a mean of 6 years (S.D. 4.1). Twenty-one patients (52.5%) stated that they did not resume sexual activities after surgery while 19 patients (47.5%) reported resuming sexual activity following 1½ months to 12 years post surgery. Of the patients who resumed sexual activity, most (16, 84%) had done so within 1 year.

To analyze the research question, is there a difference in level of sexual adjustment as measured by the SAQ of

women before and after pelvic exenteration with vaginal reconstruction?, the Wilcoxon Signed Rank test was used to total the ranks of the pre-exenteration and post-exenteration scores. The difference was significant at $p \leq .0001$ indicating women had lower levels of sexual adjustment following pelvic exenteration with vaginal reconstruction.

To analyze the research question, is there a relationship between sexual adjustment of women and the length of time since pelvic exenteration with vaginal reconstruction, the Spearman rho was performed to examine the influence of time. No relationship between length of time following pelvic exenteration and sexual adjustment was found.

To analyze the research question, do women have anatomically functional vaginas?, the data were summarized using descriptive statistics. The physicians reported 31 patients (70.4%) with functional vaginas and 13 patients (29.5%) with nonfunctional vaginas.

CHAPTER V

SUMMARY OF THE STUDY

Recurrent cervical cancer may be treated by pelvic exenteration with myocutaneous gracilis vaginal reconstruction. There are no anatomical restrictions for sexual activity associated with the vaginal reconstruction, psychological adjustments for recovery from the exenteration may require personal adjustment. Although the surgery has been performed at a 500-bed southwestern cancer center since 1977, the degree of sexual adjustment after pelvic exenteration, with myocutaneous gracilis reconstruction is unknown. This study assessed the sexual adjustment of women who had undergone pelvic exenteration to determine if there was a difference in level of sexual adjustment before and after this surgery as indicated by the sexual adjustment questionnaire (SAQ)?

Summary

Pelvic exenteration with vaginal reconstruction impacts sexuality. The purpose of the study was to assess the sexual adjustment of women undergoing pelvic exenteration at a 500-bed southwestern cancer center using a modified version of the SAQ. Forty-four patients were asked to participate in the study. On the patient's scheduled clinic visit, they were asked to fill out the questionnaire. At

the same time, the physician was asked to fill out the vaginal assessment form.

To address the research question: Is there a difference in level of sexual adjustment as measured by the SAQ?, the Wilcoxon Signed Rank test totalled the scores from the mean ranks of the pre-exenteration and post-exenteration scores. For the second research question: Is there a relationship between sexual adjustment of women and the length of time since surgery, a Spearman rho was performed to examine the influence of time. For the third research question: Do women have anatomically functional vaginas?, the data were summarized using descriptive statistics.

This chapter contains an interpretation of the findings as they relate to the research questions. Demographic information are discussed first, followed by a discussion of research findings. Conclusions, implications, and recommendations for further study are made.

Discussion of Findings

With the present study, the mean age of patients was 55.6 years (S.D. 13.3) with a range of 30 to 79 years. Pelvic exenteration was performed for recurrent cervical carcinoma in 38 patients (86%). All patients but one had received prior pelvic radiation. Years since pelvic exenteration surgery ranged from 1 to 14 years with a mean

of 6 years (S.D. 4.1). Thirty-four patients (77.2%) underwent a total pelvic exenteration with 6 patients (13.6%) undergoing anterior pelvic exenteration and 4 patients (9%) undergoing posterior pelvic exenteration procedures. Thirty-four (77%) had bilateral flaps and 10 (23%) had unilateral flaps. Thirty of the patients (68.1%) had no prolapse of the flaps according to the vaginal assessment tool, 9 (20.4%) had mild prolapse, 5 (11.3%) had moderate prolapse with no patients having severe prolapse. Only 8 patients (18%) had documented prolapse in the medical record. Eight patients (18%) experienced necrosis of the flaps.

In some aspects, Copeland et al. (1989) findings from a retrospective chart review of 107 patients who underwent vaginal reconstruction from 1977 to 1987 comparing operative morbidity conducted at the same southwestern cancer center were similar to those of this study although a higher percentage of patients (104; 97%) had bilateral flaps. The ages of patients undergoing pelvic exenteration ranging from 28 to 77 was similar. Another similarity in the studies is the reason for exenteration. Pelvic exenteration was performed for recurrent cervical carcinoma in 127 of the patients (84.1%) and 150 patients (99.3%) had received prior pelvic radiation except 1 (0.6%). Fewer patients in the current study experienced prolapse (8; 18%) compared to the

46 (45%) who experienced prolapse of the neovagina with 34 patients (33%) having some prolapse and 12 patients (12%) having severe prolapse. Also fewer patients experienced flap necrosis (8; 18%) compared with Copeland's study where 50 patients (49%) experienced necrosis of the flaps with 33 patients (32%) having some necrosis and 17 patients (17%) having severe necrosis.

McGraw et al. (1976) reported the results of 22 patients that underwent pelvic exenteration with myocutaneous vaginal reconstruction. Unlike the present study, no cases of prolapse were reported. Six patients (27%) had partial necrosis of the flaps with 1 patient (4.5%) having severe necrosis compared to the present study where 8 patients (18%) experienced flap necrosis.

In the present study of 40 patients, 21 patients (52.5%) stated that they did not resume sexual activities after surgery while 19 patients (47.5%) reported resuming sexual activity following 1½ months to 2 years post surgery. Nine of the 21 patients (42.8%) reported no sexual partner as a reason for not resuming sexual activity. Berek, Hacker, and Lagasse (1984) found that among 21 patients undergoing reconstruction 10 (48%) were sexually active compared to 11 (52%) who only had intercourse rarely or not at all which is similar to the present study.

Of the patients in this study who resumed sexual activity, most (16, 84%) had done so within 1 year. Gloeckner (1991) found that the major adjustment period for patients with ostomies was the first year after surgery. Twenty-four subjects (60%) showed a decrease in feelings of sexual attractiveness from before surgery to the year following ostomy surgery. Gloeckner and Starling's (1982) findings were in agreement with Dlin and Perlman (1971) who stated that body image disturbance is worst during the first year of surgery. The present study supports these studies.

To analyze the research question, is there a difference in level of sexual adjustment as measured by the SAQ of women before and after pelvic exenteration with vaginal reconstruction?, the Wilcoxon Signed Rank test was used to examine the difference in mean ranks of the pre-exenteration and post-exenteration scores. The mean rank of the pre-exenteration score was 66.4 and the mean rank of post-exenteration score was 48.7 showing a significant difference at $p < .0001$ between the pre- and post-exenteration scores. This finding means that the sexual adjustment of women following pelvic exenteration is less than before the surgery.

Lamont et al. (1978) examined the psychosexual rehabilitation of 12 exenterative patients that underwent vaginal reconstruction. Patients were interviewed by a

sexual counselor preoperatively and postoperatively for sexual attitudes and adjustments. Eight women (66.6%) were found to have good sexual adjustment preoperatively with 7 (87.5%) of these patients having good postoperative sexual adjustment. The patients in the present study received no formalized counselling concerning sexual attitudes and adjustments related to the surgical procedure. Bullard et al. (1980) found that 63% of the 26 patients they surveyed would have liked more information about sexual functioning after treatment and that 64% would participate in a specific counselling program. Capone et al. (1980) studied the effectiveness of individual counselling on the psychosocial adjustment of 41 patients with gynecologic malignancies. For patients who received brief psychosexual counselling interventions, sexual functioning was twice the rate of return to pre-disease frequency of intercourse in comparison to untreated control patients. These studies suggest that interventions are necessary and that it can enhance the postsurgery sexual adjustment outcomes. In the present study, a formal counselling program might help to better prepare the patients for the surgical procedure.

To analyze the research question, is there a relationship between sexual adjustment of women and the length of time since pelvic exenteration with vaginal reconstruction, the Spearman rho was performed to examine

the influence of time. There is no relationship between length of time following exenteration and sexual adjustment. However, if women had not resumed sexual relationships by one year, it was unlikely that they would do so (See Table 4).

Brown, Haddox, Posada, and Rubio (1972) interviewed 15 patients to evaluate sexual adjustment after pelvic exenteration. Seventy-three percent indicated no present sexual interest. The authors made no reference to vaginal reconstruction and no questions about sexual activity were asked. Time since exenteration surgery was not mentioned.

Lamont et al. (1978) examined the psychosexual rehabilitation of 12 exenterative patients that underwent vaginal reconstruction of multiple types but not using the gracilis myocutaneous reconstruction. According to a sexual counselor, 8 (66.6%) women were found to have good sexual adjustment preoperatively with 7 (87.5%) of the patients having a good postoperative sexual adjustment. They also found that 6 to 9 months after surgery when patients begin to hope for complete rehabilitation, the importance of sexual functioning increased.

There were no studies that address the relationship between length of time following exenteration and sexual adjustment except for the present study. A formal sexual counselling program preoperatively, during hospitalization,

and postoperatively might enhance sexual rehabilitation which then could have an effect between length of time following exenteration and sexual adjustment. However, further research would be needed to support this assumption.

To analyze the research question, do women have anatomically functional vaginas?, the data were summarized using descriptive statistics. Based upon the vaginal assessment tool, the physicians reported 31 patients (70.4%) with functional vaginas and 13 patients (29.5%) with nonfunctional vaginas. Thirty patients (68.1%) the depth of the neovagina was appropriate and 14 patients (31.8%) the depth of the neovagina was too short.

Berek, Hacker, and Lagasse (1984) examined 21 patients and found that 5 patients (24%) noted that the vaginal dimensions were unsatisfactory (4 too large, 1 too small). Andersen and Hacker (1983) interviewed 15 pelvic exenteration patients to assess sexual functioning. For the 4 (26.6%) satisfied sexually active women, the surgical reconstruction of the vagina had gone well and they were able to maintain satisfactory sexual activity. For the 3 dissatisfied patients (20.0%), problems with arousal or with the neovaginas affected sexual adjustment. Thirteen patients (29.5%) in the study had nonfunctional vaginas and with 14 patients (31.8%) the depth of the neovagina was too short.

Conclusions and Implications

Based on data collected from 40 women regarding sexual adjustment following pelvic exenteration with myocutaneous vaginal reconstruction, the following conclusions were derived:

1. Women who undergo pelvic exenteration with vaginal reconstruction experience a decrease in sexual adjustment.
2. Time following pelvic exenteration does not influence resumption of sexual activity. Descriptive statistics suggest that if women had not resumed sexual relationships by one year it was unlikely that they would do so.
3. Thirty-one patients (70.4%) had anatomical functional vaginas capable of penetration.
4. Vaginal dryness and vaginal drainage were identified as problems affecting sexual adjustment.
5. Feelings of self-consciousness including ostomy and nudity were identified as affecting sexual adjustment.
6. Anatomical problems with the neovaginas were minimal.

Based on these conclusions, the following implications are derived:

1. It is important that nurses take an active role in offering pelvic exenteration patients information about

how this surgical procedure will affect their sexuality and sexual functioning.

2. Nurses should be able to suggest specific interventions i.e. vaginal lubrication, cleansing douches for vaginal discharge, etc. for patients who have undergone pelvic exenteration to maintain sexual function.
3. Strategies should be developed to enhance sexual rehabilitation in the pelvic exenteration patient through a formalized structured counselling program.
4. Nurses should identify structural and functional changes that can be expected after pelvic exenteration surgery and educate the patient on what she can do to manage or cope with these changes.
5. Nurses should preoperatively perform a sexual assessment on these patients which is continued during the hospitalization as well as during the postoperative period after discharge.

Recommendations for Further Study

Additional research in the area of sexual adjustment after pelvic exenteration is needed.

1. A prospective research study administering the Sexual Adjustment Questionnaire (SAQ) prior to undergoing the surgery and then one year after the surgery should be

undertaken to eliminate relying on the patient's memory about presurgery sexual adjustment.

2. An additional study could examine the spouse's or partner's assessment of sexual adjustment. By administering the SAQ to patients and their partners, the results of the two groups could then be compared to see if the perceptions of sexual adjustment differed.
3. The effectiveness of nursing interventions i.e. educating the patient about the physical differences in the neovagina (need for lubrication during sexual intercourse, importance of douching, etc.) from the patient's vagina, identifying ways to promote a positive body image (wearing pouch cover over ostomy, crotchless panties, etc.) to promote sexual adjustment could be evaluated.
4. Additional research should be conducted to identify problems these patients are having with sexual adjustment with identification of appropriate interventions.
5. Other factors such as previous sexual problems that influence sexual adjustment should be studied by a sexual therapist.

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APPENDIX A

Sexual Adjustment Questionnaire

SEXUAL ADJUSTMENT QUESTIONNAIRE

In this study we are interested in all aspects of your sexual thoughts, feelings and activities. We know this is a very sensitive area, but we will not be making any judgment about your sexual expression. We hope you will be as honest as you can be in answering the questions so that we will be able to help future cancer patients as they deal with their illness and surgery.

You will probably be more comfortable completing the questionnaire in private. Please read each question carefully. Circle or check the word which best describes your thoughts, feelings, and/or experiences. Space has been left after each question for you to write comments, clarifications, or explanations if you wish.

For the purposes of this questionnaire:

Sexual activity means anything you do related to sex. This activity can include but is not limited to, intercourse, kissing, caressing, masturbation, sexual fantasies, oral sex, etc. These activities may happen alone, between people of the same sex, or between people of opposite sexes. Sexual relationship(s) means any physical and/or emotional sexual association between two persons that has developed over a period of time.

Code number _____

SEXUAL ADJUSTMENT QUESTIONNAIRE

I. Background Information

Please fill in the information requested below as completely as you can. This background information will help us to understand the results of our study. Please check or fill in the appropriate responses.

1. Marital Status at time of pelvic exenteration:

Single _____
Married _____
Widowed _____
Divorced _____
Separated _____
Living with Partner _____

2. Present marital status:

Single _____
Married _____
Widowed _____
Divorced _____
Separated _____
Living with Partner _____

3. Are you working now?

Yes _____
No _____

4. What is/was your occupation (job)?

5. What is your highest degree or last grade completed in school?

6. Do you have any health problems or conditions other than cancer at the present time (including any surgeries)?

Yes ____ (please explain) _____
No ____

7. If so, are you taking any medications or undergoing any treatment for this/these problem(s) or condition(s)?

8. Do you drink alcohol? Yes ____ No ____

9. What kind of alcohol do you drink most often?

Beer ____ Wine ____ Hard liquor ____

10. How much do you drink per day? ____

11. For how many years? ____

12. How soon after surgery did you resume sexual activity?

13. Some women have problems adjusting to sex after surgery, for each problem below, check the ones that apply to you:

Vagina feels too dry during intercourse ____

Vagina feels too dry during intercourse with
lubricant ____

Pain during intercourse ____

Unpleasant vaginal discharge ____

No longer feel pleasure when outside genital area is
touched ____

No longer feel pleasure when penis strokes inside of
vagina ____

Feel strange sensations inside of vagina, as if inner
thighs were being touched ____

Feel self-conscious about urinary ostomy
appliance _____
Feel self-conscious about colostomy appliance _____
Feel shy about my partner seeing me nude _____
Vagina feels too small for intercourse _____
Vagina feels too large or loose during
intercourse _____
Feel self-conscious about thigh incisions during
sex _____

14. Have you had any problems with your thigh incisions?

Difficulty walking _____
Difficulty sitting _____
Swelling of incisions _____
Other problems _____

15. If you had the chance to do it all over again, would you have your
vagina reconstructed as part of the exenteration surgery?

Yes _____
No _____
Not sure _____

16. Were you satisfied with the amount of information you received from
the health care team about emotional and sexual reactions to
exenterations?

Yes _____
No _____

If no, please comment:

17. What was the most important thing that the health care team told you?

II. Before Treatment

Circle the word(s) which best describe(s) your thoughts, feelings, and/or experiences before you found out you had cancer.

1. In the six months before you found out you had cancer, how often was sexual activity enjoyable?

very often often sometimes almost never never no partner

2. Were you too tired for sexual activity?

very often often sometimes almost never never no partner

3. Did you have desire for sexual activity?

very often often sometimes almost never never no partner

4. Did you desire sexual activity more often than your partner(s)?

very often often sometimes almost never never no partner

5. Did you and your partner(s) talk about your sexual relationship?

very often often sometimes almost never never no partner

6. Were you the one to initiate (start) sexual activity with your partner(s)?

very often often sometimes almost never never no partner

7. Did you have trouble becoming sexually aroused or excited?

very often often sometimes almost never never no partner

8. Did you notice dryness of your vagina during intercourse?

very often often sometimes almost never never no partner

9. Did you notice any pain or discomfort during sexual intercourse?

very often often sometimes almost never never no partner

10. Were you able to reach a climax (come) during sexual activity?
very often often sometimes almost never never no partner
11. Did you spend time being held, touched, and caressed by your partner?
very often often sometimes almost never never no partner
12. Did you spend time holding, touching, and caressing your partner?
very often often sometimes almost never never no partner
13. Did you kiss your partner(s) mouth using your tongue (French kiss)?
very often often sometimes almost never never no partner
14. Did you have intercourse facing your partner (man on top or woman on top)?
very often often sometimes almost never never no partner
15. Did you have intercourse with your partner positioned behind you?
very often often sometimes almost never never no partner
16. Did you use your mouth and/or tongue to stimulate your partner's genitals and/or other body parts?
very often often sometimes almost never never no partner
17. Did you masturbate to reduce sexual tensions?
very often often sometimes almost never never no partner
18. Did you feel satisfied after sexual activity?
very often often sometimes almost never never no partner
19. Did you feel tense or frustrated after a sexual experience?
very often often sometimes almost never never no partner

II. After Treatment

Circle the word(s) which best describe(s) your thoughts, feelings, and/or experiences presently.

1. Do you enjoy sexual activity?

very often often sometimes almost never never no partner

2. Do you find that you are too tired for sexual activity?

very often often sometimes almost never never no partner

3. Do you have desire for sexual activity?

very often often sometimes almost never never no partner

4. Do you desire sexual activity more often than your partner(s)?

very often often sometimes almost never never no partner

5. Do you and your partner(s) talk about your sexual relationship?

very often often sometimes almost never never no partner

6. Have you been the one to initiate (start) sexual activity with your partner(s)?

very often often sometimes almost never never no partner

7. Do you now have trouble becoming sexually aroused or excited?

very often often sometimes almost never never no partner

8. Do you notice dryness of your vagina during sexual intercourse?

very often often sometimes almost never never no partner

9. Do you notice any pain or discomfort during sexual intercourse?

very often often sometimes almost never never no partner

10. Are you able to reach a climax (come) during sexual activity?
very often often sometimes almost never never no partner
11. Do you spend time being held, touched, and caressed by your partner?
very often often sometimes almost never never no partner
12. Do you spend time holding, touching, and caressing your partner?
very often often sometimes almost never never no partner
13. Do you kiss your partner(s) mouth using your tongue (French kiss)?
very often often sometimes almost never never no partner
14. Do you have intercourse facing your partner (man on top or woman on top)?
very often often sometimes almost never never no partner
15. Do you have intercourse with your partner positioned behind you?
very often often sometimes almost never never no partner
16. Do you use your mouth and/or tongue to stimulate your partner's genitals and/or other body parts?
very often often sometimes almost never never no partner
17. How often do you masturbate to reduce sexual tensions?
very often often sometimes almost never never no partner
18. Do you feel satisfied after sexual activity?
very often often sometimes almost never never no partner
19. Do you feel tense or frustrated after a sexual experience?
very often often sometimes almost never never no partner

20. Has having cancer changed your sexual relationships with your partner(s)?

very often often sometimes almost never never no partner

21. Has having surgery changed your sexual relationships with your partner(s)?

very often often sometimes almost never never no partner

APPENDIX B

Vaginal Assessment Form

Code Number _____

(PHYSICIAN'S)

VAGINAL RECONSTRUCTION ASSESSMENT FORM

Please check the appropriate response.

- | | |
|--------------------------|------------------------|
| 1. Flaps | 2. Flap Loss |
| Unilateral _____ | None _____ |
| Bilateral _____ | Partial _____ |
| | Total _____ |
| 3. Prolapse | 4. Granulation Tissue |
| None _____ | None _____ |
| Mild _____ | Mild _____ |
| Moderate _____ | Moderate _____ |
| Severe _____ | Severe _____ |
| 5. Revisions of Flap | 6. Thigh Incisions |
| No _____ | Noticeable? |
| Yes _____ | No _____ |
| If yes, why _____ | Mildly _____ |
| | Moderately _____ |
| 7. Contractures of Thigh | Very Noticeable _____ |
| Incision Scars | |
| No _____ | 8. Vulva Edema Present |
| Yes _____ | No _____ |
| If yes, Mild _____ | Yes _____ |
| Moderate _____ | If yes, Mild _____ |
| Severe _____ | Moderate _____ |
| | Severe _____ |
| 9. Position of Flaps on | 10. Depth of Neovagina |
| Perineum | Appropriate _____ |
| Posterior _____ | Too long _____ |
| Positioned _____ | Too short _____ |
| Vaginally _____ | |

Based on above assessment, the vagina is functional

No _____
Yes _____

APPENDIX C
Demographic Data Form

Demographic Data Form

1. Birthdate _____
2. Race _____
3. Type of Cancer _____
4. Previous Radiotherapy
Yes _____
No _____
5. Date of Pelvic Exenteration _____
6. Type of Pelvic Exenteration _____
7. Any complications related to flaps documented in the chart
Yes _____
No _____
If yes, type of complication
Infection _____
Necrosis _____
Prolapse _____
Other _____

APPENDIX D
Consent Form

THE UNIVERSITY OF TEXAS
M.D. ANDERSON CANCER CENTER
Division of Nursing

INFORMED CONSENT

Project Title: "Sexual Adjustment of Women Undergoing Pelvic
Exenteration with Vaginal Reconstruction"

1.

Participant's Name	Study Code Number

You have the right to know about the procedures that are to be used in your participation in clinical research so as to afford you an opportunity to make the decision whether or not to undergo the procedure after knowing the risks and hazards involved. This disclosure is not meant to frighten or alarm you; it is simply an effort to make you better informed so you may give or withhold your consent to participate in clinical research. This informed consent does not supersede other informed consents you may have signed.

Description of Research

2. Purpose of Study: This research is designed to find out how pelvic exenteration with vaginal reconstruction affects a woman's sexual and marital relationships. We are also developing a program of counseling to help these patients maintain a satisfying sexual life. The information obtained from the questionnaire may be helpful in setting up such a program.
3. Description of Research: You will be asked to fill out a brief questionnaire requiring about ten minutes to complete. The questionnaire asks about your general background, your marriage or dating relationship, and your sexual function. You are free to skip any question or stop filling out the questionnaire at any time. The questionnaire will be identified with the use of codes to protect your privacy. The questionnaires will be kept in a locked file cabinet. Only the staff connected with this research project will be allowed to see them. Forty participants will be given questionnaires.

The investigator will record information about your medical history and cancer treatment from your M.D. Anderson medical chart. When you have your routine gynecological exam, your physician will also tell the investigator whether your vagina appears healthy and of normal size.

4. Risks, Side Effects, and Discomforts to Participants: Some of the questions may be regarded as delicate. Potential risks to you while involved in this study include being uncomfortable about the topic of sexuality and embarrassment because you do not understand the questions.
5. Potential Benefits: The information we learn from you may aid us in counseling future pelvic exenteration patients.
6. Alternate Procedures or Treatments: You may choose not to participate in this study. Your cancer treatment will not be affected by this choice.

Understanding of Participants

7. I have been given an opportunity to ask any questions concerning the survey involved and the investigator has been willing to reply to my inquiries. This survey will be administered under the above numbered, titled, and described clinical research protocol at this institution. I hereby authorize Catherine Ratliff, R.N., the investigator and/or the investigator she may designate to administer the survey.
8. I have been told and understand that my participation is voluntary and that I am able to withdraw my consent and to stop my participation will involve no penalty or loss of benefits to which I may otherwise be entitled and shall be without prejudice.

Should I elect to withdraw my participation from this clinical research, I have been advised that I may discuss any consequences or effects of my withdrawal with the investigator.

I will be informed of any new findings developed during the course of this clinical research study which may relate to my willingness to continue participation in the study.

9. I have been assured that confidentiality will be preserved (except that, if applicable, qualified monitors from the Food and Drug Administration or (Specify: National Cancer Institute or name(s) of sponsor(s) who furnishes the drugs/devices being utilized in this study) may review my records where appropriate and necessary). My name will not be revealed in any reports or publications resulting from this study without my expressed consent.
10. I have been informed that should I suffer any injury as a result of participation in this research activity, reasonable medical facilities are available for treatment at this institution. I understand, however, that I cannot expect to receive any credit or reimbursement for expenses from this institution or any financial compensation from this institution for such injury.
11. I understand that costs related to my medical care including expensive tests or procedures that may be specifically required by this clinical research study shall be my responsibility. I have been given the opportunity to discuss the expenses or costs associated with my participation in this research activity.
12. Add if applicable:

It is possible that this research project will result in the development of beneficial treatments, new drugs, or possible patentable procedures, in which event I herein disclaim and hereby waive any right or claim to receive any compensation or benefits from the subsequent use of information acquired and developed through participation in this research project.

13. I may discuss questions or problems during or after this study with Catherine Ratliff, RN, at (713) 792-7090. In addition, I may discuss any problems I may have or any questions regarding my rights during or after this study with the Chairman of the Surveillance Committee at (713) 792-3220 and may in the event any problem arises during this clinical research contact the parties named above.

CONSENT

Based upon the above, I consent to (participate in the research/undergo the described procedure/participate in this survey) and have received a copy of the consent form.

DATE

SIGNATURE OF PARTICIPANT

WITNESS OTHER THAN PHYSICIAN
OR INVESTIGATOR

SIGNATURE OF PERSON RESPONSIBLE
AND RELATIONSHIP

I have discussed this clinical research study with the participant and/or his or her authorized representative, using a language which is understandable and appropriate. I believe that I have fully informed this participant of the nature of this study and its possible benefits and risks and I believe the participant understood this explanation.

PHYSICIAN/INVESTIGATOR

APPENDIX E
Permission to Use Instrument



University of Delaware

COLLEGE OF NURSING
DEPARTMENT OF NURSING SCIENCE
MCDOWELL HALL
NEWARK, DELAWARE 19716

(302) 451-1253
(302) 451-1257

October 17, 1988

Dear MS Kalleff

Thank you for your interest in our Sexual Adjustment Questionnaire. We will be happy to share our tool with you for use in your research and/or practice. Please feel free to use only part of the SAQ and/or to modify individual questions to fit your own patient population.

In return for use of the SAQ, we need you to provide us with information about your intended use of the tool. Use of the questionnaire also implies agreement to share results of your findings with us upon completion of your work. This information will be used for further reliability and validity analysis and will assist us in making future revisions in the SAQ.

The fee for use of the SAQ is \$5.00. Please return a check made payable to Julie Waterhouse, along with the attached information form.

We are excited about your interest and activity in this area of oncology nursing, and look forward to hearing from you about your work.

Sincerely,

Julie Waterhouse
Julie Waterhouse

Peggy Metcalfe
Peggy Metcalfe

JW, PM:ph
Attachment

APPENDIX F

Human Subject Review Approval

TEXAS WOMAN'S UNIVERSITY
DENTON DALLAS HOUSTON
HUMAN SUBJECTS REVIEW COMMITTEE - HOUSTON CENTER

HSRC APPROVAL FORM

Name of Investigator(s): Catherine Ratliff

Social Security Number(s): 230-80-0197

Name of Research Advisor(s): Anne Young

Address: Catherine Ratliff

8 Shiloh Court

Palmyra, Virginia 22963

Dear: _____

Your study entitled: _____

(The applicant must complete the top portion of this form)

has been reviewed by the Human Subjects Review Committee - Houston Center and it appears to meet our requirements in regard to protection of the individual's rights.

Please be reminded that both the University and the Department of Health and Human Services regulations typically require that signatures indicating informed consent be obtained from all human subjects in your study. These are to be filed with the Human Subjects Review Committee Chairman. Any exception to this requirement is noted below. Furthermore, according to HHS regulations, another review by the HSRC is required if your project changes or if it extends beyond one year from this date of approval.

Any special provisions pertaining to your study are noted below:

_____ Add to informed consent form: "I understand that the return of my questionnaire constitutes my informed consent to act as a subject in this research".

_____ The filing of signatures of subjects with the Human Subjects Review Committee is not required.

_____ Other: see attached sheet.

 x No special provisions apply.

Sincerely,

Anne Young
Anne Young, Ed.D.
Chairperson, HSRC - Houston Center

4/17/92
Date