Addressing the Sexual Health Needs of Patients With Gynecologic Cancers

Kalli Stilos, RN, MScN, Catherine Doyle, RN, BScN, and Patricia Daines, RN, MN

Research indicates that sexual health and function frequently are overlooked by healthcare professionals despite being identified as an essential aspect of patient care. This article discusses the topic of sexuality as it pertains to women with gynecologic cancers, highlights barriers to addressing sexuality with patients with cancer, and provides nurses with a framework to guide them in providing information and support to patients who are experiencing sexual difficulties or who need information about sexual function. A case study addresses the challenges a woman with cervical cancer faces and the role of the nurse in supporting the patient and her partner within the PLISSIT model.

At a Glance
- Patients benefit from information pertaining to their diagnosis and treatment for sexual function.
- Nurses identify many barriers as to why they do not address sexual health issues.
- Oncology nurses play a pivotal role in addressing patients’ sexual health issues.

Advances in the diagnosis and treatment of cancer suggest that patients will live longer while experiencing the effects of their treatments (Colyer, 1996). Sexual dysfunction is the most common long-term consequence of cancer treatment, affecting 50% of the survivors of breast, gynecologic, and many other cancers (National Cancer Institute, 2004). With this in mind, it is particularly important for healthcare professionals to understand how patients with cancer live with the debilitating outcomes of treatment and how their quality of life is affected (Carmack Taylor, Basen-Engquist, Shinn, & Bodurka, 2004; Mitchell & Pilkington, 2004). Patients with cancer have identified sexuality issues as being of equal importance to other quality-of-life issues (Ananth, Jones, King, & Tookman, 2003; Dudas, 1991; Hughes. 1996).

Research indicates that sexual function is a health topic frequently overlooked by healthcare professionals, despite being identified as an essential aspect of patient care since the 1970s (American Nurses Association & Oncology Nursing Society, 1980). The World Health Organization (2002) defines sexual health as a state of physical, emotional, mental, and social well-being related to sexuality, not merely the absence of disease, dysfunction, or infirmity. Sexual health requires a positive and respectful approach to sexuality and sexual relationships, as well as the possibility of having pleasurable and safe sexual experiences that are free of coercion, discrimination, and violence.

Literature Review

Many types of cancer and cancer therapies are associated with sexual dysfunction. According to Jensen et al. (2003), 85% of women who were diagnosed with cervical cancer and treated with radiation reported little to no interest in sexual activity, 55% reported dyspareunia, 45% had difficulties in completing sexual intercourse and in attaining orgasm, and 30% reported dissatisfaction with their sexual lives, highlighting the issues facing many women and their partners.

Gynecologic malignancy and its treatment can significantly impact quality of life for women facing advancing disease (Pitch, 2003). The most common sexual issues experienced after gynecologic cancer treatment are a loss of desire and pain associated with sexual activity (Booth & Bruera, 2004).

Studies also reveal a lack of communication about sexual health between patients and healthcare professionals, as well as between patients and their partners (Hordern & Currow, 2003). Research indicates that healthcare professionals, including those using a holistic approach to patient care, are reluctant to discuss sexual issues with their patients, possibly because of
they are not sufficiently equipped with the knowledge and skills necessary to assist patients with sexual issues (Rice; Shipes, 1987; Smith, 1989). Healthcare professionals may avoid the subject because they believe that dealing with patients’ sexual issues is outside their realm of responsibility. Others may fear that they will offend patients or their partners and risk legal ramifications (Katz, 2005).

Cultural variations in attitudes, beliefs, and knowledge concerning sexuality create challenges for healthcare professionals in how care is delivered (Hammound, White, & Fetters, 2005). While sex education often is lacking or discouraged in certain societies, cultural traditions may encourage misinformation, leading to anxiety and fear about sex (Fisher, Bowman, & Thomas, 2003). Diversity among cultural, religious, and spiritual beliefs in relation to sexual intimacy also exists. Tsai (2002) reported that, in Taiwan society, sexuality is not openly discussed and patients often are hesitant to discuss sexual concerns with healthcare practitioners. Similar findings were noted in a study of student nurses and midwives in South Africa (Verkuyl, 2000), where engaging in a discussion about sexuality meant that the patient must have already evaluated his or her symptoms before sharing them with the physician. Some nurses may feel uncomfortable discussing sexual matters, particularly when the nurse and patient are of opposite gender (Katz, 2005). Cultural sensitivity is an important consideration when initiating discussions of sexuality and sexual function (South-Paul, 2003).

Another important consideration is establishing the most appropriate time to address sexual issues. Healthcare professionals should begin discussing psychosexual issues related to diagnosis and treatment during the consent process. The patient’s focus at the time of diagnosis usually is on treatment and survival. The discussion of sexual side effects may be overlooked or forgotten if it is presented during this time. However, informed consent should include a discussion about the effects of treatment on sexuality, such as premature ovarian failure, narrowing of the vagina, and body image changes from a mastectomy, stoma, or nephrostomy tubes. In addition, discussing the sexual side effects of treatment normalizes the subject for patients and their partners and communicates the willingness of healthcare professionals to further discuss the issue.

A study of 26 women who had stage I-IV invasive cervical cancer assessed the range and intensity of psychosocial concerns (De Groot et al., 2005). The women and their male partners expressed equal concern regarding the illness and its treatment as long as two years after treatment, rating sexuality, prognosis, and communication with the healthcare team highest in terms of current concerns. Healthcare professionals also should be prepared to review sexual side effects with patients during and after treatment. During treatment, patients’ and their partners’ immediate concerns should be addressed, such as questions about wellbeing, intimacy or affection, the advisability of continuing sexual activity during treatment, and how to address changing sexual relations with partners. In addition, follow-up appointments after treatment should include assessment, reevaluation, and management of sexual health issues.

The specific sexual needs and concerns of the patient and partner determine the appropriate type of intervention. A review of relevant literature indicates that the PLISSIT model (Annon, 1976) is an effective counseling model and guide for initiating patient discussions on sexuality or focused interventions (Dixon & Dixon, 2006). The model helps healthcare professionals deal with sexuality issues for patients with cancer and other illnesses and is designed to provide patients with interventions that address current needs or potential future needs in the form of anticipatory guidance (Dudas, 1991; Hughes, 1996; Shell, 2002; Shipes, 1987; Smith, 1989; Waxman, 1993).

PLISSIT is an acronym for the different phases of the model. P stands for the permission given to discuss sexuality issues, informing healthcare professionals of patients’ needs and what aspect of PLISSIT is most useful at that point (Shell, 2002). The LI stands for limited information, with healthcare professionals providing factual information to patients and partners about their specific sexual issues. The SS stands for specific suggestions for managing sexual issues (e.g., Kegel exercises), and IT stands for intensive therapy. The final stage usually is conducted by experienced therapists for patients and partners who have particularly complex issues (Shipes, 1987).

Factors Affecting Sexual Function

Women with gynecologic cancer often face common issues that interfere with normal sexual function. Nurses who can identify the issues and provide patients and their partners with accurate information about them may enhance their understanding and interpretation of the impending experience, decrease uncertainty, and promote self-care interventions (Gamel, Hengeveld, & Davis, 2000; Lamb, 1990).

Pain

Dyspareunia is one of the two most common issues experienced by women treated for gynecologic cancers (American Cancer Society [ACS], 2004). Gynecologic surgeries that may cause dyspareunia include vulvectomy, pelvic exenteration, hysterectomy, and surgery to remove cervical tumors (Jenkins & Ashley, 2002). Pelvic radiation may be used to treat cervical, endometrium, vulva, and vaginal cancers. Patients should expect anatomical changes following surgery or radiation for pelvic malignancies, including shortening and narrowing of the vagina. Jensen et al. (2003) found that women reported sexual dissatisfaction and discomfort from decreased vaginal size six months after radiation. Pelvic radiation, bilateral oophorectomy, and some chemotherapies can cause premature ovarian failure, resulting in vaginal dryness and making vaginal intercourse difficult and uncomfortable. Pain can have a significant impact on mood, affecting quality of life. Patients who experience
persistent abdominal or pelvic pain report significant interference with daily quality of life, including activity level, work, mood, and overall enjoyment (Doyle, Crump, Pintile, & Oza, 2001).

Lack of Desire

Lack of desire is the second most common issue experienced by women treated for gynecologic cancers (ACS, 2004; Booth & Bruera, 2004). Sexual activity can be affected at first diagnosis, during the treatment phase, or at time of recurrence as women are more concerned about their survival (Willmoth & Spinelli, 2000). When a woman is experiencing adverse effects from her treatment, such as nausea and vomiting, pain, and disturbed hormone imbalances, sexual activity is low on her list of priorities (ACS). Depression caused by cancer and subsequent treatments may interfere with sexual interest; however, antidepressant medications also have been associated with sexual dysfunction (Schover, 1997; Schover, Montague, & Lakin, 1997). Threats to self-esteem and body image as a result of cancer and its treatment can cause patients to devalue their sexuality, leading to diminished desire (ACS). A temporary or permanent loss of sensation after surgery can interfere with a patient’s ability to achieve orgasm (ACS). Fatigue, during and after cancer treatment, also can lead to decreased sexual desire (Canadian Cancer Society, 2006).

Anxiety, Fear, and Guilt

Anxiety, fear, and guilt can affect the communication between patients and their partners and interfere with sexual activity during and after cancer treatment (ACS, 2004). Some women experience feelings of guilt and see the cancer as some form of punishment for past sexual indiscretions. This guilt may be exacerbated for patients diagnosed with cervical cancer, which is often caused by the human papillomavirus that is transmitted via sexual contact (Southern & Herrington, 1998).

Anxiety also arises from pressure to satisfy partners as well as a fear of the unknown when resuming sexual activity after treatment (ACS, 2004; Zegwaard, Gamel, Dugris, & Logmans, 2000). Some women may hesitate to initiate sexual activity because of fears of rejection, post-coital bleeding, pain, or discomfort (Gamel et al., 2000). Post-coital bleeding can elicit extreme stress, negatively impacting a woman’s body and feelings of sexuality and adversely affecting intimate relationships. For some women, post-coital bleeding may have been the first symptom of the cancer (Lamb & Sheldon, 1994).

Despite these fears, resumption of sexual activity often is initiated by the patient over a fear of losing her partner if she is unwilling to engage in sexual activity (Zegwaard et al., 2000). However, partners also may experience anxiety associated with a fear of causing the patient pain during sexual activity (Lamb, 1990).

Body Image

A significant portion of the sense of self is comprised of sexuality, and physical changes caused by gynecologic cancer or its treatment can undermine a woman’s self-esteem (Crouch, 1999). The side effects of surgery, chemotherapy, and radiation often may be more severe than the cancer itself (Ferrell, Smith, Cullinane, & Melancon, 2003).

Surgeries that alter physical appearances may cause stress in sexual relationships. Common cancers that cause the most difficulty are cervical, vulva, and uterine (Jenkins & Ashley, 2002). Distressing symptoms that can occur include vaginal discharge and/or odor when undergoing total pelvic exenterations and having a new vagina created from a section of intestine. Patients may have concerns about odors related to stomies, the appearance of appliances and the fear they may come off during sexual activity, and concern that their partners will have a negative response to their appearance after surgery (Lamb, 1990). Some women complain of feeling empty after surgery (ACS, 2004). Chemotherapy and radiation may cause a loss of pubic hair. Risk factors for lower limb lymphedema include pelvic radiation and pelvic node dissection, any of which may threaten a patient’s femininity, self-esteem, and sexual function (Lamb).

Case Study

Brenda, a 50-year-old woman, was diagnosed with cervical cancer. She and her husband, Jim, have two children—an adult son and a teenage daughter. Brenda worked part-time as a dog walker prior to her diagnosis and led an overall healthy lifestyle. Her treatment plan involved chemotherapy, external beam radiation to the pelvis, and brachytherapy to the cervix.

Using the PLISSIT Model

The PLISSIT model is used in the case study to illustrate the role a primary oncology nurse can play in approaching sexual health issues. For illustrative purposes, the model will be discussed from beginning to end. It is important to note, however, that the model is not a linear process but rather a process that is continuous and interchangeable depending on the needs identified by patients and their partners.

Permission: Brenda’s first visit to the cancer center provided an opportunity for her primary oncology nurse to explore sexual health issues with Brenda and Jim. As they learned of the proposed treatment, including risks, benefits, and side effects, from the oncologist, Brenda had some questions related to anatomical changes. The nurse reviewed this information with the couple, including the fact that shortening and narrowing of the vagina are expected side effects of the radiation treatment. The nurse told Brenda that it was normal to have concerns about how treatment might affect her sex life and asked what worries she had. The open-ended question gave Brenda and Jim an opportunity to ask questions about their sexual concerns (see Figure 1). Their response gave the nurse permission to proceed with an exploration of their anxiety and uncertainty surrounding the sexual side effects of the proposed treatment.

Limited Information: A diagram of female reproductive organs was used to provide the couple with a visual explanation of the anatomical changes likely to occur. Helping the woman and her partner understand the physical changes associated with treatment prior to beginning treatment allows time for adjustment (Booth & Bruera, 2004). Discussion during the
At the Time of Diagnosis and Treatment

- How has this diagnosis affected your relationship with your partner?
- It is normal for you and your partner to have concerns about how treatment might affect your sex life. What worries do you have?
- Many patients wonder about sexual activity during treatment. Do you have any questions or concerns about this?
- Patients and their partners often have questions about resuming sexual activity after treatment is completed. Is this something that you would like information about?

After Treatment

- Often, cancer survivors notice changes in their sex lives after treatment. Has your sexual experience changed? Would you like to discuss this further?
- Women who have received the same treatment often describe certain symptoms. Have you been experiencing these symptoms?

During Palliative Care

- How is your health affecting your relationship?
- What concerns or questions do you or your partner have about fulfilling your sexual needs?

Note. These open-ended questions are used in clinical practice with patients and their partners at various stages of their diagnosis and treatment and may help frame discussions about sexual concerns.

Figure 1. Questions to Open a Dialogue About Sexual Function Issues in Women With Cancer

pretreatment phase about sexual changes enhances the likelihood of sexual satisfaction between the patient and her partner (Booth & Bruera).

Specific Suggestions: Following treatment, Brenda was menopausal and experienced delayed healing, complaining of dyspareunia and a persistent foul-smelling discharge. The dyspareunia interfered with the arousal stage of the sexual cycle, preventing her from relaxing during sexual activity and achieving orgasm. Her nurse helped Brenda to understand that these symptoms and concerns were not uncommon. Specific suggestions were made to manage the dyspareunia, including the use of water-based vaginal lubricants during foreplay and penetration and vaginal moisturizers. Kegel exercises were suggested to help Brenda relax her pelvic floor muscles. The nurse also suggested that Brenda and her husband engage in extended foreplay as it can help lengthen the vagina prior to penetration. Various positions to help intercourse after cancer treatment (ACS, 2004) were discussed that could allow Brenda more control over the depth of penetration and improve comfort and anxiety. Brenda also was prescribed an oral antibiotic (metronidazole) to reduce vaginal odor.

Brenda’s symptoms alleviated for a period of time; however, two years after treatment, she presented to the emergency department with heavy vaginal bleeding. An examination and biopsy were performed, as was a magnetic resonance imaging scan. Brenda was found to have local recurrence. She was deemed unsuitable for a pelvic exenteration, and she declined palliative chemotherapy. Brenda became angry and frightened, denying her poor prognosis. She began experiencing back pain and leg pain as a consequence of lymphedema. As her pain and lymphedema continued to increase, she was referred to a palliative pain and symptom management clinic and to a lymphedema clinic for teaching, manual drainage, and compression garments. Brenda was fatigued much of the time and admitted that she felt unattractive because of the changes to her body. The specific suggestions at that time were focused on managing fatigue and on supporting Brenda and Jim’s relationship. The nurse suggested that Brenda gauge sexual activity around her fatigue and pain level. Brenda was given information on metastatic cancer support groups, and Jim was informed of a caregivers’ support group. Arrangements were made for nursing and other supportive services in the home.

Brenda’s disease continued to progress with the development of a rectovaginal fistula requiring a diverting colostomy. She now wore baggy clothes to disguise her ostomy and appliance. She refrained from letting her husband touch her, and she and Jim struggled to maintain a close relationship. The nurse further explored Brenda’s concerns with her and suggested that she could plan intimacy around times when her ostomy was less active. She might consider removing the appliance and covering the stoma during intimate contact to enhance her body image. In addition, the nurse also explored with Brenda and Jim the idea of experimenting with other forms of expressing pleasure while gauging their comfort level with the topic. Both patient and partner need to feel comfortable with trying alternative forms or the specific strategies will not be helpful. The oncology nurse also offered the couple a booklet which would help address some of their concerns (see Figure 2).

Intensive Therapy: Jim’s visits to the clinic increased as Brenda became more fatigued and anxious about her health status. Her thoughts were preoccupied with how unfair this disease was to her husband in that she was unable to fulfill what she believed were her roles as a wife. Her sexual feelings were absent most of the time, posing a fundamental threat to her self-worth and relationship with her husband. The earlier specific suggestions given by the nurse were no longer helpful as Brenda’s diminished desire, guilt, depression, fears of

Articles or Publications


Web Sites

American Association of Sexuality Educators, Counselors, and Therapists (for a list of local therapists): www.aasect.org

American Cancer Society: www.cancer.org

United Ostomy Associates of America: www.uoaa.org

Women’s Cancer Network: www.wcn.org

Figure 2. Patient Resources That Discuss Sexual Issues
mortality, and anger overwhelmed her. The oncology nurse, in consultation with the radiation oncologist, recommended a referral to an outpatient psychiatrist who specializes in women with cancer, thinking that the psychiatrist could assist the couple in coping with all of the psychosexual changes. Brenda and Jim were open to the referral.

As a result of their interactions with the psychiatrist, Brenda and Jim were able to maintain their close relationship, continued communicating with each other, and learned to express pleasure through talking and maintaining physical closeness (i.e., hugging, hand holding, and kissing).

Brenda and Jim’s visits to the clinic during the treatment phase included time with her primary nurse to confidentially discuss the couple’s sexual lifestyle. The initial discussion around sexual concerns created an open forum in which Brenda and Jim could freely discuss the issue. During the visits, the nurse listened to the couple’s interactions and provided them with information and suggestions. The couple, from visit to visit, would discuss the changes they had been experiencing. What was once a regular and satisfying sex life was becoming more unpredictable and difficult to sustain. The discussions that took place with the nurse helped redefine what gave each of them comfort and pleasure and what they found meaningful during the evolution of Brenda’s disease, treatment, and palliative phase.

Discussing Sexual Health Issues

Discussing sexual health issues with women and their partners is a skill that develops over time. Most oncology nurses find the topic difficult and tend to avoid it, leaving patients with many unanswered questions. Oncology nurses first need to examine their own biases and assumptions about the topic and come to terms with them. Once this is accomplished, nurses can be open-minded and able to listen, understand the perspective of others, freely interact with patients and their partners, and provide individualized care. Nurses should avoid judgments, withhold instincts to control, and avoid attempts at fixing situations to ensure they maintain the principles of a patient-centered model of care (Stilos, Moura, & Flint, 2007).

Oncology nurses should have a general understanding of the sexual issues that can occur with the various cancer diagnoses and their treatment modalities (Stead, Fallowfield, Brown, & Selby, 2002). Nurses should feel comfortable simply asking questions about all aspects of health to give patients the opportunity to share their concerns. When a nurse routinely inquires about patients’ sexual concerns, it increases the nurse’s comfort and confidence (Magnan & Reynolds, 2006). Tools such as the PLISSIT model help oncology nurses initiate patient discussions on sexuality and can assist in conducting sexual assessments. Figure 3 details additional resources useful for discussions of sexual issues.

A routine role of nurses should be to provide patients with culturally appropriate written material, brochures, or Web sites (Stead et al., 2002). In Crowther, Corney, and Shepherd’s (1994) study, 50% of women younger than 50 believed that more information on sexual matters should have been given to them and their partners before surgery to prepare them for the treatment aftermath.

Conclusion

A cancer diagnosis can interfere with normal sexual functions in many ways. Sexuality encompasses feelings about one’s body, the need for touch, interest in sexual activity, communication of one’s sexual needs to a partner, and the ability to engage in satisfying sexual activities (Carmack Taylor et al., 2004). Healthcare professionals must take a leading role in providing sex-related information and supporting couples affected by cancer as they adjust to their new sexual roles and explore alternatives to expressing physical affection.

Nurses must acknowledge patients’ and their partners’ sexual issues as unique, make patients feel open to discussing sexual concerns, and evaluate interventions as required (Stead et al., 2002). Couples may need to redefine what normal sexual expression is for them, as a disruption may occur to their previous sexual routines. Healthcare professionals should emphasize that it is common to experience changes in sexuality and that these changes may threaten identity and self-esteem. Addressing the issues in a tailored and patient-specific manner will allow healthcare professionals to understand what each patient and partner experience, what issues matter to them, and how to improve their sexual health. Assessment and care plans should have an individualized patient- and family-centered approach similar to the approaches used in the assessment and management of pain and other symptoms.

Next Steps

Although not available at the time of Brenda’s treatment, the Sunnybrook Odette Cancer Centre developed a sexual health and rehabilitation (SHARE) clinic to specifically address the unmet needs of women with gynecologic cancer and their partners. In addition to assessing, counseling, and providing information and referrals to patients seen at the clinic, the SHARE oncology nurses provide leadership throughout the oncology program. Knowledge is shared and the awareness of sexuality as a quality-of-life issue for patients with cancer
is heightened through ongoing professional development, the creation of patient education materials, and communication among nurses across disciplines about the development of care plans for patients.

**Author Contact:** Kalli Stilos, RN, MScn, can be reached at kalli.stilos@sunnybrook.ca, with copy to editor at CJONEditor@ons.org

**References**


