Sexuality and Cancer: The Final Frontier for Nurses

Mary K. Hughes, MS, RN, CNS, CT
2009 Mara Mogensen Flaherty Lectureship

Although I had been a member of the Oncology Nursing Society (ONS) since the 1980s, it was not until 1991 that I first attended Congress. That year, Dorothy Smith, from the University of Texas M.D. Anderson Cancer Center, delivered the Mara lectureship, and I was thrilled to be present because I had worked with Dot. Alas, I am no Dot Smith, but I do hope I inspire many of you to address sexuality issues with your patients.

We talk about everything with our patients—bowel and bladder habits, nausea and vomiting—but we do not address sexuality issues. It is the last frontier for us, and I will give you tools to use to help make you more comfortable addressing these issues. Our patients think they are the only ones with sexual concerns because we talk about everything else with them. When they are in the waiting room, they chat with each other about everything but sexuality issues. So they feel very lonely and isolated with these concerns.

It is very hard for us to think about sexuality and cancer at the same time because they do not seem to go together. When you think about sexuality, you usually use positive or neutral words, but cancer usually is associated with negative words. We are very focused on treating cancer and forget about sexuality and its importance to patients.

Defining Sexuality

According to Winze and Carey (1991), sexuality is genetically endowed, phenotypically embodied, and hormonally nurtured. Smith (1994) described sexuality as being matured by experience and something that cannot be bought, sold, or destroyed, despite what is done to a person. It is not age related because humans are sexual beings in utero (Whipple & Komisaurak, 1999). The World Health Organization (2002) further described sexuality as including pleasure, sexual activity, eroticism, and sexual orientation. It is a broad term that encompasses love of one's self as well as love of another, body image, intimacy, relating to another, pleasure, and reproduction (Southard & Keller, 2009). Southard and Keller went on to describe sexual quality of life as having a mind/body connection, feeling attractive and potent, having choices, and being able to enjoy sexual activities. Being able to trust (not only your partner, but your body to perform and respond to sexual stimulation) is a very important part of sexual quality of life. Sexual quality of life involves stimulation of all of the senses—smell, touch, taste, hearing, as well as seeing—and includes a positive and respectful approach to each other (World Health Organization).

Leiblum, Baume, and Croog (1994) asserted that patients of all ages, sexual orientations, marital statuses, and life circumstances should have the opportunity to ask about and discuss sexual matters with healthcare professionals. How do we promote and encourage such discussion?

Cancer's Effects on Sexuality

The problems one experiences when diagnosed with and treated for cancer that affect sexuality include erectile dysfunction, decreased libido, and vaginal dryness. Urinary incontinence can make it embarrassing to be involved with sexual activity for fear of an accident. Likewise, bowel dysfunction can interfere with sexual functioning because if constipation is a problem, women will experience discomfort with sexual activity, and if diarrhea is a problem, there is discomfort as well as fear of incontinence. Fatigue is the longest-lasting side effect from cancer treatment and interferes with all aspects of sexuality in the same way anemia does. It takes energy to engage sexually. Some people are concerned about birth-control issues and are not able to use their prior forms of contraception (e.g., women with breast cancer cannot use oral contraceptive pills). Pain interferes with all aspects of sexual functioning because efforts to control pain distract from other activities. Muscle loss from inactivity or steroid use makes

it difficult to engage in sexual activity. A person needs to have stamina to complete sexual activity. Treatments can affect body image in a negative way and make it very difficult for a person to feel attractive or sexually desirable (Southard & Keller, 2009). It is important for us to allow patients to talk about poor body image and not say, "You look good with clothes on." People usually do not engage in sexual activity while they are dressed. Some people have poor relationships before they get cancer, and it is highly unlikely that those relationships will improve after cancer. It is not that uncommon for men to leave women with cancer but very rare for a woman to leave a man with cancer because women usually are caretakers. So when performing a sexual assessment, ask how the relationship was before the cancer diagnosis.

What do women complain about? With a poor body image, women do not like for their partners to see their bodies because of scarring, changed skin color, or drains. Some women report painful intercourse that was not a problem before cancer treatment. Many complain about vaginal dryness, which can cause pain. Some women report that their vaginas feel smaller or shorter, which interferes with their sexual pleasure. It is very hard to engage in sexual activity with low or absent libido. Many experience fear of abandonment because friends have abandoned them. Women sometimes ask me not to tell their husbands that they are not interested in sex because that is the one thing they can still do despite having cancer and a way they feel they can give back to the relationship. Many women notice changes in their orgasms—they usually take longer to happen because of genital numbness or changed sensation (Hughes, 2008). Younger women often have fertility concerns because they would like to have children, but cancer treatments may cause premature menopause.

Menopausal symptoms can interfere with sexuality and include migraine headaches that may start at this time of hormone shift instead of at menarche (Moloney, Strickland, DeRossett, Melby, & Dietrich, 2006). According to Daly et al. (1993), insomnia can begin with menopause and lack of sleep can cause fatigue. Vaginal atrophy and dryness, decreased vaginal ridges, labia minora atrophy, and decreased clitoral sensitivity change the geography of the female genitalia and a woman's responsiveness. It can be more difficult to deal with these changes for a stable partner who does not know how the sexual response is going to be. Hot flashes make it difficult for a woman to be physically close and can also interfere with sleep. Some menopausal women have to be treated for depression for the first time in their lives as a result of the hormone shift, which also can cause irritability. Libido can be lower, making it difficult for women to want to engage in sexual activity. Both women and men notice a change in body aroma, not an unpleasant odor, but different with menopause.

It is important for us to allow patients to talk about poor body image and not say, "You look good with clothes on." People usually do not engage in sexual activity while they are dressed.

Men's sexual complaints are much fewer: erections may not be as hard or last as long. They may lack desire, depending on the type of treatment and cancer, as well changes in orgasm or ejaculation (Schover, Montague, & Lakin, 1997). Orgasms might not feel as powerful as they had in the past. Relationship conflicts that existed before cancer continue. Some couples have not had sexual activity for years even though they are only in their 40s; following a diagnosis of cancer, sexual activity does not resume.

Treatment's Effects on Sexuality

Each type of treatment has its own sexual side effects. Surgery that results in a stoma or ostomy affects body image, as does an amputation, regardless of the type. Changes in ejaculation that result in dry orgasm or retrograde ejaculation can be difficult for men to accept. If a man has a retrograde ejaculation, the next time he urinates, the urine will be cloudy. Any surgery that causes changes in the female genitalia such as vulvectomy or vaginectomy can cause dyspareunia (genital pain associated with intercourse that can occur before, during, or after in either men or women), vaginal dryness, or decreased sexual responsiveness.

Radiation therapy can cause fatigue (a long-lasting side effect), loss of libido, erectile dysfunction, changes in ejaculation, incontinence of urine and stool, and changes in bowel habits, either diarrhea or constipation. Dry mouth affects a person's ability to kiss and perform oral sex, something we do not often consider (Hughes, 1997). I was seeing a man with head and neck cancer who had dry mouth as well as erectile dysfunction and was trying to help problem-solve around the issues. He reminded me how difficult performing oral sex was without any saliva.

Early menopause brings with it all of the side effects of menopause, but they may be more dramatic because of younger age. Radiated vaginal tissue can become inflamed and tender and when healed can lose its elasticity and lubrication, just like any other mucus membrane that has been irradiated. Skin color over the irradiated area can change; this, along with other changes, can cause poor body image.

Hormone therapy includes drugs to block estrogen and testosterone, as well as steroids. Higano (2006) described a multitude of side effects from androgen-deprivation

therapy, including loss of desire and competitiveness. Men have said that they do not care about winning at golf; that their job performance has dropped; that they are not interested in sex; and that they have erectile dysfunction, changes in ejaculation, hot flashes or night sweats, fatigue, weight distribution changes or gain, gynemastia, and insomnia. If they are diabetic, their blood glucose levels can fluctuate. Blood pressure and serum cholesterol also may change. Women on hormone therapy have hot flashes, insomnia, and weight distribution changes or gain. They complain of increasing abdominal girth, changes in vaginal elasticity, lack of vaginal lubrication, or interruption of their menstrual cycles. Incontinence can accompany severe vaginal atrophy. With aromatase inhibitors, there can be muscle and joint pain, insomnia, and osteoporosis (Gholz, Conde, & Rutledge, 2002).

Chemotherapy has short-term effects on sexuality that include fatigue, nausea, vomiting, weight gain or loss, mucositis, and bowel changes. There can be a loss of sexual desire, but it can return when chemotherapy is over. For most women, the loss of hair is very traumatic and profoundly affects their sexuality and body image, which surprises them. It is important to acknowledge this loss and let them talk about what it means to them. Immunosuppression can increase herpes simplex virus and human papillomavirus flares, sexually transmitted diseases, and other infections. Long-term side effects of chemotherapy include neuropathy in not only the hands and feet but also the clitoris or the glans of the penis, which can delay or prevent orgasm. A patient called me after reading an article on sexuality changes with cancer treatment that I had written in a patient-focused magazine. She had been sent to numerous physicians, including a psychiatrist, to find the cause of her sexual dysfunction. She had received platinum- and taxane-based chemotherapy for her ovarian cancer five years earlier and still was searching for a reason she was not having orgasms. I deduced that she had clitoral neuropathy from her treatments and told her that it was highly unlikely that the sensation would return to the clitoris after all of those years. She was relieved to know the cause of her dysfunction and said she could focus on other ways to enjoy sexual activity with her understanding husband. Having neuropathy in the hands can change sexual interaction because they are not as sensitive and also may be painful. Infertility can be very distressing for people who delayed having families. If they are unpartnered, they may feel undesirable because of their infertility. Women who are older than 35 years have a higher risk of permanent menopause from chemotherapy. Fortunately, most side effects seem to decrease over time.

Other Factors

It is also important to take into account a person's medical history of hypertension and diabetes mellitus, which are well-known to cause erectile dysfunction. Antiemetics such as prochlorperazine, promethazine, and metoclopramide can cause akathisia, which looks like anxiety but can be treated with antihistamines and a substitute for the offending antiemetic. Selective serotonin reuptake inhibitors are very effective in treating depression and anxiety but can have sexual side effects such as low libido and delayed orgasm (Holland, Greenberg, & Hughes, 2006). If you have a patient on this class of drug who complains about sexual dysfunction, bupropion is an antidepressant with no sexual side effects. Duloxetine has no sexual side effects for women. Also, look at history of substance abuse, including alcohol, which can lower a person's inhibitions about sexuality but make it harder to perform, especially for men. Tobacco is notorious for causing sexual dysfunction because it constricts the blood vessels.

A variety of psychological factors contribute to sexual dysfunction in patients with cancer (see Figure 1). Fear is one of the first emotions a person experiences after diagnosis, including fear of dying, pain, never getting better, rejection, contagion, being a burden, and abandonment. Fear can interfere with a person's ability to even think about sexuality or any type of pleasure (Hughes, 2006).

Treating depression and anxiety, which occur in 20%–70% of cancer survivors, is very important. The conditions are underdiagnosed and undertreated but treatable. Both conditions make it very difficult for a person to think about sexuality and enjoy it.

Assessing Sexual Dysfunction

Maurice (1999) described the sexual response cycle as including libido or sexual desire. Sexual excitement includes the penis becoming erect enough to use and vaginal lubrication. Women sometimes become sexually excited before they have desire. Orgasm is the height of sexual pleasure, when the vaginal walls rhythmically contract and the cervix lifts out of the vaginal vault; in men, a

- Lowered self-esteem
- Guilt and shame
- Frustration
- Anger
- Attitude toward cancer
- Misinformation
- Disappointment
- Performance anxiety
- Sadness
- Depression
- Anxiety
- Feeling contaminated or isolated
- Control
- Poor body image

Figure 1. Psychological Factors Contributing to Sexual Dysfunction

series of rhythmic contractions release semen through the urethra. The resolution phase is when the genitals return to their normal, nonexcited state. Anything that interferes with this cycle is considered sexual dysfunction, which Goldstein (2007) reported to be 90% physiologic and 75% psychological. Sexual dysfunction has a combination of causes. Almost all of the patients I see have primarily physiologic reasons for their sexual dysfunction (i.e., cancer or its treatment). Seventy-seven percent of the 558 patients I saw for psychiatric reasons over a seven-year period had some type of sexual dysfunction. In a study by Shifren, Monz, Russo, Segreti, and Johannes (2008), 43% of 31,581 women without cancer reported some type of sexual dysfunction but only 22% reported any sex-related distress. Just because we find sexual dysfunction, it does not mean a person is distressed by it. When performing a sexual assessment, be sure to ask whether changes that have occurred bother patients.

The American Psychiatric Association classifies sexual disorders according to desire, arousal, orgasm, pain, general medical conditions, substance-induced sexual disorders, or paraphilias.

The American Psychiatric Association (2000) classifies sexual disorders according to desire, arousal, orgasm, pain, general medical conditions (which is the diagnosis I use: sexual dysfunction secondary to cancer treatment), substance-induced sexual disorders, or paraphilias.

Several models are available for assessing sexual dysfunction, but the two I use the most are Annon's (1976) PLISSIT model and Mick, Hughes, and Cohen's (2004) BETTER model. Annon did not intend for the PLISSIT model to be used for sexual assessment, but it is easy to remember and works well. By talking about cancer and sexuality with patients at the same time, you give them ***p****ermission* to think about them at the same time. They will remember that you are the nurse who brought up sexuality and will bring questions about it to you when they arise. **LI** stands for *limited information* that you can give to patients about possible sexual side effects from treatments. **SS** is *specific suggestions*, such as recommending a vaginal lubricant for vaginal dryness. **IT** is *intensive therapy*, which some patients need because their issues are long-standing relationship issues that require a marriage counselor's intervention.

In Mick et al.'s (2004) BETTER model, **B** is to *bring up* the subject of cancer and sexuality. Explain that you are concerned about quality-of-life issues, including sexuality. The ***t****ell* patients that you want to help them find the resources to address their concerns. The second **T** is *timing*. It might not seem appropriate to do a sexual assessment at the time of a new diagnosis, but express that you are available to address patients' concerns when they are ready. **E** means *educate* patients about the possible sexual side effects of cancer treatments. **R** means *record* your assessments and interventions in medical records.

First ask, "Sexually, how have things changed?" Patients usually lower and shake their heads. That is when you assess their desire, which as you know, is mediated by testosterone in men and women. Ask them when they last remember thinking about sex or being interested in participating in sexual activity or any activity. When was their last sexual activity? You would be surprised to know how long some people have gone without sexual activity in monogamous relationships. Desire can be affected by physiologic status, mood, psychosocial stressors, body image, and medications. Hypoactive sexual desire is when sexual fantasies are deficient or absent and libido is persistently reduced. It occurs in 20%–40% of all women (Sarason & Sarason, 2001). A sexual aversion disorder is more extreme and is an avoidance or aversion to genital sexual contact with another person (American Psychiatric Association, 2000).

Second, ask about arousal or excitement: Are men able to have and sustain an erection? Do women experience vaginal lubrication and engorgement? Do they feel sexually excited or feel like they could have an orgasm? There is an informal erection scale that is easily understood by men: 0 (no erection), 1 (the penis gets a little bigger), 2 (the penis is stuffable), 3 (the penis is stickable), or 4 (diamond-cutter [like when they were teenagers]). You chart it this way: "Patient reports erections are 2 on a 0–4 scale and unsustainable." Stress, anxiety, neuropathies, and medications can affect sexual excitement, as can vaginal dryness and dyspareunia. Vaginismus is the involuntary or persistent spasm of the lower third of the vagina when penetration is attempted.

Men usually do not go to a doctor unless they are desperately ill, but they go for erectile dysfunction. This often is when heart disease is diagnosed because the risk factors for heart disease and erectile dysfunction are very similar: smoking, dyslipidemia, diabetes, hypertension, lack of exercise, and obesity. Both are vascular conditions. When men have erectile dysfunction, they stop initiating nonsexual touch, and their partners do not want to seem demanding, so affection diminishes. Women rate this as more distressing than loss of sexual pleasure.

Assess for orgasm by asking whether they can have an orgasm with or without a partner, with or without erections. Has the length of time to achieve orgasm or its intensity changed? In men, is there a change in ejaculation? This can be the result of surgery. They may have dry orgasm or retrograde ejaculation. Men have orgasmic capacity without erections. Medications and psychosocial or relationship stressors can be causes for diminished orgasms.

Southard and Keller (2009) stressed the importance of a sexual history. Never make assumptions that patients are

Set aside enough time, and do not wait until you are leaving the room to ask about sexual concerns. Show respect for patients by waiting until they are dressed or at least covered to talk about sexuality. Show genuine interest and concern by looking at them and avoiding facial or verbal expressions despite what they tell you. Maintain a nonjudgmental attitude. Ask open-ended questions.

too old or young to be sexually active. Create a climate conducive to confidentiality and trust. Set aside enough time, and do not wait until you are leaving the room to ask about sexual concerns. Show respect for patients by waiting until they are dressed or at least covered to talk about sexuality. Show genuine interest and concern by looking at them and avoiding facial or verbal expressions despite what they tell you. Maintain a nonjudgmental attitude. Ask open-ended questions such as: "How have things been going sexually?" "What sexual changes have you noticed?" Use correct anatomic words; there are numerous words for penis and vagina. Know your own values. Remember, it is not reflective of your own sex life to be able to talk about a variety of sexual behaviors. Have basic knowledge about possible causes of sexual dysfunction and where help can be found.

Barriers to Open Discussion

These are barriers that prevent patients from asking about sexuality: fear of dying, fear of bringing up the subject, and anxiety which can keep them from thinking about sex. Depression can cause decreased libido, as can grief. If patients are feeling guilt or shame about having cancer or about thinking about sex while they have cancer, they will not ask about sexuality. They may have misinformation about being contagious or about being sexually active. They may have some medical concerns about getting sicker if they have sex, which may prevent them from addressing sexuality issues. Being dependent on someone for their care, which creates a role change, may make it hard for them to address sexuality concerns. Patients' religion might make them feel guilty for thinking about sexuality issues while dealing with cancer, so sexuality goes unaddressed. Often, couples are not married, but with a cancer diagnosis may feel they need to marry for religious reasons. When patients are a different sexual orientation than a healthcare provider, they might feel uncomfortable bringing up the subject.

There are numerous reasons we do not address sexuality issues with patients. The main one is our misconceptions about the importance of sexuality and intimacy issues to our patients. If we have professional or personal discomfort with discussing sexuality, as well as a lack of education on the topic, it will be hard to discuss. We are not sure what language to use because there are so many terms for genitals. The diversity, age, race, ethnicity, and religion of our patients may hinder us from addressing sexual issues as well as sexual orientation and our embarrassment with the subject. Role strain and change make us leery of adding any more functions to our jobs, and our own performance anxiety about how we will handle the subject also is a barrier. We are pushed for time, but addressing sexuality issues does not take that much time. I wrote an article for a professional journal last year, and a nurse with a history of breast cancer and currently on an aromatase inhibitor wrote to say that when she complained about sexual function, her oncologist ran a hormone level and declared her normal. After she read the article, she reported that it gave her hope that her sex life would improve once she got off the aromatase inhibitor.

Conclusion

Our patients' lives go on whether we address sexuality issues or not, but imagine how much better their lives could be if they did not feel isolated and alone and knew that cancer and its treatment can cause sexuality changes. Remember, you do not have to do it to talk about it. We talk about all sorts of things that we do not have personal experience with, and so it can be with sexual dysfunction. You are just addressing another quality-of-life issue with your patients.

The author gratefully acknowledges the ONS Foundation for continuing to support this award and the committee for choosing her as its recipient. She thanks Michelle Hammond, BS, RN, Houston ONS Chapter president, who nominated her; those who championed the nomination; and the Houston Chapter for its encouragement. The author's department, Psychiatry, has always supported and sustained her work. She is grateful to the University of Texas M.D. Anderson Cancer Center for providing the opportunity to do the work she does in caring for patients with a multitude of psychosocial issues on their cancer journeys. Lastly, the author is indebted to her family for their ongoing support and love: her brother and his family, her children and their families, and her husband, who is her biggest champion and "the wind beneath her wings."

Mary K. Hughes, MS, RN, CNS, CT, is a psychiatric clinical nurse specialist at the University of Texas M.D. Anderson Cancer Center in Houston. No financial relationships to disclose. Mention of specific products and opinions related to those products do not indicate or imply endorsement by the *Oncology Nursing Forum* or the Oncology Nursing Society. Hughes can be reached at mhughes@mdanderson.org, with copy to editor at ONFEditor@ons.org. As the recipient of the 2009 Mara Mogensen Flaherty Memorial Lectureship, Hughes presented this article at the 34th Annual Oncology Nursing Society Congress in San Antonio, TX.

Digital Object Identifier: 10.1188/09.ONF.E241-E246

References

American Psychiatric Association. (2000). *Diagnostic and statistical manual of mental disorders: DSM-IV-TR*. Washington, DC: Author.

Annon, J.S. (1976). The PLISSIT model: A proposed conceptual scheme for the behavioral treatment of sexual problems. *Journal of Sex Education and Therapy, 2,* 1–15.

Daly, E., Gray, A., Barlow, D., McPherson, K., Roche, M., & Vessey, M. (1993). Measuring the impact of menopausal symptoms on quality of life. *BMJ, 307*(6908), 836–840.

Gholz, R.C., Conde, F., & Rutledge, D.N. (2002). Osteoporosis in men treated with androgen suppression therapy for prostate cancer. *Clinical Journal of Oncology Nursing, 6*(2), 88–93.

Goldstein, I. (2007, February). Causes of women's sexual dysfunction. Presented at the International Society for the Study of Women's Sexual Health 2007 annual meeting, Orlando, FL.

Higano, C. (2006). Androgen deprivation therapy: Monitoring and managing the complications. *Hematology/Oncology Clinics of North America, 20*(4), 909–923.

Holland, J.C., Greenberg, D.B., & Hughes, M.K. (2006). *Quick reference for oncology clinicians: The psychiatric and psychological dimensions of cancer symptom management*. Charlottesville, VA: IPOS Press.

Hughes, M.K. (1997). Sexuality issues of the cancer survivor. *Coping, 11*(2), 51–52.

Hughes, M.K. (2006). Sexual dysfunction. In J. Holland, D. Greenberg, & M. Hughes (Eds.), *Quick reference for oncology clinicians: The psychiatric and psychological dimensions of cancer symptom management*. Charlottesville, VA: IPOS Press.

Hughes, M.K. (2008). Alterations of sexual function in women with cancer. *Seminars in Oncology Nursing, 24*(2), 91–101.

Leiblum, S.R., Baume, R.M., & Croog, S.H. (1994). The sexual functioning of elderly hypertensive women. *Journal of Sex and Marital Therapy, 20*(4), 259–270.

Maurice, W.L. (1999). *Sexual medicine in primary care*. St. Louis, MO: Mosby.

Mick, J., Hughes, M., & Cohen, M.Z. (2004). Using the BETTER model to assess sexuality. *Clinical Journal of Oncology Nursing, 8*(1), 84–86.

Moloney, M.F., Strickland, O.L., DeRossett, S.E., Melby, M.K., & Dietrich, A.S. (2006). The experiences of midlife women with migraines. *Journal of Nursing Scholarship, 38*(3), 278–285.

Sarason, I.G., & Sarason, B.R. (2001). *Abnormal psychology: The problem of maladaptive behavior* (10th ed.). Upper Saddle River, NJ: Prentice Hall.

Schover, L., Montague, D., & Lakin, M. (1997). Sexual problems. In V.T. Devita, S. Hellman, & S.A. Rosenberg (Eds.), *Cancer: Principles and practices of oncology* (5th ed., pp. 2857–2871). Philadelphia: Lippincott-Raven.

Shifren, J.L., Monz, B.U., Russo, P.A., Segreti, A., & Johannes, C.B. (2008). Sexual problems and distress in United States women: Prevalence and correlates. *Obstetrics and Gynecology, 112*(5), 970–978.

Smith, D.B. (1994). Sexuality and the patient with cancer: What nurses need to know. *Oncology Patient Care: Practice Guidelines for the Specialized Nurse, Bulletin 4,* 1–3.

Southard, N.Z., & Keller, J. (2009). The importance of assessing sexuality: A patient perspective. *Clinical Journal of Oncology Nursing, 13*(2), 213–217.

Whipple, B., & Komisaurak, B.R. (1999). Beyond the G spot: Recent research on female sexuality. *Psychiatric Annals, 29*(1), 34–37.

Winze, J.P., & Carey, M.P. (1991). *Sexual dysfunction: A guide for assessment and treatment*. New York: Guilford Press.

World Health Organization. (2002). Sexual and reproductive health. Retrieved August 14, 2009, from http://www.who.int/reproductive health/en/