SEXUAL DYSFUNCTION

Among women affected by cancer, the further affliction of sexual dysfunction is widespread

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Sexual dysfunction is common among women in the United States. One recent study put the prevalence of distressing sexual dysfunction at 22.2%.1 When cancer enters the picture, that percentage rises—dramatically. A 2010 survey from the Lance Armstrong Foundation found that 46% of people affected by cancer report problems with sex after treatment.2

In this article, I highlight three recent studies that explore the sexual effects of cancer and its treatment:

- a prospective cohort study showing that a majority of women treated for breast cancer experience sexual dysfunction afterward
- two longitudinal studies of women affected by gynecologic cancer, which show significant disruption of sexual function in the short and long term.

I also present the experiences of two cancer survivors who volunteered to relate their stories so that you might develop a better understanding of some of the challenges they face about their sexual function.

Sexual function deteriorates in many women after they are treated for breast Ca


According to this prospective cohort study from Australia, a majority of women report significant sexual dysfunction after treatment for breast cancer—even when their sexual function was good, and satisfying, at the time of diagnosis (TABLE, page 22).

The Health and Wellbeing after Breast Cancer Study enrolled 1,684 Australian women within 12 months of their first diagnosis of invasive breast cancer. Each woman completed a questionnaire at the time of enrollment, and will complete annual follow-up questionnaires for 5 years to assess the impact of invasive breast cancer on physical, psychological, and socioeconomic wellbeing. Embedded within the 12-month questionnaire was the validated Menopause-Specific Quality of Life Questionnaire (MEN-QOL), which was used in this study to explore the sexual consequences of the diagnosis and treatment of invasive breast cancer.

Of the initial cohort, 1,011 women completed the 12-month questionnaire. These were women younger than 70 years who...
After breast Ca, women experience low desire and less frequent sexual activity—as well as distress over both outcomes

<table>
<thead>
<tr>
<th>Symptom</th>
<th>Yes</th>
<th>No</th>
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<tbody>
<tr>
<td>Decreased desire</td>
<td>71.7%</td>
<td>19.7%</td>
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<tr>
<td>Decreased sexual activity</td>
<td>72.5%</td>
<td>21.1%</td>
</tr>
<tr>
<td>Distressed by sexual function</td>
<td>49.1%</td>
<td>8.1%</td>
</tr>
<tr>
<td>Seeking increase in desire</td>
<td>64.1%</td>
<td>19.9%</td>
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</tbody>
</table>

Source: Panjari et al.

had a sexual partner and no evidence of active breast cancer. The authors describe the women in this cohort as representative of all women in Victoria, Australia, who have a new diagnosis of invasive breast cancer, in regard to both age (mean, 59 ± 11 years) and the stage of tumor (stage I, 48%; stage II–IV, 52%) at diagnosis.

Of this group, 70% were treated with lumpectomy and radiation therapy, and 30% were treated with mastectomy (2.6% with bilateral mastectomy). Of the women who underwent mastectomy, 9.6% had reconstructive surgery during the first year after diagnosis.

Forty-nine percent of women were treated with tamoxifen, and 28.2% were treated with an aromatase inhibitor.

More than two thirds of women reported sexual dysfunction

12 months after treatment

At baseline, 83% of women described their prediagnosis sexual function as good and satisfying. Twelve months later, 70% reported significant sexual dysfunction, and 77% reported vasomotor symptoms.

Women who reported new-onset sexual dysfunction were more likely to:
- have become menopausal since diagnosis
- experience hot flashes or night sweats
- be treated with an aromatase inhibitor.

There was no association between sexual dysfunction and stage of disease at diagnosis; type of surgery (lumpectomy or mastectomy); breast reconstruction; lymphedema; or axillary dissection.

Vasomotor symptoms in women taking endocrine therapy were associated with sexual dysfunction

Further analysis demonstrated that, among women who experienced vasomotor symptoms, those taking an aromatase inhibitor were more than three times as likely to report sexual dysfunction (odds ratio [OR], 3.49; 95% confidence interval [CI], 1.72–7.09), compared with women who were not on endocrine therapy—and those taking tamoxifen were almost twice as likely to report sexual dysfunction (OR, 1.73; 95% CI, 1.04–2.89). Chemotherapy was not independently related to sexual dysfunction.

In summary: 70% of women who were free of breast cancer 1 year after enrollment reported bothersome sexual consequences of their disease and its treatment; 77% reported vasomotor symptoms. Women who were rendered menopausal and those who experienced vasomotor symptoms while taking an aromatase inhibitor were at high risk of sexual dysfunction.

What this evidence means for practice

Be aware of the side effects of breast cancer and its treatment, and not only prepare your patients for the likely consequences but also make yourself knowledgeable about strategies to ameliorate their vaginal dryness and to improve elasticity and arousal for them.

Proactive stretching, use of vaginal dilators and topical oils, and, most important, psychological strategies to help your patients and their partners adjust to the inevitable physical changes will go a long way toward improving their sexual experiences.

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Gynecologic cancer disrupts sexual function, over the short term and the long term


The two studies explored sexual function after treatment for gynecologic cancer. The investigators found significant disruption of function.

Jensen et al: Radical hysterectomy for cervical Ca damages sexual function significantly
This was a prospective cohort study of 173 women who had early-stage cervical carcinoma and who underwent radical hysterectomy with pelvic lymphadenectomy (all of them node-negative). A validated questionnaire was administered six times, from 5 weeks to 24 months after surgery. An age-matched group of women without cancer was used for comparison. At the 12-month follow-up, patients were asked to report their sexual function at baseline and compare it to their current status. Overall, the women had a higher level of dissatisfaction with their sexual experiences 12 months after surgery than at baseline.

Details of the study
Women in the Jensen study were 23 to 75 years old (median age, 42.7 years), and 93% were sexually active at the time of diagnosis, reporting an average of one to two sexual activities in a week. Forty-six women (25%) were postmenopausal at diagnosis, compared with 34% of the control group. Only 8% of patients were using HT at study entry, compared with 25% of women in the control group. By 12 months after surgery, however, 25% of gynecologic cancer patients were taking systemic HT.

Findings included low libido and other ills
Severe lack of lubrication and low or no sexual desire were reported by cancer patients throughout the first 2 years after surgery. Patients also reported severe problems achieving orgasm as long as 6 months after surgery, as well as reduced vaginal size; both problems rendered their sexual experiences unsatisfactory. Nevertheless, 40% of patients reported at least some sexual activity by 5 weeks after surgery. By 6 months after surgery, there were almost as many sexually active women among the patient group as there were in the control group. However, at 18 months after treatment, patients reported less interest in intimacy—among both themselves and their partners—than among women in the control group. Overall, women treated for cervical cancer had a higher level of dissatisfaction with their sexual experiences 12 months after surgery than they did before diagnosis.

Although 91% of women who were sexually active before surgery resumed intercourse within 12 months, the frequency of sexual activity declined from one to two times per week to three to four times per month. Major long-term changes occurred in regard to libido (interest in sexual relations), arousal (vaginal lubrication), and vaginal size. Although dyspareunia was a significant problem 5 weeks to 3 months after surgery, it resolved within 1 to 2 years.

Jensen and colleagues concluded that
Two survivors report frustration—and resignation—when they sought help for sexual complaints

Katie* and Julie* tell typical stories of deep dissatisfaction with the health system after their cancer treatment

Katie: “I wasn’t prepared”
When my doctor told me I had locally advanced breast cancer 3 years ago, when I was 50, I wasn’t that surprised by the cancer diagnosis (I have a strong family history of breast cancer)—only by the fact that the tumor had developed so fast since my previous mammogram 15 months earlier. As treatment, I underwent neoadjuvant chemotherapy and bilateral mastectomy (I had the unaffected breast removed as a preventive measure). I also had breast reconstruction and started taking an aromatase inhibitor.

At the time of my diagnosis, I lost all desire for sexual intimacy—no big surprise there. But even after my treatment was over, my desire did not return. Part of the problem was the fact that chemotherapy rendered me menopausal, and the aromatase inhibitor I was taking compounded the menopausal experience. Quite suddenly, I was experiencing hot flashes, vaginal dryness and itching, pain during intercourse, severe bone and joint aches, weight gain (particularly around my abdomen), and general lethargy.

No one in my family had ever mentioned these effects of cancer. And none of my doctors prepared me, either. In fact, when I raised the subject, they seemed genuinely surprised! They offered no remedy other than a recommendation to apply a “moisturizer”—but they gave no details about what kind or how to use it. My oncologist did say that local estrogen would help relieve the pain of intercourse—but then she recommended strongly against it because my cancer was hormone-receptor positive.

My plastic surgeon did a much better job of explaining the effects and outcome of reconstruction than any of my other physicians, including my ObGyn, did of preparing me for menopause and sexual dysfunction. All of my physicians strike me as caring, sensitive people, but their underlying attitude, as I perceive it, is that I should be grateful to be alive. In their view, it seems, enjoyment of sex is icing on the cake and, quite frankly, I am plenty lucky to have the cake. My oncologist even told me to let her know if I started “feeling better and having fewer hot flashes” so that she could perform ovarian ablation (and start the whole cycle over again). I was struck by how matter of factly she gave this advice, as though quality of life counts for nothing.

Three years into my postcancer life, I can say I have “adjusted” to my problems rather than overcome them. I am still taking an aromatase inhibitor. Sex is still slightly painful; I still struggle with vaginal dryness; and I sometimes feel like an old woman because of my bone and joint stiffness and pain. I did find out about an over-the-counter vaginal suppository, made with vitamin E and coconut oils, from another breast cancer survivor. And I switched from one aromatase inhibitor to another in an attempt to alleviate my achy joints. It helped.

I am grateful for my life—very much so—and for the expertise of my physicians, who helped to save it. But I wish they had prepared me better for the aftermath of cancer treatment. And I wish there were more remedies for women like me, who cannot take hormones.

Julie: “I’m on my own”
It was more than a surprise when my new doctor told me I had cancer. Until then, I had avoided doctors. That attitude can mean a premature death sentence when it comes to cervical cancer. It was a pretty awful realization that I could have avoided the drastic measures it took to save my life if I had just gotten annual Pap smears and exams. I was 39 at the time of diagnosis.

But after all the surgery and chemo and radiation were finished, the message I received was essentially: “OK, you’re good, for now. Just come back every few months for a check-up.”

What about the aftermath of all that treatment? What about the other aspects of the experience? I found that my doctors had very little to offer outside of surgery and drugs and the quick advice to get counseling or some other support services.

“I’m on my own” is what I’ve been telling concerned folks who ask how I’m doing. I am truly grateful for the skill, medicine, and machinery that made the killing of an invasive tumor possible. But I’m on my own when it...
Two survivors report frustration—and resignation—when they sought help for sexual complaints.

My partner and I have had to be persistently creative, careful, delicate, uncritical, and extremely patient with each other to bring about the return of a “normal” sex life. We have been successful, for the most part, but there is also a slightly new definition of what “normal” is for us. Our latest triumph is that we no longer have to use copious amounts of lubricant to engage in intercourse. Sex is no longer painful, as the vaginal tissues have been slowly, patiently engaged on a regularly scheduled basis. Can you imagine sex on a schedule? Neither could I, but that is what we found worked from as early as 1 week postradiation. As it turns out, this was good advice—really, the only advice I got when it came to the practicalities of restoring function, but it required a fair amount of tweaking and personalization as well.

Another big change in perception that I had to accept as part of my new norm is learning to talk about my most personal areas in a matter of fact way. The cancer conveyor-belt approach to treatment is a very streamlined, well-run system. I’ve been impressed with the expertise, efficiency, and demeanor of all the professionals I have encountered. Everyone—even receptionists—has been helpful and empathetic, especially my own ObGyn, who has hugged me and cried with me and offered to put herself on the line for me and speak out to the media when I had no health insurance. But for most patients post-treatment, we figuratively walk off a cliff and find ourselves in new territory without any network or structure like we experienced during the “war” on our cancer. This new territory is a place of possibility within the health-care field—one I hope is developing now.

Dr. Barbara S. Levy asks: How do we respond? We physicians are so focused on treating or curing disease that we often lose sight of the woman who has the disease.

Katie’s case is much too common. Women are often reluctant to address their sexuality with us—especially when we have been dismissive. We must recognize this important aspect of quality of life and relationships and be prepared to raise the issue with our patients before they begin therapy.

Educating ourselves and then our patients about strategies to reduce the impact of treatment and menopause on sexual function is the first step. Acknowledging and validating their concerns and being able to offer practical steps to preserve healthy sexual function is something, I think, that all ObGyns should be able to do. Strategies to maintain vulvovaginal elasticity include avoidance of soaps and drying chemicals, daily perineal and vaginal stretching—either manually, with a dilator, or via frequent sexual intercourse. And topical lubricants and moisturizing agents should be recommended to maintain vaginal pH and reduce the dryness, itching, and overall dysesthesia.

As the studies highlighted in this Update on Sexual Dysfunction demonstrate, the sexual consequences of radical hysterectomy are significant. Julie also became menopausal as a result of treatment—yet no one prepared her for the symptoms she would experience, and no member of her treatment team helped her understand the likely impact of therapy. Radiation oncologists do address the need for vaginal dilators or daily intercourse to maintain depth and caliber of the vagina during and after therapy, but they are less likely to prepare a patient for menopausal symptoms.

If our patients are to have an optimal experience, we need to provide coordinated, cross-disciplinary care that includes management not only of immediate side effects of treatment but also psychosocial and long-term hormonal and sexual sequelae of therapy. Julie charted her own course with the help of a very dedicated and sensitive partner to successfully overcome the negative effects of radiation, chemotherapy, surgery, and menopause on her sexuality.
Radical hysterectomy for treatment of early-stage cervical cancer has significant negative effects on sexual function in the short and long term. They postulated a neurogenic basis for the sexual complaints and discussed both histologic and clinical studies to support this hypothesis. They also emphasized the need to discuss the risks and management of sexual dysfunction with patients before and after surgery. Better management of the psychosocial consequences of a cancer diagnosis and the physical effects of radical hysterectomy may help avoid the negative experiences that were reported in this study.

**Vaz et al: Rate of dyspareunia was high among women treated for endometrial or cervical Ca**

Investigators followed 107 women from initial consultation for radiation therapy through 3 years post-treatment. Although a significant percentage (50%) of the cohort was lost to follow-up—many due to death or tumor recurrence—50% of those who remained reported dyspareunia 3 years after radiotherapy.

Women in this study were 21 to 75 years old (median age, 60 years) and had cervical or endometrial carcinoma. Eighty-nine women (83%) received external pelvic radiation as well as brachytherapy. Before beginning radiation therapy, 37.4% of the cohort underwent surgery for treatment of their cancer. Sixty-four percent of the cohort had stage III or IV disease.

At enrollment, 50% of women reported having a life partner, 82% were postmenopausal, and 11.2% were taking HT. However, only 21.5% of women reported sexual activity. The authors opine that this low rate of sexual activity may have been due to recent surgery, bleeding, or pain related to cancer.

All women were offered “standard” interventions for their dyspareunia, including the use of vaginal dilators twice daily for 2 years, as well as the use of vaginal lubricants. Patients who experienced menopausal symptoms—hot flashes, decreased libido, dyspareunia—were referred to a menopause outpatient clinic.

Before treatment, 20% of women reported dyspareunia. Three years later, 44% of patients reported sexual activity, but 50% had dyspareunia. Twenty-one percent reported lower sexual interest relative to baseline, 8% reported vaginal dryness, and 21% reported vasomotor symptoms. Although there was a trend toward increasing sexual activity with decreasing vaginal dryness, the rise in dyspareunia from 20% to 50% over 3 years is troubling.

**References**

When a patient has undergone treatment for cancer, ask about her sexual function

A symposium on sexual health yields recommendations for your broader care of cancer patients

How likely are you to encounter a cancer survivor in your practice?

Very.

According to the Centers for Disease Control and Prevention (CDC), there were 6.3 million female cancer survivors in the United States as of 2007—and that number has likely increased by a million or more. In fact, the number of cancer survivors is expected to double by 2016.

How likely is that cancer survivor to have sexual dysfunction?

Highly.

According to a 2010 survey by the Lance Armstrong Foundation, 46% of cancer survivors report problems with sexual functioning after treatment—and that’s probably a conservative figure, given that 64% of all people with cancer have a malignancy that directly affects sexual organs.

One more question for you to ponder: How likely is the cancer patient’s sexual dysfunction to go unaddressed?

Extremely.

According to speakers at the Cancer Survivorship and Sexual Health Symposium, held June 17–19, 2011, in Washington, DC, cancer survivors are ill prepared for many of the symptoms of sexual dysfunction that develop after treatment, and many physicians fail to address this dimension of their health.

The symposium, sponsored by the International Society for Sexual Medicine and the Sexual Medicine Society of North America, was organized to address these gaps in care. During the 3-day conference, speakers from oncology, gynecology, mental health, urology, and other specialties presented data and described their experience managing cancer patients. They also offered recommendations for clinicians:

- **Talk about it.** Address the “highly prevalent but commonly ignored” adverse sexual effects of malignancy and its treatment. Ask: “How has cancer affected your sex life?”
- **Try to prevent it.** Consider nerve-sparing strategies during radical hysterectomy, radical trachelectomy, and clitoral preservation, which may lead to improved sexual function
- **Encourage and support use of dilators.** Advise women who have gynecologic cancer to use dilators to maintain vaginal patency, and be aware that compliance is linked to support from a health-care provider
- **Encourage sexual activity,** which can help preserve function
- **Consider local estrogen.** When it is appropriate, prescribe vaginal estrogen, which is minimally absorbed, to reduce vaginal symptoms of menopause. (The safety of local estrogen remains in question for women who have breast cancer.)
- **Check for problems at each follow-up appointment,** and be prepared to explain function and treatment options more than once
- **Promote female genital blood flow.** For example, it may be appropriate to begin sexual rehabilitation, such as use of vaginal dilators, during treatment
- **Consider referral** to a sexual rehabilitation program that includes medical and psychological approaches
- **Build a network** of psychologists, sex therapists, and other professionals who can assist you in managing your patients’ complaints.

“Discomfort around human sexuality is the main reason the issue doesn’t get raised by health-care providers,” said symposium speaker Sharon L. Bober, PhD, of the Dana-Farber Cancer Institute in Boston. “No one wants to initiate the conversation.” Dr. Bober emphasized the importance of asking about sexual function when a cancer survivor presents for care. “A majority of cancer patients in the community don’t hear this question from their providers.”

—Janelle Yates, Senior Editor