Counseling Cancer Patients About Changes in Sexual Function

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Cancer treatments often cause sexual dysfunctions that remain severe long after therapy is over. Nevertheless, sexual counseling is not routinely provided in most oncology treatment settings. Most patients and their partners can benefit from brief counseling that includes education on the impact of cancer treatment on sexual functioning; suggestions on resuming sex comfortably and improving sexual communication; advice on how to mitigate the effects of physical handicaps, such as having an ostomy, on sexuality; and self-help strategies to overcome specific sexual problems, such as pain with intercourse or loss of sexual desire. Brief counseling can be provided by one of the allied health professionals on the oncology treatment team. A minority of patients will need specialized, intensive medical or psychological treatment for a sexual dysfunction. In a large cancer center, such treatment could be provided as part of a reproductive health clinic serving the special needs of cancer patients. In smaller settings, the oncologist should build a referral network of specialists. Not all managed care organizations reimburse for these services, however. [ONCCOLOGY 13(11):1585-1591, 1999]

Introduction

Sexual dysfunction is one of the more common, enduring consequences of cancer treatment. About half of women who survive breast or gynecologic cancer report severe, long-lasting sexual problems.[1-3] Probably as many as 70% of men who are undergoing active treatment for localized prostate cancer will experience sexual impairment.[4-8] Although disease-free breast or prostate cancer survivors typically report that their overall health-related quality of life is normal, their sexual problems remain bothersome exceptions to this general good functioning.[1,6] For other cancers, such as testicular cancer, leukemia, or Hodgkin’s disease, at least one-quarter of patients are left with sexual dysfunction.[9-11]

Recent research has also highlighted that sexual dysfunction is highly prevalent among the general population of US men and women 18 to 59 years old, and that these problems are associated with both poor physical health and emotional distress.[12] Sexual problems become progressively more common with aging in men,[12,13] whereas menopausal women in the community are more likely to maintain good sexual function if they still have a partner.[14] Because sexual problems can contribute to poor self-esteem and interfere with relationships, it is worth some effort to try to remediate them.

Barriers to Providing Sexual Counseling in Oncology Settings

For a variety of reasons, sexual counseling has not become a routine part of oncology care in most settings.

Time Constraints

One important barrier is the time required for such counseling. A recent study found that the average duration of an outpatient visit to a family physician is now 10 minutes, including all patient-physician communication and the physical examination.[15] When a patient reported being emotionally distressed, the duration of the visit only increased to an average of 12.8 minutes.[16] In busy oncology clinics, where outpatient visits must include educating patients about their disease, prognosis, and treatment, physicians and nurses often do not have the luxury of assessing quality-of-life issues. They may hesitate to bring up a topic such as sexuality because discussing it will take too much time and is not high enough on the list of priorities. Even when a patient returns for periodic follow-up visits, time is short and the focus is on the results of diagnostic tests. Under managed care, more patients are being followed after the completion of cancer treatment by family physicians rather than oncologists. Nonspecialist physicians may not be as familiar with the long-term side effects of cancer treatment, including the risks of sexual dysfunction. Physicians may also be working within systems that discourage referrals for specialty care. Furthermore, even in traditional indemnity plans, many private insurers exclude mental health
treatment of sexual dysfunction from their list of reimbursed services.

**Discomfort About Discussing Sexual Issues**

Another barrier is the discomfort health care providers and patients may feel about discussing sexuality. Despite the ubiquity of sexual topics in the media, our society still considers sexuality “dirty” and titillating. A young physician may fear that an older cancer patient will regard a question about sexual function as disrespectful or even flirtatious. When the physician and patient are of different religious or ethnic backgrounds, fears of being insensitive or intrusive may be exacerbated. Yet, hidden sexual issues may interfere with patients’ compliance with cancer treatment, as the following vignette illustrates:

A female medical oncology fellow who had spent her life in the Midwest was puzzled when one of her first patients in Texas, an 80-year-old Mexican-American widower, refused his third shot of hormonal therapy for metastatic prostate cancer. The elderly man, who spoke fluent English, said that he understood when the doctor stressed that stopping the hormones would allow his bone metastases to spread. The man offered no explanation for his refusal. However, after a few minutes, the patient’s son, who was also present during the visit, explained: “My father feels that if he can’t still be a man, it is time to die.”

“You mean he’s worried about his sex life? But your father is a widower and he told me he had no girlfriends!” the fellow exclaimed.

“That’s true,” the son agreed, “but he still expects to be able to have erections, even if they just happen in the morning or in the shower. Without that ability, he doesn’t want to go on.”

**Structure for Providing Basic Sexual Counseling**

Oncology health care providers can easily become more comfortable and knowledgeable about sexual counseling, if they are willing to invest the time to do so. The American Medical Association, recognizing the limited training that physicians are given in this area, has designed a special workshop on this topic for continuing medical education.[17] For oncologists who want to gain more knowledge about understanding, assessing, and treating sexual problems related to cancer, comprehensive reviews of the literature are available.[2,18]

**Routine Quality-of-Life Screening**

The most practical way to include sexual counseling routinely in oncology clinics is to provide routine screening and counseling for quality-of-life issues related to cancer treatment. When treatment teams are organized by disease site (for example, in a breast cancer clinic) or by treatment modality (such as on a bone marrow transplant unit or in radiation oncology), each treatment team should designate an allied health professional, usually an oncology nurse specialist, physician’s assistant, or social worker, to assess and triage patients for quality-of-life problems. Even in a smaller oncology setting, such an allied health professional is often available.

In a brief, 30- to 45-minute interview, it is possible to assess the patient’s social support network, reaction to cancer, past and current mood or anxiety disorders, past and current substance abuse, current major life stresses, quality of the patient’s intimate relationship, and any sexual problems or concerns. Although conducting such an interview with each new patient requires an investment of time on the part of the health care provider, it can save valuable physician-hours by identifying patients who need more intensive mental health or social work services.

When adequate support is provided in the medical setting, a distressed patient or chaotic family is less likely to demand an inappropriate amount of time and energy from the physician actually treating the cancer.[19] Patients also feel that they have an advocate on the treatment team who knows them as individuals—a factor that can greatly enhance patient satisfaction and possibly even compliance with treatment.

Perhaps an even more efficient way to screen patients for quality-of-life problems is to ask all new patients to fill out a questionnaire designed to measure quality-of-life concerns for cancer patients. Several of these are available that include subscales to measure sexual function and satisfaction. Patients who indicate specific sources of distress on the questionnaire can then be evaluated further and referred for needed services.

The most thorough, most detailed of these quality-of-life questionnaires is the Cancer Rehabilitation and Evaluation System (CARES).[20] It includes several questions about sexual function and satisfaction, as well as providing information on concerns about marital or dating relationships.
Functional Assessment of Cancer Therapy (FACT) has the advantage of brevity and is available in both a general version and several site-specific versions that assess sexual symptoms more extensively.[21]

At follow-up visits during or after cancer treatment, a brief questionnaire or face-to-face assessment of quality of life, including sexuality, should also be routine. Sexual problems, in particular, often become more apparent, or at least more distressing, during the first months after a patient finishes active treatment.

**Extent of Counseling**

Once patients with sexual problems or concerns have been identified, most do not require extensive medical or psychological treatment. Rather, they need information about the impact of cancer treatment on sexuality and suggestions for getting their sex life back to normal.

In a review of close to 400 patients who consulted a psychologist in a cancer center for sexual rehabilitation, 73% were seen only once or twice.[22] For a subset of patients who provided follow-up data, about 64% reported some improvement in their sexual problems. Thus, a large majority of patients can benefit from brief counseling.

**Brief Sexual Counseling: Content Areas**

The expert in sexual counseling on the primary oncology team should be able to provide brief sexual counseling, spending anywhere from a few minutes to a few hours with a patient. Brief sexual counseling includes: educating the patient (and often the partner) about the ways that cancer treatment can interfere with sexual function; giving suggestions on how to resume sex comfortably; encouraging more open communication about sex between partners; helping patients cope with physical changes that make them feel less attractive to a partner or interfere technically with sex; and helping patients obtain treatment for specific sexual problems.

**Educating Patients About Treatment-Related Sexual Problems**

Both men and women are often surprisingly uninformed about the anatomy of the sexual organs and the normal sexual response cycle. For example, women who have undergone a radical hysterectomy may not have an accurate visual image of which organs were removed and may mistakenly believe that surgery will interfere with their sexual desire or capacity to achieve an orgasm.[23]

Men who have had a radical prostatectomy may not know where the prostate is located or how the prostate and seminal vesicles produce seminal fluid. If they have been told that the surgery may result in nerve damage to the erection reflex, they may interpret this to mean that the penis will be numb after the operation. Many men do not realize that it is possible to experience an orgasm after undergoing a radical prostatectomy, even without an erection or ejaculation of semen.[24]

Moreover, lack of information or negative expectations about sexual functioning after prostate cancer therapy can create problems where none actually exist, as illustrated by the following vignette:

The author gave a lecture on sexual function after prostate cancer to a large audience of survivors and their spouses. At a workshop the next day, a woman approached the author and told her the following story: My husband and I had not tried sex at all for the past 3 years, since he began taking hormone therapy for his prostate cancer because we thought that he would be unable to have intercourse. We also hardly ever discussed sex because we both felt so discouraged. Yesterday, we both heard you speak about the fact that some men can function sexually even while they are taking hormones, and that it is always worthwhile to try some lovemaking and see what is possible. We did try, and were amazed to find that we could have successful intercourse!

Since most men and women with cancer are over age 50 years, it is also very important to place the changes in their sex lives into the context of the normal slowing of sexual response due to aging and menopause.[25] However, women who experience premature ovarian failure as a result of chemotherapy for breast cancer are at particular risk for sexual dysfunction, including a loss of desire and pain with intercourse.[1,26]

The designated sexuality expert on a treatment team should become familiar with the impact on sexual functioning of the treatments that the team typically administers. It is also helpful to know the sexual side effects of commonly prescribed medications for cancer patients, such as antiemetics, narcotic analgesics, tranquilizers, and antidepressants.[25] Almost all of these medications can decrease sexual desire in men and women. The newer antidepressants also commonly delay or
prevent orgasm, and these agents may occasionally interfere with erections in men. Although the treatment team may wish to develop some site- or treatment-specific hand-outs on sexual problems, detailed patient education materials on sexuality and cancer are available, including brochures for men and women published by the American Cancer Society[26,27] and a recent self-help book.[25]

**Encouraging Patients to Resume Sex During and After Treatment**

For most patients, cancer treatment creates some type of hiatus in their sex lives. Once patients are feeling well enough to think about sex—for example, after recovery from surgery, or even during radiation therapy or chemotherapy—they are often apprehensive about resuming sex. When this topic is discussed, it is often helpful to have both patient and partner in the room, since partners may sometimes be more worried than the patient about resuming sexual activity.

**Safety Concerns**[2] First, the provider of brief counseling should address any fears about the safety of sexual activity. It is worth emphasizing that cancer cannot be spread through sexual contact (a common misconception), and that it is not harmful for the partner to be intimate with a patient during external-beam radiation therapy or after brachytherapy is completed. Also, sex usually is not unhealthy for either partner during chemotherapy but may not be desirable during periods of extreme immunosuppression.

Some women may notice periodic vaginal irritation if they are receiving drugs that cause mucositis. Occasionally, partners of men receiving chemotherapy have complained of vaginal irritation. If this occurs, the man should consider using a condom during periods when metabolites of his chemotherapeutic drugs may be present in his seminal fluid. In fact, this is a good time to discuss contraception with couples who are in their childbearing years, and to discuss prevention of sexually transmitted diseases with patients who are not in a monogamous relationship.[25]

**Concerns About Sexual Attractiveness** Even more common are concerns about whether cancer treatment will detract from the patient's sexual attractiveness, especially if therapy included head and neck surgery, a mastectomy, or creation of an ostomy. Even when physical changes are subtle, such as a radiation tattoo, or temporary, such as chemotherapy-induced alopecia, it is normal for men and women to feel insecure.

**Fear of Sexual Dysfunction** Another typical source of anxiety about resuming sex is the fear that a dysfunction will occur. Men often focus on being able to achieve and maintain an erection. Women worry that they will not be able to get in the mood for sex or that intercourse will hurt. Some of these concerns are quite realistic, given that cancer treatments can directly affect sexual function. The counselor can suggest that a patient resume sex gradually, perhaps starting by getting accustomed to looking at or touching areas of the body changed by cancer treatment in private. Then patient and partner can give each other backrubs, kiss while clothed, or take a bath or shower together. Before trying to have sexual intercourse, the couple may wish to get comfortable with nonsexual touching and cuddling and then progress to manual or oral caressing of breasts and genitals. Various self-help materials provide a series of several structured touching exercises to facilitate this process.[25,27,28]

**Encouraging Open Sexual Communication Between Partners** Many couples in long-term relationships rarely discuss sex. Their lovemaking may have fallen into a routine that worked well, or, if minor problems did occur, they did not seem worth discussing. The trauma of cancer treatment may change sexual functioning in ways that necessitate more open sexual communication if a couple is to continue sexual activity, however. Perhaps it will be important to engage in sexual activity at a time of day when the patient is not exhausted or when pain medications provide their maximum effect. Erotic pleasure from certain types of caressing may decrease, for example, after breast conservation changes breast sensation. If it is not possible for a man to attain firm erections or for a woman to have pain-free intercourse, some couples may be willing to find alternative ways to bring each other to orgasm. Other couples may simply forego sex. The counselor can help partners communicate by encouraging them to discuss these issues openly in a joint counseling session. Alternatively, the counselor could provide the couple with suggested ground rules that will help them establish good communication about sex:

- Find a private time and place to talk about sex before you try to make changes. Ask your partner to change only one or two behaviors at a time.

- Make a specific, positive request for change rather than criticizing your partner’s sexual technique.
Remember to use nonverbal sexual communication, with one partner actually showing the other what would feel pleasant.

Try to regard sex as a time to share pleasure, rather than as an occasion to perform for each other.

Helping Patients Cope With Physical Handicaps
As a result of cancer treatment, some men or women sustain a major physical change that can interfere with their sex lives. Such changes include amputation of a limb, removal of the larynx, or creation of a urinary ostomy, ileostomy, or colostomy. Patients treated for tumors of the central nervous system may also suffer damage to cognitive abilities or to mobility or physical sensation. The specialists who provide rehabilitation services after cancer can often help patients resume sexual activity despite such handicaps and are excellent educational resources for the sexual counselor. For example, an enterostomal therapist can explain how to make ostomy appliances or tracheostomies less intrusive or unattractive. A respiratory therapist may be able to suggest sexual positions for a patient who is connected to a respirator. Physical therapists can advise patients about such issues as whether to wear a limb prosthesis during sex or what type of sexual positions may work when one partner has had a hemipelvectomy.

Advising Patients on Overcoming Specific Sexual Dysfunctions
The most common sexual problems after cancer treatment include loss of sexual desire (both men and women), erectile dysfunction (men), and pain with sexual activity (women).[2,18,22,25] Some of these problems are mild or transient and may respond to brief counseling.

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<td>Brief counseling interventions that the clinician can suggest before referring a patient for more specialized services.</td>
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Some sexual problems will not improve without more intensive medical or psychological treatment, however. Loss of desire for sex is often a multifactorial problem that requires a medical intervention combined with intensive sex therapy.[18,25] Erectile dysfunction after cancer is typically caused by damage to nerves or blood vessels involved in the erection reflex. New oral medications, such as sildenafil (Viagra), are less likely to be successful if the medical impairment is severe.[30] Clinics that treat erectile dysfunction now offer a variety of modalities for more intractable erection problems. These include penile injections, vacuum devices, and surgery to implant a penile prosthesis.[31]

Creating a Reproductive Health Clinic in a Cancer Center
Ideally, every comprehensive cancer center should offer reproductive health services, including treatment of sexual problems resulting from cancer therapy, counseling on special cancer-related issues regarding contraception or postmenopausal hormone replacement therapy, provision of sperm-banking and, possibly, cryopreservation of ovarian tissue before cancer treatment,[32] genetic counseling for cancer survivors who are interested in having children,[33] high-risk obstetrical consultation for women who are pregnant during or after cancer treatment, and infertility therapy or adoption counseling for survivors who are having trouble conceiving or have a known impairment in fertility as a result of cancer treatment.[33]

Some of these services are so specialized that they require referral of patients to an outside clinic. Ideally, however, a core set of professionals should be part of the cancer center staff, at least on a part-time basis. These include a mental health professional trained as a sex therapist and familiar with cancer and its treatment; a gynecologist well versed in issues of pelvic pain after cancer treatment, fertility in women treated for cancer, and hormone replacement in cancer survivors; and a urologist or internist specializing in male health who is familiar with the many medical and surgical options available to treat male sexual dysfunction.[25,31]

The reproductive health clinic may offer appointments with one or more specialists at a single location on certain days of the week, serving as a resource for the entire cancer center. Alternatively, it may be a clinic without walls[8] that consists of an organized system of cross-referrals, perhaps with a periodic meeting of the staff members to discuss complex cases. Although such a clinic is unlikely to be a major source of revenue, these areas of patient care are sufficiently procedure-oriented that a well-organized clinic providing such services should break even.

As mentioned above, reimbursement by insurers can be a problem for mental health services, but this is less of an issue for medical treatment of sexual problems. A reproductive health clinic in a
cancer center could also serve as a useful setting in which to conduct externally funded research projects. Unfortunately, no cancer center has yet developed such a clinic to serve as an initial model.

Building a Referral Network

It probably is not practical for smaller cancer centers, hospitals with an oncology unit, or outpatient oncology practices to establish a reproductive health clinic solely for cancer patients. In those settings, the sexual counseling specialist on the treatment team can assume responsibility for creating a network of specialists who can provide similar services. A comprehensive referral network would include:

- A mental health professional who provides sex therapy and sexual counseling
- A gynecologist who has expertise in assessing and treating pain with sexual activity
- A gynecologist or specialist in women’s health who can help women make decisions about hormone replacement therapy after cancer
- A urologist or male health specialist who provides medical treatment for loss of sexual desire and erectile dysfunction
- A sperm bank that can store semen samples for men about to begin cancer treatment that could potentially damage their fertility
- An infertility clinic offering in vitro fertilization and donor gamete programs that has a good success rate and staff who are familiar with cancer-related infertility in men and women
- A genetics clinic that can counsel cancer survivors regarding their concerns about birth defects or cancer risks in their offspring[33]
- A high-risk obstetrician familiar with cancer treatments that may influence pregnancy outcome
- Adoption agencies or specialists who can provide realistic guidance to cancer survivors seeking to adopt a child.

Conclusions

Although providing sexual counseling for cancer patients requires some specialized knowledge and interest, it is best performed by a member of the oncology treatment team. Furthermore, an assessment of sexual function should not be performed in isolation, but rather, should be part of a more general assessment of each patient’s quality of life, carried out at diagnosis and during treatment follow-up.

Sexuality is part of reproductive health. Thus, one way to offer specialized, intensive treatment for sexual dysfunction is to make it part of a range of more comprehensive services that also address the needs of cancer survivors for expert help with contraception, fertility, and options for having children.

References:


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