Obstacles of cancer survivorship: Sexuality issues - Need to break communication barriers

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ABSTRACT

Many types of cancer and cancer therapies are frequently associated with sexual dysfunction. Previously sexual problems in cancer patients were mostly linked to breast or gynecologic cancer in females and prostate cancer in males. However, recent studies indicate that several other cancers are associated with sexual problems with estimates of sexual dysfunction ranging from 40% to 100% across various sites. Conversation related to sexual problems is not often the comfort zone for both patients and doctors. Numerous barriers contribute to this lack of communication, including lack of provider training, lack of time and lack of access to resources should the need arise to tackle the problem. Although clinicians often worry that patients will be offended or embarrassed if asked about sexual health, it is important to remember that multiple studies clearly indicate that patients want to talk about this topic with their doctors and that they desire more information about possible sexual side effects of treatment. It is essential that clinicians prepare patients for potential changes that may be encountered and let them know that discussion about sexual health concerns is welcome. Patients should be offered sexual counseling and informed about the availability of therapies for sexual dysfunctions. In this article, we aim to provide a concise review of the most common sexual problems experienced by survivors and discuss treatment options to overcome the problem.

Key words: Cancer, chemotherapy, radiotherapy, sexual

INTRODUCTION

With improved cancer survival rates, it is becoming increasingly important to focus on quality-of-life issues. Sexuality is an important factor in the quality-of-life for patients and is intrinsic to a person’s sense of self and can be an intimate form of communication that helps relieve suffering. Physical pleasure and emotional intimacy provide enormous stress relief and calm in the midst of a tenuous and often pressured time. For patients who endure so many losses, as a result of cancer, including social, financial, physical, and emotional disruptions, the additional loss of sexual function leads to profound sense of shame and embarrassment. Patients often assume that their sexual dysfunction cannot be adequately addressed, and this loss cannot be undone. Often, oncologists do not feel comfortable addressing sexual problems, preferring instead to focus on treatment outcomes related to survivorship rather than quality-of-life.

Several studies have examined medical professionals’ barriers to communication about sexual health needs with their patients. It has recently been suggested that these barriers appear to fall into three categories: Issues related to patient characteristics, provider characteristics, and systems issues. Patient characteristics, that is, doctors may assume that an older person who is widowed or divorced is no longer sexually active or that if a patient is from another culture it would be inappropriate to ask about sexual concerns. Provider characteristics, that is, lack of experience and lack of knowledge of health care provider regarding changes in sexuality in cancer patients. Finally, systems issues are often reported as major barriers to this topic, that is, no time to address a topic like sexuality when there is barely enough time to manage more pressing concerns and “lack of resources to provide support if needed.”

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The causes of sexual dysfunction are often both physiological and psychological. The most common sexual problems for people with cancer include loss of desire for sexual activity in men and women; erectile dysfunction (ED) in men and dyspareunia (pain with intercourse) in women. Men may also experience an ejaculation (absence of ejaculation), retrograde ejaculation (ejaculation going backward to the bladder) and inability to reach orgasm. Women may experience changes in genital sensations due to pain or a loss of sensation and numbness and decreased ability to reach orgasm.

Previously sexual problems in cancer patients were mostly linked to breast or gynecologic cancer in females and prostate cancer in males. However, recent literature suggests that many types of cancer and cancer therapies are frequently associated with sexual dysfunction [Table 1 shows the prevalence of common sexual problems among cancer survivors].

**PROSTATE CANCER**

Survival rates for early detected prostate cancer are excellent. The relative 5 years survival rate has increased in the past 20 years from 67% to 99% making sexual dysfunction following prostate cancer treatments a progressively more important issue.

During radical prostatectomy, the seminal vesicles are also removed leading to dry orgasm (inability to ejaculate semen). Damage to cavernous nerves responsible for erection which run bilaterally along prostate results in semen). Damage to cavernous nerves responsible for erection which run bilaterally along prostate results in spermatogenesis and reaching orgasm. ED after surgery is 65 or fewer years of age. Erectile function presurgery is also an important predictor, with those who report poor functioning presurgery being more likely to develop severe ED after surgery. Another important factor in the recovery of erections after prostatectomy is the use of ectogenic medications in the 24 months postoperative period when the cavernous nerves are healing. There is good evidence to suggest that the use of ectogenic therapy immediately post-surgery reduces tissue fibrosis of the corporeal smooth muscle by increasing corporeal oxygenation.

There appear to be several predictors of erectile functioning after surgery. Younger men are more likely to retain erections after surgery and although there seems to be a clear association between age and ED, a number of physicians believe a reasonable cut-off point to consider is 65 or fewer years of age. Erectile function presurgery is also an important predictor, with those who report poor functioning presurgery being more likely to develop severe ED after surgery. Another important factor in the recovery of erections after prostatectomy is the use of ectogenic medications in the 24 months postoperative period when the cavernous nerves are healing. There is good evidence to suggest that the use of ectogenic therapy immediately after surgery reduces tissue fibrosis of the corporeal smooth muscle by increasing corporeal oxygenation.

With the advent of sildenafil, the first-line treatment for ED is oral medications. Unfortunately, oral medications may not be effective immediately after prostatectomy and during the 18–24 months when the cavernous nerves are healing.

### Table 1: Prevalence of common sexual problems among cancer survivors

<table>
<thead>
<tr>
<th>Cancer</th>
<th>Sexual problems</th>
<th>Prevalence (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Prostate</td>
<td>ED</td>
<td>14-90(8-10)</td>
</tr>
<tr>
<td>Testicular</td>
<td>Inability to ejaculate</td>
<td>30(11)</td>
</tr>
<tr>
<td></td>
<td>Reduced semen volume</td>
<td>16(11)</td>
</tr>
<tr>
<td></td>
<td>Loss of sexual drive</td>
<td>2(11)</td>
</tr>
<tr>
<td></td>
<td>Reduced erectile function</td>
<td>1(11)</td>
</tr>
<tr>
<td>Bladder</td>
<td>Men-ED</td>
<td>86 with radical cystectomy; 5 with potency preserving surgery; 25 with radical radiotherapy</td>
</tr>
<tr>
<td></td>
<td>Women-diminished or absent orgasm, decreased lubrication, dyspareunia, decreased sexual desire</td>
<td>22-45(10)</td>
</tr>
<tr>
<td>Colorectal</td>
<td>Erectile and ejaculatory problems in men</td>
<td>40(11)</td>
</tr>
<tr>
<td></td>
<td>Dyspareunia, changes in genital arousal, decreased lubrication and altered orgasms</td>
<td>6-50(10)</td>
</tr>
<tr>
<td>Breast</td>
<td>Absent/low desire, Arousal/lubrication problems</td>
<td>48-64(17)</td>
</tr>
<tr>
<td></td>
<td>Dyspareunia</td>
<td>42(17)</td>
</tr>
<tr>
<td></td>
<td>Orgasm problems</td>
<td>38(17)</td>
</tr>
<tr>
<td></td>
<td>Body image concerns</td>
<td>30(17)</td>
</tr>
<tr>
<td></td>
<td>Poor nipple sensation</td>
<td>30-67(8)</td>
</tr>
<tr>
<td>Gynecologic cancers</td>
<td>Vaginal dryness and painful intercourse</td>
<td>&gt;90(9)</td>
</tr>
<tr>
<td>(cervical, ovarian)</td>
<td></td>
<td>57 in ovarian cancer; 26 in cervical cancer</td>
</tr>
<tr>
<td>Lymphoma</td>
<td>Decreased interest</td>
<td>28(22)</td>
</tr>
<tr>
<td></td>
<td>ED</td>
<td>61(23)</td>
</tr>
<tr>
<td>Lung cancer</td>
<td>Loss of libido, decreased desire</td>
<td>40-100(24)</td>
</tr>
</tbody>
</table>

ED: Erectile dysfunction
Oral medications enhance the effects of nitric oxide (NO). The NO that impacts erectile function is secreted from the cavernous nerves that run bilaterally along the prostate. If these nerves are injured intraoperatively, the amount of NO secreted is dramatically reduced, and oral medications will have little positive effect on increasing NO or enhancing erectile function. Because oral medications may not be effective for 18–24 months after surgery, intracavernous prostaglandin E1 penile injection therapy is considered by many as a second-line treatment option for men in this period. This has been found to be effective for 94% of patients. The primary concern with this treatment is that the thought of penile injections is anxiety-provoking, and many patients worry that this type of therapy will disrupt the “mood” of a sexual experience. However, with appropriate training it is possible for many couples to use this treatment successfully. Other treatment options include vacuum constriction devices and penile prosthesis. Penile prosthesis achieves patient satisfaction rates between 92% and 96%. However, this involves an invasive procedure that is irreversible.

External-beam radiation and brachytherapy are also treatment options for men with early-stage prostate cancer. However, the data suggest that the rates of ED are similar between the radiation and surgery groups at 3–5 years posttreatment. However, the course of ED is different in each treatment. As stated previously with surgery, rates of ED are highest after treatment and then improve slightly up to approximately 2 years after surgery. For radiation therapy, rates of ED are lowest directly after treatment and then slowly increase up to 3 years after treatment. The mechanism for this decline in function is that the fibrosis continues to develop up to approximately 3 years after radiation and interfere with the neurovascular bundles and blood vessels adjacent to the prostate and necessary for erections. As a result, men who have undergone radiation therapy have equivalent rates of ED to those undergoing nerve-sparing surgery at a 5 years medical follow-up. The options for ED treatments after radiation are similar to those stated previously, and the first-line therapy continues to be oral treatment. Overall, 50–60% of men regain erections with medication.

The primary treatment for men diagnosed with late-stage prostate cancer is androgen deprivation therapy is accompanied with a number of side effects including loss of libido and ED along with other side-effects such as gynecomastia, hot flushes and osteoporosis. The treatments for ED associated with hormone therapy remain oral medication for first-line therapy and secondary-line of therapies if oral medications fail. Men treated with hormone therapy do not respond well to any ED treatments, but data are limited.
Body image often takes a hit after a testicular cancer diagnosis. Many men feel a loss of masculinity and sexuality following treatment. Men consider them as “half men” following orchidectomy which is not true. Men who are significantly worried about their body image can be offered implantation of a testicular prosthesis.

In summary, data suggest that although men with testicular cancer may report more problems with some aspects of sexual function, negative changes are mostly short term, with long term function and activity being comparable to function and activity in the general population.

## BLADDER CANCER

Bladder cancer is the fourth most common cancer in men. Nonmuscle invasive bladder cancer (superficial bladder cancer) is treated with resection and adjuvant intravesical chemotherapy or immunotherapy. Invasive bladder cancer requires radical cystectomy. Radical cystectomy has been associated with negative implications on sexual functioning. A standard radical cystectomy for treating bladder cancer in men involves the removal of the bladder as well as the prostate, seminal vesicles, vasa deferens, and the removal or damage of the neurovascular bundles, leaving the patient with the likely consequent loss of sexual function. Following radical cystectomy ED was prevalent in 86% patients. There were initial encouraging results with potency preserving cystectomy which included cystectomy with sparing of prostate, vasa deferens, seminal vesicles, and resection of a prostatic adenoma to avoid bladder outlet obstruction and bladder reconstruction with an orthotopic reservoir. However, a multicenter study showed that the cancer outcome following potency-sparing cystectomy is significantly worse than results from the standard radical treatment, and that the 10–15% higher treatment failure rate is too high of a price to pay in exchange for the advantage of preserving sexual functioning. The study concluded that the sexuality-sparing cystectomy for bladder cancer is a step in the wrong direction and should be abandoned. The main criticism about so-called sexuality-sparing cystectomy has been the presence of consistent prostatic remnants. Performing intrrafascial prostatectomy together with supra-ampullar cystectomy was shown to achieve preservation of erection in 95% patients while better preserving oncological safety. Bladder preservation with use of chemoradiation in muscle invasive bladder cancer has also shown to be associated with high incidence of ED.

Treatment of ED following radical cystectomy follows the standard of care for ED in men treated with prostatectomy. Preoperative sexual counseling is very essential as around 47% patients do not seek help for sexual dysfunction postoperatively. Sexual counseling might also be useful to a number of men and women under surveillance for nonmuscle-invasive bladder cancer, some of whom mistakenly report being afraid of harming their partner through sexual contact.

The standard radical cystectomy for bladder cancer in women involves the removal of the bladder, urethra, anterior vaginal wall, uterus, and ovaries, and it is likely to result in sexual dysfunction. The large prevalence of sexual dysfunction in women after radical cystectomy has also sparked a search for alternative procedures, and the literature that is available documents promising results for women undergoing the nerve-sparing cystectomy. However, very little has been reported on these procedures and their impact on sexual functioning versus their oncologic risks. Symptoms of sexual dysfunction reported by women after radical cystectomy include diminished ability or inability to achieve orgasm, decreased lubrication, decreased sexual desire, and dyspareunia. Therapies for sexual problems in women bladder cancer survivors follow many of the same recommendations for women survivors of breast, gynecologic, and colorectal cancer.

## COLORECTAL CANCER

Colorectal cancer is the third most common cancer in men (10% of total) and the second most common in women (9.2% of total) worldwide. Treatment includes multimodality approach including surgery, radiotherapy and chemotherapy with surgery being the most important aspect of treatment in nonmetastatic disease. The survival rates are excellent with 5 years overall survival rate of 64% and a 5 years survival rate of 90% for localized disease. Many survivors report significant sexual dysfunction after treatment that may adversely affect their quality-of-life in survivorship. Urinary and sexual dysfunctions are common problems after rectal cancer surgery, and the likely cause is damage to the pelvic autonomic nerves during surgery resulting in erectile and ejaculatory disorders in men, and dyspareunia, decreased libido, and changes in the orgasm experience in women. The autonomic nerves consist of the paired sympathetic hypogastric nerve, sacral splanchnic nerves, and the pelvic autonomic nerve plexus. In recent years, attention has been focused on preserving the autonomic nerves through a technique which is usually combined with total mesorectal excision or radical pelvic lymphadenectomy.

Following autonomic nerve-preserving operation for rectal cancer 87.7% and 66.9% of patients maintained erectile and ejaculatory potencies respectively, which were higher rates than those after extended and conventional pelvic dissections. Both hypogastric nerve and the pelvic plexus preservation are necessary to maintain ejaculate function.
and orgasm. In general, with respect to pelvic surgeries for rectal cancer, abdominoperineal resection is associated with a higher risk of postoperative sexual dysfunction compared to sphincter preservation surgeries. Studies indicate that men and women who undergo colonic resection are less likely to experience sexual dysfunction following surgery than those who undergo rectal excision.

Even though the impact of radiotherapy in colorectal cancer survivors has rarely been addressed, the available research suggests that the radiation is associated with sexual dysfunction in both men and women. In men, sexual dysfunction after pelvic radiotherapy may result from damage to pelvic nerves and blood vessels and also from slowing of testosterone production. Sexual dysfunction in women after pelvic radiotherapy is generally the result of alterations in vaginal anatomy and decreased vaginal lubrication. Radiation to the whole pelvis is likely to result in ovarian failure and thus radiation-induced menopause in premenopausal women. When patients with resectable rectal cancer were randomized to total mesorectal excision with or without preoperative radiotherapy (PRT), increase in general sexual dysfunction, ED and ejaculatory problems were reported by 76.4%, 79.8%, and 72.2% of the male patients, respectively. Risk factors were nerve damage, blood loss, anastomotic leakage, PRT, and the presence of a stoma. In female patients, increase in general sexual dysfunction, dyspareunia and vaginal dryness were reported by 61.5%, 59.1%, and 56.6%, respectively. This was associated with PRT and the presence of a stoma. Bonnel et al. also reported that PRT for primary resectable rectal carcinoma may impair male sexual function for patients having a sphincter-saving, nerve-preserving total mesorectal excision.

Therapies to manage sexual side effects of colorectal cancer treatment in men and women have rarely been studied. However, therapies recommended for prostate cancer survivors, such as the use of sildenafil, appear to be adequate for a number of male colorectal cancer survivors who suffer from ED following treatment. Therapies recommended for breast and gynecologic cancer survivors, such as the use of water-based lubricants, vaginal moisturizers, and vaginal dilators, can also be recommended for female colorectal cancer survivors who suffer from vaginal dryness and/or stenosis after radiation. More specific to colorectal cancer survivors are the negative emotional reactions to the colostomy, such as poor body image and reduced self-esteem, which are commonly present and may negatively impact intimacy. Patients with ostomies should receive information on deodorants to minimize odor, as well as on foods that are likely to cause stronger odors, gas, or diarrhea. Patients should also receive information on pouch covers, and suggestions such as changing positions to avoid pain during intercourse and emptying the stoma before sexual activity.

**BREAST CANCER**

Breast cancer is the most common cancer in female worldwide according to GLOBOCON 2012 data. Five years survival rate of localized breast cancer is 97%. Difficulties with sexual functioning are the most common and most distressing problems experienced by survivors which include low desire, arousal, lubrication problems, and pain.

Mastectomy causes significant damage to woman’s core sense of femininity, body integrity, and attractiveness. Concern about body image is reported in approximately 30%–67% of women. Body image problems were associated with mastectomy and possible reconstruction, hair loss from chemotherapy, concern with weight gain or loss, lower self-esteem, and partner’s difficulty understanding one’s feelings. Breast-conserving surgery and breast reconstruction help women maintain a positive body image. With breast reconstruction, breast shape is restored but not the loss of feeling. There is a complete lack of sensation, including nipple sensation.

Nipple sparing mastectomy has also been tried but majority of patients rated sensation as fair or poor.

Women who received chemotherapy in addition to surgery had more negative sexual outcomes than women treated with surgery alone. Chemotherapy induced menopause causes intensive estrogen deficiency leading to severe vaginal dryness and vaginal atrophy. Painful intercourse due to vaginal dryness is one of the most common sexual problems after breast cancer, and it is one of the primary factors also implicated in women’s experience of decreased desire. Endocrine therapy, including selective estrogen receptor modifiers and aromatase inhibitors play an important role in breast cancer treatment. Although vaginal dryness and low desire have been reported with tamoxifen, in the large-scale breast cancer prevention trial there were no differences found in the frequency of sexual activity between those using tamoxifen versus placebo. Aromatase inhibitors are associated with exacerbation of postmenopausal gynecological symptoms such as vaginal dryness and dyspareunia which if not managed appropriately, results in sexual dysfunction.

Hardly any research has been conducted that specifically examines the effects of breast cancer-related radiotherapy on sexuality. Radiation can result in skin fibrosis, an additional loss of sensitivity in the skin, and fatigue, all which can contribute to low desire.
To decrease vaginal dryness, vaginal moisturizers can be applied at bedtime. Vitamin E gel caps can also be used as a vaginal moisturizer. Women should be advised to apply water-based vaginal lubricants such as K-Y Jelly/Astroglide around and inside the entrance of the vagina and also to spread it over partner’s penis and fingers. Petroleum jelly (Vaseline), skin lotions, and other oil-based lubricants are not good choices for vaginal lubrication. Low doses of estrogen in gels, creams, rings, or tablets can also be kept inside the vagina. These methods focus small amounts of hormones on the vagina and nearby tissues, so that very little gets in the bloodstream to affect other parts of the body.

Nurse-delivered, individually based counseling is more successful in managing sexual problems in breast cancer survivors.\(^{[50]}\) Interventions that produce stronger effects tend to be couple-focused and include treatment components that educate both partners about the woman’s diagnosis and treatments, promote couples’ mutual coping and support processes, and include specific sexual therapy techniques to address sexual and body image concerns.\(^{[51]}\)

**OTHER GYNAECOLOGIC CANCERS**

Sexual dysfunction is common among survivors of cervical cancer, endometrial cancer, and ovarian cancer. Hysterectomy is an important part of treatment in these patients. Hysterectomy does not usually change a woman’s ability to feel sexual pleasure. The area around the clitoris and the lining of the vagina generally stay as sensitive as before. Some women feel less feminine after a hysterectomy. They may view themselves as “empty,” or not feel like a “real” woman. A trained therapist often can help with such concerns. Pelvic radiation commonly employed in these patients often affects a woman’s sex life. Larger doses of radiation therapy can lead to permanent damage to ovaries, premature menopause and subsequent severe estrogen deficiency causing vaginal dryness and painful intercourse. A woman’s vagina may feel tender during radiation treatment and for a few weeks afterward. As the irritation heals, scarring may occur. The thick walls of the vagina may become fibrous and tough and might not stretch out as much during sexual excitement and activity. The scarring that can occur after pelvic radiation can shorten or narrow the vagina. To prevent this, it is necessary to stretch the walls of the vagina with vaginal penetration during sex at least 3 or 4 times a week or using a vaginal dilator on a regular basis. As a general recommendation, vaginal dilation should start as soon as possible. This is comfortable but usually within 4 weeks after completion of radiotherapy.\(^{[52]}\) Psychoeducational interventions that combine information with motivational and behavioral skills are more effective than information alone in improving adherence to the use of vaginal dilators in younger women treated for gynecologic cancer.\(^{[52]}\)

**LYMPHOMA**

The sexual functioning of male lymphoma survivors has rarely been studied. In a survey of 459 Hodgkin’s lymphoma (HL) survivors, transient or long term reduction of sexual interest and activity was reported by 28%.\(^{[22]}\) Similarly, in another study, 24% reported at least one sexual problem.\(^{[54]}\) When using a standard questionnaire on erectile function, 36 (61%) of 59 lymphoma survivors aged 18–55 years reported reduced erectile function.\(^{[23]}\) Thus, the prevalence of self-reported reduced sexual function may be higher when more detailed questionnaires are used. Both chemotherapy and radiotherapy can damage Leydig cell and/or pituitary function, resulting in subnormal testosterone levels that could potentially lead to sexual problems.\(^{[55,56]}\) In a follow-up survey of 294 male lymphoma survivors, 30% had low testosterone and/or elevated luteinizing hormone.\(^{[57]}\) The most important factors associated with reduced sexual function in lymphoma survivors were older age, more emotional distress, and poorer physical health. Sexual domain scores on the brief sexual function inventory were similar in survivors of HL and non-HL. Survivors with low testosterone and/or elevated LH had impaired sexual function compared with those with normal hormones, even after taking other health factors into account.\(^{[58]}\) It is generally assumed that if a man’s testosterone levels are below the normal range, testosterone supplementation will improve sexual function. A conservative approach would be to treat cancer survivors with sexual dysfunction initially by encouraging a healthy lifestyle, particularly in terms of increasing physical exercise and eventual weight reduction. Such an approach may reduce proinflammatory cytokines, in addition to improving hypertension, diabetic control, and other cardiac risk factors which all can reduce testosterone levels.

**LUNG CANCER**

The 5 years survival rates are 6.1% for small cell lung cancer and 17% for nonsmall cell lung cancer. Thus, there are few long-term survivors of lung cancer.\(^{[59]}\) Unlike other cancers, where survival is improving, lung cancer management still often focuses on short term quality-of-life improvement and palliative care. Researchers have estimated that sexual dysfunction affects between 40% and 100% of lung cancer patients who undergo cancer treatment. Studies have shown that these problems can persist as time passes, rather than improving.\(^{[24]}\) Sexual dysfunction usually starts with postdiagnosis grief and depression. To tackle the problem, lung cancer patients should seek out doctors who specialize in matters of sexual health early in the cancer treatment process. The goal is to start a frank conversation, often together with their partner, about how their cancer and cancer treatment might impact sexual function. There is
sparse literature regarding sexual problems in lung cancer survivors, and a lot of work is needed to increase the awareness of sexual problems in lung cancer survivors.

CONCLUSIONS

The absence of frank dialogue about sexuality and cancer treatment is particularly problematic because it underscores many of the erroneous assumptions made by survivors. Most survivors assume that the sexual dysfunction falls in the category of treatment-related collateral damage that cannot be undone. Sexual dysfunction and the accompanying distress can be significantly alleviated by taking an integrative approach and providing survivors with appropriate screening, information, and support.

REFERENCES


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