Management of sexual problems in cancer patients and survivors

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Current Problems in Cancer

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Foreword

Most patients with cancer in the United States now live many years posttreatment. However, these treatments that potentially cure cancer also often bring burdensome physical and psychological late effects that can significantly impair the survivor's functioning and quality of life. Sexual dysfunction is one of the most frequent, persistent, and distressing side effects of treatment endorsed by patients and survivors. In spite of this, sexual problems are still rarely addressed in the context of cancer care. The Institute of Medicine has called for a standard of cancer care where patients and survivors' psychosocial issues become an integral part of the scope of services. Sexual health most certainly falls under that scope, as research has shown that it is significantly related to a person's overall well-being. There are clearly identified barriers to addressing sexual function in cancer care, and it is therefore imperative that medical providers familiarize themselves with these challenges and learn effective strategies to overcome them. In this special issue of Current Problems in Cancer, we seek to provide practitioners with an overview of the literature available on sexuality in a cancer context. More specifically, we present (1) integrative models for understanding sexuality in the context of cancer care, (2) prevalence estimates of the most common sexual problems during and after cancer, and (3) a discussion of strategies to overcome barriers to successfully assess and address sexual function concerns with survivors and patients with cancer.

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Sexuality and cancer: Conceptual frameworks

As patients with cancer are now living long lives after cancer diagnosis and treatment, there has been a growing need to address specific treatment-related side effects that affect quality of life. In particular, sexuality is one of the most fundamental and complex experiences that is often profoundly affected by cancer treatment. Over the past century, researchers have constructed several models for understanding human sexuality. Within the oncology setting, a more mechanistic model of sexuality has been predominant, with focus almost exclusively on addressing physical sequelae and disruptions in organ function. More recently, efforts have been made to raise awareness regarding the complexity of sexuality after cancer, and some integrative models have been proposed. In this section, 3 of these models are briefly reviewed. The review of these models is not exhaustive, but rather meant to provide a prologue for a more comprehensive understanding of sexuality in the context of cancer care and to further frame the content presented throughout this article.

Bober and Varela’s (2012) integrative bio-psycho-social model for intervention

Bober and Varela\(^1\) propose that sexuality comprises psychological, relational, biological, and cultural elements, and therefore only a bio-psycho-social approach to conceptualization and intervention can adequately capture and address cancer survivors’ experience. Biological factors include hormonal alterations, structural changes to the body (scars and amputations), alterations to the sensory experience, pain, and fatigue. Psychological factors may include emotional responses to the cancer experience and to the changes in body function, as well as cognitive processes such as body perception and motivation. Interpersonal factors include changes to the couple’s relationship and to family dynamics, fear of intimacy, and communication barriers. Finally, socio-cultural factors include religious beliefs, values, and norms relevant to sexuality. Understanding sexuality based on this approach necessitates that practitioners go beyond a traditionally narrow and mechanical view of sexuality to become familiar with resources available to address related elements such as mental health (anxiety and depression), relationship problems (sex therapy and marital counseling), and basic tenants of
cultural competence in addition to medical interventions (gynecology, urology, endocrinology, and pelvic floor rehabilitation).

**Cleary and Hegarty’s (2011) neo-theoretical framework of sexuality**

Cleary and Hegarty discuss the lack of available conceptual frameworks to understanding sexuality in the context of gynecologic care and propose a Neo-theoretical Framework of Sexuality, encompassing 3 key factors: sexual self-concept, sexual relationships, and sexual functioning. Sexual self-concept relates to concerns relevant to body image (hair loss and feelings of femininity), sexual esteem (evaluative form of sexual self-concept), and sexual self-schema (thoughts about sexual aspects of the self). Sexual relationships relate to concerns relevant to communication and intimacy. Finally, sexual functioning relates to concerns relevant to the sexual response cycle (desire, arousal, and excitement). The authors argue that the Neo-theoretical Framework provides a suitable and holistic model for health professionals to use when addressing sexual concerns with patients with gynecologic cancers and when developing relevant research protocols. Although this model has been proposed in the specific context of gynecologic cancer care, it could also prove helpful in understanding sexual concerns of women survivors of other cancers (eg, breast, bladder, and colorectal).

**Emilee, Ussher, and Perz’s (2010) material-discursive-intrapsychic approach**

The authors propose an approach that acknowledges women’s intrapsychic experience and the influence of the discursive construction of femininity and sexuality following changes in sexual function after cancer. More specifically, the authors discuss sexuality concerns as the combination of the material effects and changes to sexual functioning following the diagnosis and treatment of breast cancer (eg, pain, fatigue, vaginal dryness, and decreased desire), the emotional response to breast cancer as a complex and lingering process, the cultural appreciation of breasts as functional, gendered, and sexualized organs, and the shifts in relationship dynamics including the experience of “sexual renegotiation.”

**Sexual problems following cancer: Review by cancer site**

The literature still largely reflects an almost exclusive focus on the functional aspects of sexuality after cancer treatment. The aim of the following review of key sexual problems related to cancer is to not only overview symptoms and prevalence by cancer site but also to convey available strategies for intervention that address physical, psychological, relational, and contextual factors. For a brief overview of prevalence of sexual problems focused on cancer site and organ function, please refer to Table. Following the review of key problems in sexual function, we specifically address the issue of clinical inquiry and assessment and propose different levels of intervention to manage sexual problems in cancer settings.

**Breast cancer**

Over the course of their lifetime, approximately 1 in 8 women in the United States will be diagnosed with breast cancer. Breast cancer has arguably carried the baton of creating awareness for early detection, treatment, and research. As such, the literature on quality-of-life issues following breast cancer has also developed greatly over the past decades and has included concerns relevant to sexuality. Breast cancer treatment can involve surgery, chemotherapy, radiation, and hormone therapy. Any of these treatments are likely to have an effect on the woman’s sexuality and quality of life, and breast cancer survivors are significantly more likely to suffer from sexual problems when compared with the general population. Sexual problems
<table>
<thead>
<tr>
<th>Cancer diagnosis</th>
<th>Most common sexual problems reported</th>
<th>Prevalence rate (%)</th>
<th>Studies</th>
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<td>Breast</td>
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<tr>
<td></td>
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<td>13-80</td>
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<td></td>
<td>Orgasm difficulty or intensity change</td>
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<td></td>
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<tr>
<td></td>
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<td>14-62</td>
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<td></td>
<td>Erectile dysfunction</td>
<td>17-40</td>
<td></td>
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<td></td>
<td>Orgasm difficulty or intensity change</td>
<td>20-38</td>
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<td></td>
<td>Ejaculation dysfunction</td>
<td>6-85</td>
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<td>Bladder</td>
<td>Unable to have vaginal intercourse (women)</td>
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<tr>
<td></td>
<td>Libido changes (women)</td>
<td>27-78</td>
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</tr>
<tr>
<td></td>
<td>Orgasm difficulty or intensity change (women)</td>
<td>44-72</td>
<td></td>
</tr>
<tr>
<td></td>
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<td>35-78</td>
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following breast cancer include changes in desire, arousal, vaginal function (dryness and stenosis), orgasm, body image, self-esteem, intimacy, and relationship to the partner.3,5,7,8

Surgical treatment for breast cancer can include breast-conserving procedures (lumpectomy and nipple-sparing procedure) or mastectomy (single or double). Women might have a choice for a procedure based on the stage of the disease. However, any of these surgical procedures will result in scars and loss of sensation as well as other potential side effects such as edema.9 Women are therefore at risk for developing body image concerns and experiencing changes in satisfaction owing to loss of an erogenous zone of the body10 and pain, all of which can negatively affect sexual function.

Radiation treatment may follow surgical procedures for breast cancer. Although the literature on the direct effect of radiation to the breast on sexuality continues to be scarce, radiation treatment may result in factors that affect sexual function, including fatigue (affecting desire and arousal and relationship dynamics), pain (affecting desire and arousal), and skin changes including burns and tattoos (affecting body image and self-esteem).

Chemotherapy is commonly used as a treatment for breast cancer in addition to surgery, and its effect can result in significant changes in body image (eg, weight gain and alopecia) as well as the suppression of ovarian function. Chemotherapy use has therefore been associated with changes in desire, arousal, lubrication, orgasm, pain, and satisfaction.11 Chemotherapy-induced alopecia (hair loss) is considered among the most distressing and traumatic side effects of chemotherapy in women with breast cancer, with a potential significant effect on body image and self-esteem.12 When chemotherapy impairs ovarian function permanently, women also experience a significant and negative effect on sexual desire as well as changes in vaginal function.5,13

Most breast tumors are hormone sensitive, and therefore endocrine therapy often plays a crucial role in treatment for breast cancer.14-16 Endocrine therapy works by eliminating estrogen production or blocking estrogen receptors, and therefore radically reducing or eliminating the possibility of growth of the hormone-dependent tumor. These therapies, however, also result in significant changes in women's sexual function including loss of desire, vaginal atrophy, pain, hot flashes, and vaginal dryness. Moreover, young women appear to be more likely to experience the worst side effects of endocrine therapy,15 resulting in high levels of distress and function, and therefore these problems should be highly deserving of attention.

Several factors other than diagnosis and treatment have also been found to play a role in the extent to which women can maintain sexual function after breast cancer. Some of these factors
include general health, personality characteristics, and health behaviors such as smoking. Moreover, younger patients might be most vulnerable to sexual disruption as are patients with disseminated disease. The quality of the relationship between the woman and her partner has also been found to be an important correlate of sexual well-being. Women who perceive their partners' adaptation to the illness as positive are more likely to report better psychosocial outcomes related to sexuality (better self-efficacy, more hope and social support, and less psychological distress). Furthermore, perception of greater support from the partner has been found to associate with less sexual difficulties among patients with breast cancer during treatment and 6 months after surgery. Other factors such as culture and ethnicity can also be a cause in women's report of psychosocial concerns, including sexuality. For example, women who are Hispanic have been found to be more spontaneously expressive of their perception of the toll of the disease. At the same time, it has also been documented that women of minority backgrounds tend to be diagnosed at later stages of disease (not only for breast cancer) and therefore are more likely to receive more aggressive treatments and experience more severe side effects (including more psychological distress and lower quality of life). More research on individual and cultural factors, however, is needed to more comprehensively understand their effect on sexual function during and after cancer.

Progress has been made in making the management of sexual problems after breast cancer a research priority. Although research findings continue to be limited, some surgical, pharmacologic, and psychosocial interventions for sexual concerns have gained acceptance and are reviewed in the following sections.

**Surgery**

Albornoz et al provide an overview of trends in breast reconstruction after breast cancer surgery since 1998. Breast reconstruction after surgery can include autologous tissue reconstruction or implants (saline or silicone), and the authors found that autologous reconstruction rates have remained constant over time, whereas implant use rates have risen 203%. The authors found that some of the predictors of implant (vs autologous) reconstruction include procedures that are performed after the year 2002, whether the woman is covered by Medicare insurance, the presence of bilateral mastectomy defects, and geography (patients in the Western and Midwestern region of the United States). Possible reasons for the increase in use of implants also may include reapproval of their use by the Food and Drug Administration, cultural shifts in favor of the appearance of breasts after implant surgery, and complications associated with autologous reconstruction procedures (additional scars and infections). Satisfaction with reconstruction after breast cancer surgery tends to be overall high. However, a number of factors also appear to influence this report. For instance, in spite of the high rates for performing the procedure, implants, prosthetic reconstruction appears to be less favored by women, and satisfaction with the outcome of reconstruction has been found to be associated with the presence of scars. Moreover, women who felt being well informed about the reconstructive procedures reported more satisfaction with the results. Preoperative counseling regarding reconstruction appears to be critical in influencing later satisfaction, and this was highlighted by Eldor et al who proposed that women should receive a multidisciplinary consultation to better understand reconstruction procedures and options, and expectations for results, especially for women undergoing prophylactic mastectomy. Nipple-sparing procedures also appear to be preferred by women, whenever possible, and women who preserve the nipple tissue express a high level of satisfaction for having done so.

**Hormone therapy and alternatives to hormone therapy**

For women who experience menopausal symptoms, hormone replacement therapy can be a valuable and effective treatment. However, for many women undergoing breast cancer treatment, hormone replacement might not be a viable option. The safety of using even low-dose hormone interventions to alleviate symptoms such as vaginal atrophy continues to be debated, and more research on the long-term effects of such therapies is needed. Therefore, women with breast
cancer who present with menopausal symptoms might instead be provided with counseling to use nonhormonal therapies. Buijs et al\textsuperscript{14} conducted a randomized, double-blind study of clonidine and venlafaxine (serotonin-norepinephrine reuptake inhibitors, SNRIs) to improve treatment-related menopause symptoms, including hot flashes. The authors found that both drugs carried side effects but overall were well tolerated and with similar efficacy regarding improving hot flashes (2 out of 3 women reported more than 50\% reduction of symptoms). In spite of the symptom reduction, the authors also found that the drugs did not directly affect reports of sexual functioning. Women who present with vaginal dryness might also be recommended the use of hormone-free vaginal moisturizers and water-based lubricants. In addition, behavioral interventions (such as the ones described in the later section) might prove helpful as interventional strategies to regulate hot flashes and mood.

\textit{Nonpharmacologic and psychosocial intervention}

Although the evidence is still scarce, nonpharmacologic interventions for sexual concerns after breast cancer treatment show promise and should be considered a research priority. Rowland et al\textsuperscript{32} found that a 6-week psychoeducational intervention improved relationship adjustment and communication as well as increased satisfaction with sex after breast cancer compared with controls. Befort et al\textsuperscript{33} conducted an intervention trial for obese women, who were postmenopausal, younger than 75 years, and who had been treated for breast cancer (stages I-III) in the past 10 years. The intervention consisted of providing participants with a prescribed diet, a calorie intake daily target goal, an exercise routine, and the requirement to keep a log of their meals. Participants also received calls from counselors and group support throughout the trial. The goal of the study was for the women to achieve a target of 10\% weight loss. The authors found that the intervention was feasible and that, on average, women lost 12.8\% of their weight at the 6-month mark and reported improved satisfaction with appearance and sexual activity. Duijts et al\textsuperscript{34} designed and evaluated the effect of a 4-arm study of Cognitive-Behavioral Therapy (CBT), Physical Exercise (PE), CBT and PE (combined), and wait-list control. The interventions consisted of 6 weekly group sessions of 90 minutes each, including relaxation exercises (CBT component) with a booster session held 6 weeks after program completion, and the physical exercise program consisted of a 12-week, individually tailored, home-based self-directed exercise program of 2.5-3 hours per week. The authors conducted the trial with the primary focus of evaluating the effect of the intervention arms on hot flashes and night sweats after breast cancer treatment, and they found that the intervention groups had a significant decrease in levels of endocrine and urinary symptoms and showed improvement in physical functioning. The participants who received CBT also showed a significant decrease in perceived symptom burden of hot flashes and night sweats and an increase in sexual activity. These effects appeared to be sustained at 6-month follow-up. The authors concluded that cognitive and emotional factors can positively modify the experience of menopausal symptoms, whereas stress reduction strategies and physical exercise may have a more direct effect on symptom reduction. Interestingly, Sayakhrot et al\textsuperscript{35} found that partners of women with breast cancer reported that they perceived exercise and having less stress as the most effective strategies for women in helping them manage menopause symptoms. Given the effect of perceived social and partner support on women’s adjustment to breast cancer, interventions that target the couple are of particular interest. Kalaitzi et al\textsuperscript{36} studied 20 women who received a structured brief couples and sex therapy intervention and compared them with 20 controls (postmastectomy patients who did not receive the intervention). The authors found that patients in the intervention group showed significant improvement in depression and state anxiety scores as well as in body image, satisfaction with relationship, presumed attractiveness to their partner, orgasm frequency, and communication of desire.

\textit{BRCA mutation carriers}

Women with BRCA1 or BRCA2 mutation represent a vulnerable patient population who often receive little attention regarding treatment-related sexual dysfunction. Women who carry a BRCA1 or BRCA2 mutation have a considerably heightened lifetime risk of breast cancer (55\%-85\%) or
ovarian cancer (15%-44%) and both. For BRCA1 and BRCA2 carriers, prophylactic risk-reducing surgery is the single most effective method for breast and ovarian cancer risk reduction; prophylactic bilateral mastectomy reduces the risk of breast cancer by more than 90% and prophylactic risk-reducing salpingo-oophorectomy (RRSO) reduces risk of ovarian cancer by more 80% and also reduces breast cancer by approximately 50%. High-risk women are advised to have prophylactic surgical removal of their ovaries and fallopian tubes by 35 years of age or on completion of childbearing. A recommendation for RRSO at age 35 years means that young women undergoing RRSO often face abrupt and severe sexual side effects of surgical menopause including vaginal dryness and irritation, pain with penetration, decreased arousal, and loss of desire. High-risk women who opt for prophylactic bilateral mastectomy often face side effects that also affect sexual function, such as loss of skin and nipple sensation, scars, and changes in self-image.

BRCA carriers who undergo prophylactic surgery typically receive little or no preparation about how to manage these changes before surgery. It is often assumed that BRCA carriers are young and healthy and do not need additional support when in fact, they often face significant treatment-related sexual problems without receiving any information or intervention. For male BRCA1 and BRCA2 carriers, mutation status also confers higher risk for cancer, including breast, prostate, and pancreatic, but risk management strategies for male carriers are limited to screening and self-examination thus avoiding comparable surgery-related sexual side effects.

Regarding intervention, there is enormous unmet need for BRCA carriers to receive the same information and education regarding management of premature menopause as is given to other female patients with cancer including recommendations for how to manage menopause symptoms and optimize vaginal health. Guidance may include use of vaginal moisturizers and water-based lubricants. Use of short-term hormone replacement therapy for BRCA1 and BRCA2 carriers does not appear to negate the risk-reduction benefit gained by prophylactic surgery, thus making systemic hormone replacement as well as localized vaginal estrogen reasonable options to be explored. Regarding preventive mastectomy, women often struggle with how the loss of breast and nipple sensation negatively affects sexual arousal. Women may also feel guilty about asking for help because the cosmetic results may look good and women feel that the loss sexual function is part of the “price to be paid” for preventing cancer. Support such as short-term sexual rehabilitation counseling may be instrumental in helping women explore alternate modalities for arousal. An additional consideration is that one of the reasons that mutation carriers reject recommendations for prophylactic surgery is because of the loss of sexual function. If women believe that effective support and resources are available to address these issues, this may also improve uptake of this potentially life-saving procedure.

Gynecologic cancers

More than 80,000 women in the United States are expected to be diagnosed with a gynecologic cancer every year. Gynecologic cancers and their treatments are likely to result in some form of sexual dysfunction as they directly affect women’s sexual organs. Unfortunately, sexual problems following gynecologic cancers are not solely limited to organ function. Survivors also report an influence to their feelings of femininity, mood, self-esteem, and the way they relate to and discuss sexual issues with their partners. Therapies for gynecologic cancers usually involve surgery which can be accompanied by radiation, chemotherapy, and hormone therapy, and the more aggressive the disease and treatment, the more probable and severe the sexual dysfunction is likely to be. Survivors of gynecologic cancers have been found to experience worse sexual problems than women in the general population, to suffer from sexual problems regardless of specific cancer site (ie, endometrial, vulvar, and cervical), treatment type, and time from diagnosis and age, and to have sexual problems that do not improve over time but rather may intensify. Surgeries for gynecologic cancers may include radical hysterectomy, bilateral salpingo-oophorectomy, vulvectomy, and pelvic exenteration, and the direct effect of these surgeries on a woman's sexual function varies. For example, hysterectomies and vulvectomies can result in
problems such as pain, loss of sensation, changes in body image, vaginal dryness, and difficulty reaching orgasm, and these sexual problems vary in severity largely based on the extent of the area affected by the surgery. On the contrary, a salpingo-oophorectomy procedure in a premenopausal woman triggers premature menopause symptoms including hot flashes, changes in mood, and sleep disturbances, and over time, other symptoms such as vaginal dryness, dyspareunia, and low libido can also occur. When treatment includes radiation, or chemotherapy or both in addition to surgery, women are likely to experience an increased risk of developing more severe sexual problems. For example, external beam radiation treatment for gynecologic cancers involves high protons irradiated to the pelvis with the possibility of resulting in damage to all pelvic organs including the vagina, uterus (if present), bladder, and rectum. Therefore, women who are treated with external beam radiation are vulnerable to sexual problems such as vaginal stenosis, as well as bowel problems that can exacerbate sexual dysfunction and sexual function–related distress.

Interventions

Gynecologic cancer survivors experiencing vaginal dryness may use hormone-free vaginal moisturizers to restore some of the natural lubrication of the vaginal tissue, and for lubrication problems, women can be counseled to use water-based lubricants generously during sexual activity, gynecologic examinations, and vaginal and pelvic floor rehabilitation that involves insertion of dilators into the vagina.

Use of vaginal dilators several times a week is recommended for women who experience vaginal stenosis, and this intervention seems most helpful when initiated early in the recovery period and as a proactive approach of preventing stenosis. Research has found that compliance with the use of vaginal dilators is low, and specific barriers have been identified relevant to their use. A qualitative study of cervical cancer survivors found that women can experience dilator use as embarrassing, reliving the invasive and aversive experience of treatment, and not as a priority of treatment and recovery. In a study of endometrial cancer survivors, noncompliance with dilator use was also associated with low libido, vaginal dryness, and feeling that dilator use was unnatural. However, in this same study, women who adhered to dilator use reported that their reasons for compliance included following the doctor’s recommendation (71% of adherers) and to ease pelvic examinations (56% of adherers), in addition to worrying more about their sex lives when compared with nonadherers. Therefore, the importance of having providers directly and competently address this issue with patients with and survivors of gynecologic cancer cannot be overstated. Moreover, Cullen et al. reported on a series of recommendations made by survivors to address the low adherence of dilator use. These recommendations included having providers introduce the topic of dilator use in a light and direct way, to facilitate access to dilators, to introduce this rehabilitation strategy early in the course of treatment, to emphasize the importance of dilator use for health-related reasons (eg, ease gynecologic follow-up examinations) rather than to improve sexual health, to take into consideration women’s attitudes and beliefs regarding sexuality, to have providers be sensitive and more aware to possible emotional reactions related to dilator use, to enhance psychoeducation on this rehabilitation strategy, and for the treatment team and institution to have a consistent approach to these recommendations. In addition, Robinson et al. have reported that particularly for younger survivors compliance is improved by providing them with information, motivational strategies, and behavioral skills geared toward improving fears about sexuality after cancer and dilator use.

Pain management should also be directly addressed with patients, as dyspareunia is likely to occur as a result of surgery and radiation and to negatively affect sexuality and quality of life. In addition to pharmacologic pain management, pelvic floor exercises can be recommended to help regulate pain by promoting control over pelvic function and increasing relaxation.

Relaxation training and mindfulness-based interventions can also help gynecologic cancer survivors improve sexual function. Brotto et al. found that a brief, structured mindfulness-based intervention was effective in improving perceptions of desire, lubrication, orgasm, and
satisfaction in a group of cervical and endometrial cancer survivors compared with controls. Noticeably, the authors also found that the improvements perceived and reported by the survivors were not observed when measured objectively in the laboratory. However, the women who received the intervention reported less sexual-related distress than controls, and these perceptions of improvement were maintained over a period of at least 6 months.

Supportive and psychoeducational interventions may also prove helpful to survivors of gynecologic cancers. For example, in a qualitative study of a web-based support group for patients with gynecologic cancer with sexual distress, Wiljer et al found that a 12-week long, web-based supportive forum was generally well received by participants who reported that the intervention helped them feel more supported and normalized their feelings. Participants also reported that the web-based group intervention could be most helpful toward the end of active treatment and in preparation for survivorship. At the same time, women also reported potential benefit from accessing support of this nature at different points in time during their recovery. Although women in this study reported that they did not think the group itself would improve quality of life and that the live chat or format was at times difficult to navigate, they also reported overall satisfaction with the intervention and willingness to recommend the group to others.

Addressing sexual problems in gynecologic cancer survivors should also involve discussion of function-sparing procedures as options for treatment whenever possible. In cases where extensive surgery is indicated, reconstruction procedures might be necessary. De la Garza et al provided a case report where significant reconstruction was performed on a patient after total pelvic exenteration so that the patient required no external ostomies, and sexual function was reported to be adequate after the procedure. Fotopoulou et al reported on 7 patients who had undergone neovaginal reconstruction with sigmoid loop technique following treatment for gynecologic malignancies. The reconstruction procedure was proven safe, and the vagina to be functional. However, factors such as a cancer diagnosis and mood appeared to negatively affect the outcome or the reconstruction regarding sexuality, and therefore the authors suggest a bio-psycho-social approach to counseling patients before reconstructive procedures.

As with function-sparing and reconstructive procedures, hormone replacement treatment (systemic or local) after gynecologic cancer could be considered on a case-by-case basis, based on whether the cancer is estrogen-recipient or not and on the survivors' preference for intervention strategies. However, for survivors who are good candidates, hormone treatment can help increase libido, alleviate pain, and improve vaginal dryness.

Prostate cancer

Over the course of their lifetime, approximately 1 in 6 men born in the United States today will be diagnosed with prostate cancer, making it the most common cancer among American men. Perhaps more than any other cancer, prostate cancer population may be the one that best illustrates the need to adopt a chronic illness model in addressing cancer survivorship as the 5-year relative survival rate for those diagnosed with localized stage disease approaches 100%. Because of the direct effect of treatment on sexual organs, men surviving prostate cancer are more often than not faced with having to cope with the significant effect that treatment can have on their sexual function.

Surgery

For those diagnosed with early-stage prostate cancer, radical prostatectomy is a common treatment option which is associated with lower disease-specific mortality. Unfortunately, it can have a major effect on patient sexual functioning. First, during the prostatectomy, the seminal vesicles are removed and the vas deferens is cut. This results in dry orgasms and urinary incontinence during orgasm which is associated with decreased orgasmic satisfaction and avoidance of sexual activity. Second, the cavernous nerves that facilitate erectile function may be affected during surgery, resulting in potential erectile dysfunction. Rates of erectile dysfunction...
dysfunction vary widely in the literature from 6%-90%, which may be the result of different methods of assessing sexual function. Despite this variation in rates, the general consensus has been that radical prostatectomy has a significant effect on a man's erectile function. If feasible, nerve-sparing prostatectomy is associated with increased likelihood of maintaining at least some erectile function after surgery, except in men who had low preoperative levels of erectile function. Bilateral nerve-sparing surgery is associated with better rates of erectile function recovery than those who undergo unilateral nerve-sparing surgery. Even if nerve-sparing surgery is successful, the data indicate that it may take at least 18-24 months for the nerves to heal and for erectile function to recover. Factors positively associated with postsurgical sexual function include patient age, preoperative sexual and overall physical function, extent of neurovascular bundle preservation, surgical experience, and ethnicity. Surgical technique may or may not affect the degree to which prostatectomy affects sexual function. Finally, the denervation caused by surgery may result in smooth muscle atrophy, erectile tissue apoptosis, and hypoxia-induced tissue damage, all of which may be contributing factors to the decrease in penile size observed after surgery. Penile length and circumference have both been demonstrated to be reduced following prostatectomy, with penile changes observed to continue for at least a year afterward.

After prostatectomy, there is evidence to suggest that prompt delivery of penile rehabilitation therapy can be helpful in the preservation of erectile tissue, and is associated with improved erectile function. Following radical prostatectomy, where spontaneous and nocturnal erectile function is poor or absent, the penile tissue may fail to achieve proper oxygenation. The use of penile rehabilitation therapy immediately after surgery reduces tissue fibrosis in the corporeal smooth muscle by increasing corporeal oxygenation. Oxygenation-preserving strategies can include the use of vacuum erection devices, daily low-dose PDE-5 inhibitor use, and intracavernous injection of vasoactive agents, as well as novel treatments such as hyperbaric oxygen therapy. Current research on the efficacy of penile rehabilitation therapy has primarily focused on the daily low-dose use of PDE-5 inhibitors. This research is hampered by study design limitations, including a lack of randomized controlled trials, medication compliance issues, confounding variables (eg, patient age, nerve status, and surgeon experience), as well as contradictory findings that indicate that on-demand dosing of PDE-5 inhibitors may be more effective than daily dosing in improving erectile function. Thus, questions remain regarding major issues related to penile rehabilitation therapy (its efficacy), as well as minor issues (medication dosing and the timing of penile rehabilitation therapy). The benefit of penile rehabilitation therapy is an issue of current debate, with recent evidence suggesting that there may be subsets of patients who would benefit from therapy.

From a therapeutic, rather than a rehabilitative, perspective, there is far less debate as to whether treatment options can be effective tools in helping patients manage posttreatment sexual dysfunction. To treat erectile dysfunction, oral PDE-5 inhibitors are commonly used as the first-line treatment as they are effective and less invasive than other delivery mechanisms. However, oral medications may be ineffective in older men, men who had low erectile functioning before surgery, men who have had neurovascular bundle damage because of surgery, and during the first 9 months after surgery. Peak satisfaction with oral PDE-5 inhibitor use appears to be between 1.5 and 2 years following prostatectomy. Unfortunately, there are a number of men who discontinue PDE-5 inhibitor use for a variety of reasons, including physical side effects (eg, headache, muscle pain, dyspepsia, and facial flushing) and psychological concerns (eg, anxiety about medication use). For men who fail to respond to oral PDE-5 inhibitors, intracavernous injection therapy, transurethral alprostadil, and vacuum erection devices are alternative treatment modalities to consider. Intracavernous injection therapy is effective in up to 85% of individuals who report erectile dysfunction, and those who are adherent to treatment report increases in sexual activity and improvements in sexual satisfaction. Unfortunately, intracavernous injection therapy is often anxiety provoking for patients, and up to half of patients who are offered this treatment either refuse or stop treatment over the first 6 months. With appropriate training, couples are able to tolerate treatment,
and many continue to use injection therapy for 3-plus years after initiation. Transurethral alprostadil is effective in approximately 57% of postprostatectomy patients, though research indicates that intracavernous injection therapy is likely to be more efficacious. Though evidence indicates that the use of vacuum erection devices may be most beneficial for those men who experience penile shortening, they are helpful in facilitating both sexual activity as well as potentially earlier erectile function. However, some patients report low satisfaction with these devices, and approximately 1 in 5 men discontinue use owing to discomfort, difficulty with operating the device, penile bruising, and social inconvenience. Finally, the use of penile prosthesis has been reported to be a very helpful treatment for erectile dysfunction that is well tolerated, though is typically reserved for patients who fail other treatments, given its invasive and irreversible nature. For patients for whom nerve-sparing surgery is not an option, the simultaneous placement of a penile prosthesis with prostatectomy has been associated with better postsurgical outcomes. Recent research is highlighting the possibility that combination treatments (ie, both PDE-5 inhibitors and vacuum erection devices) may provide the most hope for erectile function recovery.

Radiation

Men diagnosed with early-stage prostate cancer may believe that external beam radiation and brachytherapy are treatment options that have a lower effect on erectile function than surgery. Though men who undergo radiation therapy still experience decrements to their sexual function, it is not as marked as for those who undergo surgery. Up to 5 years after treatment, those who underwent surgery report sexual dysfunction more frequently and with greater severity than those who received radiation therapy. However, sexual function tends to recover over time for surgery patients, whereas radiation therapy patients report their highest sexual functioning immediately after treatment and then proceed to decline after that. Up to a third of radiation therapy patients become impotent 3 years after treatment, although there are better outcomes for younger men (≤60 years). This continued decline can be explained by the fibrosis that continues to develop after radiation treatment is completed, which interferes with the neurovascular bundles and blood vessels adjacent to the prostate and necessary for erections. Given this trajectory, it is not surprising that there are no noted between–treatment group differences in erectile functioning at 15 years after surgery or radiation therapy. Rates of sexual activity 15 years after treatment are low (22% having had sexual activity within the past year), whereas erectile dysfunction and sexual bother remain elevated. Brachytherapy or seed implants also have a significant effect on sexual function. Most men report changes to their overall sexual function, including reduced ejaculate volume, premature or diminished orgasms, and declines in erectile function. Risk factors for erectile dysfunction after brachytherapy include greater age, poorer pretreatment functioning, and prostate volume. Data indicate that brachytherapy may have less of an effect on sexual function than surgery in both the short term and up to 6.5 years after treatment. Treatment options for erectile dysfunction in those who chose radiation therapy are similar to those who underwent surgery, with oral PDE-5 inhibitors being the first-line therapy. Recent findings indicate that intervening with daily PDE-5 inhibitors immediately after brachytherapy is associated with elevated sexual function and should be considered after treatment.

Hormone therapy

The primary treatment for men diagnosed with late-stage prostate cancer is hormone therapy, also known as androgen ablation therapy and androgen deprivation therapy, though it has also been used previously in managing localized disease and in conjunction with surgery. Like other forms of treatment for prostate cancer, it is also associated with negative effect on sexual function following therapy, including decreased libido, erectile dysfunction, and lower levels of sexual activity amongst those treated for localized and metastatic disease for years after treatment. Other side effects of treatment, such as body
feminization, and fatigue can also serve to affect sexual health among men who undergo hormone therapy.\textsuperscript{183}

The treatments for erectile dysfunction associated with hormone therapy remain oral medications, with second-line therapies such as intracavernous injection therapy if oral medications fail. The more difficult side effect of treatment to address is low libido. Medical options, such as increasing testosterone levels, would be counter to the cancer control purposes of hormone therapy. There has been recent interest in investigating the role of estrogen restoring libido among men undergoing hormone therapy.\textsuperscript{184} However, at present, behavioral and psychological interventions designed to facilitate improved couple’s communication, reduce relationship distress, broaden the definition of sexual activity, and improve coping skills are the best available resource to support the patient,\textsuperscript{185-189} though it can be challenging work for the prostate cancer couple.\textsuperscript{190}

\textbf{Cryoablation}

Primarily used for those diagnosed with localized stage disease, cryoablation (or cryotherapy) is also an option for patients with prostate cancer who have failed other treatments. Though it is an effective treatment,\textsuperscript{191} much like other treatments for prostate cancer, it too is associated with compromised sexual function.\textsuperscript{192} When compared with radiation therapy, cryoablation is associated with poorer short- and long-term sexual function.\textsuperscript{193}

\textbf{Quality-of-life implications of sexual dysfunction after prostate cancer}

All active treatment options for prostate cancer are associated with compromised sexual functioning.\textsuperscript{194} Sexual dysfunction plays a significant role in the overall quality of life for patients with prostate cancer, and declines in sexual function have been identified as the most common cause of disease-specific distress in this population.\textsuperscript{75,194-197} In addition to overall quality-of-life decrements, there are specific psychological implications for men struggling with erectile dysfunction. Prostate cancer survivors who report erectile dysfunction are more likely to endorse depressive symptomatology, even 4 years after diagnosis.\textsuperscript{198} Additionally, despite a recovery to a new baseline level of sexual function at roughly 2 years after treatment, men who undergo radical prostatectomy continue to report sexual bother, indicating that significant struggles remain in their efforts to cope with their functional decrements.\textsuperscript{199} This may be the result of the ongoing effect of diminished masculinity that these men experience, owing to changes to their functional status.\textsuperscript{200} As these men continue to report struggling with their adjustment to sexual changes, well after treatment is complete, it is advised that they be promptly evaluated and referred to the appropriate resources,\textsuperscript{201} with evidence to indicate that this can help facilitate recovery in their sexual life.\textsuperscript{202} Sexual dysfunction presents as a biopsychosocial challenge that requires multidisciplinary management from physicians, nurses, physical therapists, and psychologists who can work together in treating both the physical and psychological consequences of treatment for prostate cancer.\textsuperscript{203-206} Studies have shown that social support, and relationship functioning play an important role in the adjustment process of patients with prostate cancer.\textsuperscript{207-209} However, prostate cancer dyads report poor communication about sexual difficulties.\textsuperscript{210} Thus, it is critical to incorporate the prostate cancer dyad into any discussion that involves sexual functioning,\textsuperscript{211} though this occurs infrequently in our current system of care.\textsuperscript{212,213}

\textbf{Testicular cancer}

As the most common cancer among men between the ages of 20 and 34 years,\textsuperscript{214} testicular cancer affects the lives of men who are in an age group where sexual functioning is likely to play an important role in their lives.\textsuperscript{215} The body of research which has investigated the effect of testicular cancer and its treatment on sexual function reveals that between 18\% and 39\% of men report sexual problems, including dissatisfaction regarding changes in orgasm, difficulties with sexual desire, and erectile dysfunction,\textsuperscript{216-219} while up to 51\% have ejaculatory difficulties.\textsuperscript{218}
Consequently, they report reduced sexual activity (43%) and general sexual dissatisfaction (19%) following treatment.219,220 This can have a long-term trajectory as 3-5 years after treatment they remain more likely to report low sexual desire and erectile dysfunction compared with age-matched controls.221 Testicular cancer survivors who report erectile dysfunction generally respond well to PDE-5 inhibitors, though there is a sizeable minority who do not.222 Despite the presence of sexual function issues for a portion of testicular cancer survivors, many report that the effect of their treatment on sexual function was limited223 and that their level of sexual interest, activity, and enjoyment did not change very much.224,225 Overall, these men tend to report that they have accepted whatever sexual dysfunction may arise as a consequence of their treatment.226

The specific treatment modality has generally been demonstrated to be unrelated to sexual functioning,218,225 but some evidence indicates that retroperitoneal lymph node dissection219,223,227 and chemotherapy and radiation treatment may be associated with elevated rates of overall sexual dysfunction, chemotherapy may be associated with delayed ejaculation, and radiation therapy may be associated with erectile dysfunction.228 Sexual function appears to reach a nadir approximately 3 months after orchiectomy and returns to above baseline levels after 1 year,225 which is similar to patterns seen in patients treated with chemotherapy.229,230 It should be noted that the risk for sexual dysfunction increases amongst older testicular cancer survivors. These men are more likely to report sexual dissatisfaction, decreased sexual frequency, and erectile dysfunction after treatment,231-234 which may be related to androgen deficiency.235 In addition, when compared with healthy controls, these older survivors report decreased sexual enjoyment and desire.236-238 Most men who report sexual dysfunction also report a desire for further information regarding these issues.239

For patients with testicular cancer, another salient issue following treatment is fertility. In particular, men who received chemotherapy and secondary resection of residual retroperitoneal tumor mass appear to be at elevated risk for infertility.223 Although there is variation in findings, abnormal sperm concentrations can be seen in as many as 50% of the patients.217,240 These men have the opportunity to cryopreserve their sperm, which permits testicular cancer survivors the opportunity to have children, should they desire. Furthermore, intracytoplasmatic sperm injection, which only requires one sperm to fertilize an egg, allows for those patients with a low sperm count to provide adequate sperm for in-vitro fertilization.241,242 Patients with testicular cancer who are interested in having children benefit greatly from receiving proper education on the availability of reproductive technology.217

**Bladder cancer**

Approximately 72,570 new cases of bladder cancer are expected to be diagnosed in 2013, with men approximately 3-4 times more likely to be affected than women.243 In most patients, the tumor would present as a non–muscle invasive transitional cell carcinoma (also known as urothelial cell carcinoma). Most commonly, these tumors recur, and some progress in stage or grade.244 Treatment for recurrent bladder cancer includes surgery, radiation therapy, immunotherapy, and chemotherapy, with surgery being the most common course of action. The long-term prognosis for those who undergo radical cystectomy is good,245 though it is a treatment that is very much associated with decrements in sexual functioning.246 The use of laparoscopic surgery has been recently studied in the context of oncologic control.247-249 Research is pending on whether the use of laparoscopic radical cystectomy, compared with open radical cystectomy, may affect long-term quality-of-life outcomes such as sexual function.250

Standard radical cystectomy for men diagnosed with bladder cancer involves the removal of the bladder, as well as the prostate, seminal vesicles, and vas deferens, with consequent removal of or damage to the surrounding neurovasculature. Thus, treatment is often associated with the loss of sexual function, most notably erectile dysfunction.251 The high prevalence of erectile dysfunction, postsurgically, has driven researchers to consider whether nerve-sparing cystectomy is a safe alternative in the treatment of bladder cancer. Nerve-sparing surgery is
associated with positive outcomes in erectile function. Most men experience a temporary
decrease in function immediately following surgery, which is then followed by a steady return to
function. However, there are significant questions which remain regarding oncologic
safety of nerve-sparing treatment, owing to factors including the probability of prostatic disease
in residual tissue as well as urethral tumor involvement. Evidence indicates that potency-
sparing cystectomy may result in a 10%-15% higher oncologic failure rate when compared with
standard radical cystectomy, with ongoing debate about minimizing oncologic risk while
preserving sexual function. Furthermore, men and women also suffer psychological
effect of treatment in addition to the physical challenges. They often report body image concerns
after urinary diversion following radical cystectomy, which is associated with a
significant loss of sexual function and satisfaction up to 5 years later. Limited literature
indicates that cutaneous ureterostomy is associated with worse body image than Bricker or
Paduan ileal neobladder diversions.

Treatment for erectile dysfunction in male bladder cancer survivors is similar to that for
prostate cancer survivors, with evidence suggesting that early intervention with PDE-5
inhibitors is associated with better sexual function and satisfaction. It is important to note
that almost half of male bladder cancer survivors do not seek treatment for sexual dysfunction
after surgery. Therefore, preoperative consultation regarding sexual health issues appears
critical for these men. Additionally, it has been reported that both men and women under
surveillance for non–muscle invasive bladder cancer mistakenly believe that they can harm their
partner through sexual contact, again highlighting the need for improved awareness regarding
sexual health issues amongst this population.

During radical cystectomy in women with bladder cancer, neurovascular bundles located on
the lateral walls of the vagina can be damaged, and significant devascularization of the clitoris
can occur during the removal of the bladder, urethra, anterior vaginal wall, and uterus and
ovaries. This neurovascular damage is likely to create prominent sexual dysfunction and
has resulted in a greater focus on the use of nerve-sparing surgical procedures. However, very
little has been reported on the effect of these procedures on oncologic risk.

The preservation of internal genitalia is associated with better sexual function, as a result
neurovascular preservation, as well as increased potential of fertility preservation. Women
who undergo nerve-sparing surgery tend to retain good sexual function that is comparable to
presurgical levels. Conversely, women who received non–nerve sparing surgery report
significant compromises to their sexual function. Women report weakened libido, dyspareunia,
decreased lubrication, and diminished ability or inability to achieve orgasm. Given these
difficulties, it is not surprising to see that many women who undergo non–nerve sparing
cystectomies report discontinuing sexual intercourse by 1 year after treatment.

Treatment for sexual dysfunction amongst female bladder cancer survivors is similar to
recommendations for female survivors of breast, gynecologic, and colorectal cancers described
elsewhere in this article. For women who experience physical burden or psychological burden or
both resulting from the extent of their cystectomy, vaginal reconstruction surgery is a viable
option that can help restore sexual activity.

Head and neck cancers

In the United States, approximately 53,640 people will be diagnosed with head and neck
cancers, accounting for approximately 3%-5% of those newly diagnosed. Men are more likely
to be diagnosed with head and neck cancer, and it is more common in those older than 50
years. These cancers usually present as a squamous cell carcinoma and are strongly associated
with tobacco and alcohol use. Treatment for head and neck cancer is varied, and can
include surgery, radiation therapy, targeted therapy, and chemotherapy. Despite significant
efforts to use function-sparing approaches, as well as improvements in our ability to reconstruct
defects, treatment can still result in facial alterations and disfigurement, as well as
persistent changes to saliva quality and quantity or both, breathing, and speech.
As the function and appearance of the head and neck region plays such a critical role in our social interactions, treatment can have implications on quality of life for survivors. In addition, the psychological distress associated with alcohol withdrawal and tobacco withdrawal or both, and the stigma of being diagnosed with a cancer that is often perceived as self-inflicted, can contribute to overall sexual dysfunction in this population. Because of these difficulties, head and neck cancer survivors report decrements to their self-esteem and body image, affecting both their intimate relationships, as well as their broader social network. Specifically, these survivors report feeling less attractive, reduced libido, and decreased satisfaction with their sexual relationships. Not surprisingly, these symptoms have an effect on relationship functioning, with survivors endorsing worsened relationships with their partner and increased social isolation. Those with more advanced disease, who underwent surgery rather than other forms of treatment (eg, radiation therapy), who experienced more extensive disfigurement, and women appear to be at greater risk for reporting sexual dysfunction. Conflicting evidence has been presented as to whether age is associated with sexual health issues in this population.

Despite a third of survivors reporting that they would like to discuss the possible side effects of treatment on sexual health with their physicians, the overwhelming majority of patients with head and neck cancer do not do so. In particular, younger patients (29-49 years of age) report interest in receiving information about sexuality after treatment. Evidence indicates that open communication about sexuality and more information regarding sexual side effects is associated with improved psychosocial adjustment. Although rehabilitation is an important part of the overall treatment process for patients with head and neck cancer (eg, physical therapy and speech therapy), sexual rehabilitation, specifically, is poorly understood in this population. Multifaceted rehabilitation services and psychosocial interventions appear to be helpful in improving physical and psychological symptoms as well as overall quality of life. Practitioners are encouraged to follow recommendations made in other sections of this article when sexual functioning is compromised by body image and physical functioning impairments secondary to treatment.

Blood, bone marrow, and lymph node malignancies

Every year, more than 100,000 cases of hematologic malignancies are diagnosed in the United States. Of all the concerns relevant to disease and side effects of treatment for hematologic cancers, sexual function might not be initially an obvious one for this group of patients as the malignancy is not directly linked to a sexual organ. However, high-dose chemotherapy, total-body irradiation, stem cell transplantation, and even the placement of a central venous catheter can be significantly detrimental to patients’ body image, intimacy, and sexuality. Studies on sexual function in patients with and survivors of hematologic cancers vary in methodological approach, and the literature overall remains scarce. However, a few studies document the prevalence and course of sexual problems, and some of these findings can be considered of great value. In a study of survivors of aggressive non-Hodgkin’s lymphoma, it was found that sexual problems affected at least 25% of the sample. For Hodgkin’s lymphoma (HL) survivors, prevalence reports of sexual problems have been found to range between 12% and 62.5%, and reports vary in terms of how long these sexual problems may last. A prospective study of 3208 patients with HL reporting on level of sexual interest, activity, and satisfaction found that sexual functioning during follow-up was significantly related to sexual function before HL treatment, and that patients with advanced disease were more likely than patients diagnosed in earlier stages to report sexual dysfunction that lasted after treatment completion and that did not reach a rate of function comparable with controls.

For patients suffering from the most aggressive hematologic malignancies, stem cell transplantation (SCT) represents a potentially life-saving treatment option. However, this powerful treatment also carries the likelihood of severe side effects and long-term effects including sexual dysfunction. Rates of sexual problems in SCT patients range between 6% and 80% depending on the time since treatment and sexual problem reported, and these issues tend
to be long lasting or even likely to worsen over time if left unattended. In addition to sexual problems such as erectile dysfunction in men, vaginal dryness in women, and pain and difficulty with orgasm for both men and women, survivors of allogeneic stem cell transplantation are at risk for graft-vs-host disease (GVHD) of organs including the skin and genitals, which can greatly and negatively affect sexual function. Female genital tract GVHD has been reported by at least 25% of women survivors who underwent allogeneic SCT, and although this is a condition that can be managed relatively well with pharmacologic intervention when it is diagnosed in earlier stages, the absence of patient education on gynecologic self-surveillance and the lack of patient-provider communication regarding sexual problems after SCT compound this already devastating problem.

Research on interventions for sexual problems following treatment for hematologic cancers is largely absent, and the clinical management of sexual problems in this population generally follows the same recommendations made to women following breast and gynecologic cancers and to men following prostate cancer. In terms of female tract GVHD, however, the management of sexual problems deserves particular attention given the potential challenges for overall symptom management in the context of stem cell transplantation. Hirsch et al conducted a retrospective study with 32 women survivors of stem cell transplantation and presenting with genital chronic GVHD and found that the median time for genital GVHD diagnosis was 13 months, with some cases found to be nearly asymptomatic except for vaginal dryness. The authors also found that topical treatment with corticosteroids was most helpful in women who presented low-grade genital GVHD, highlighting the importance of routine surveillance to prevent higher-grade complications and the need for more aggressive symptom management. Based on their findings, the authors suggest that gynecologic follow-up should begin around day 100 following transplantation and continue to be performed routinely regardless of whether women report symptoms.

Colorectal cancer

Colorectal cancer is expected to affect more than 140,000 men and women every year, and its treatment usually involves surgery, with or without chemotherapy and radiotherapy. Colorectal cancer surgery often causes nerve damage, and depending on the area affected, it is likely to result in urogenital dysfunction. Sexual problems following colorectal cancer include erectile and ejaculatory dysfunction in men and desire, pain, and orgasm difficulties in women. In recent years, a growing number of studies have been published focusing on the effect of colorectal cancer and its treatments on patients’ sexual function. On the contrary, research on interventions to manage sexual problems following treatment for colorectal cancer continues to be scarce, and the clinical management of sexual problems in this population generally follows the same recommendations made to prostate cancer survivors, such as the use of sildenafil for men suffering from erectile dysfunction, and for breast and gynecologic cancer survivors, such as the use of water-based lubricants, vaginal moisturizers, and vaginal dilators for women suffering from vaginal atrophy or dryness. Most unique to colorectal cancer survivors, sexual function can be affected by emotional reactions and adjustment to colostomy. Patients and their partners could greatly benefit from receiving information and support relevant to managing the effect of an ostomy on sexuality and providers can therefore play a crucial role in this process. In particular, patients should be able to readily access information on strategies to minimize odor from the colostomy (deodorants), gas or diarrhea or both (dietary considerations), and timing for sexual intercourse (while the stoma is empty).

Children and young adults

Intensive treatments that cure those diagnosed with cancer in childhood and adolescence can also compromise their psychosexual development well into adulthood, if not properly addressed. However, there is limited research that has examined the effect of cancer on the development of sexual dysfunction amongst this population. Those diagnosed with
cancer at a young age are exposed to significant challenges that can affect their sexual health, from both a physical and psychosocial perspective. Physically, treatment can impair their hormonal, vascular, genitourinary, and neurologic function, placing these survivors at risk for both sexual dysfunction as well as infertility. Psychosocially, they tend to be less sociable and more isolated, are less likely to marry, show greater restriction in their sexual behavior (eg, masturbation and talking to friends about sex), delays in reaching sexual milestones (eg, dating and intercourse), and decreased sexual interest and satisfaction with sex. Despite these issues, approximately two-thirds of survivors indicate that they are doing well with their overall sexual functioning. The remainder indicate that their sexual dysfunction and fertility issues are associated with elevated psychological and quality-of-life impairments, with females more likely to report sexual dysfunction. Interestingly, sexual functioning was not related to cancer diagnosis for this population. There is a pressing need for incorporating age-appropriate psychosexual support for this population as part of their long-term survivorship care, which has largely gone unmet. Young adult cancer survivors consistently report unmet needs for information and counseling related to sexuality issues, with most reporting that their oncology providers did not discuss sexual health issues with them. The single intervention conducted amongst adolescents and young adults to address sexual health challenges has demonstrated that a psychosocial intervention can help to improve knowledge about sexual issues, improve body image, and decrease sexual and general anxiety. In addition, fertility issues are also often not discussed in sufficient depth, if at all, which is problematic given that most survivors who were childless at diagnosis would eventually like future offspring and that up to a third of parents of male childhood cancer survivors assume that their children would retain normal fertility following treatment. In males, cryopreservation of semen (which can be acquired via masturbation, electroejaculation, or testicular sperm extraction and aspiration after puberty) is a well-established procedure that is recommended as part of routine care. More invasive options (biopsy and hemicastration) can be considered before puberty. There may be challenges in broaching this potentially sensitive subject with families during an already challenging period in their lives. Females have a potentially more challenging, and costly, path toward fertility preservation but do have a number of options (eg, embryo, oocyte, and ovarian tissue cryopreservation; intensity-modulated radiation therapy; ovarian transposition, ovarian suppression; and conservative gynecologic surgery) that should be discussed with the patient as soon as possible.

Assessment of sexual problems in patients with and survivors of cancer

Effective interventions follow an adequate assessment of patients’ concerns, and few concerns are perceived as more difficult to assess than those related to patients’ sexuality. True barriers exist on behalf of patients, providers, and institutions to discussing and addressing sexual dysfunction during and after cancer treatment. In this section, we discuss assessment strategies that target provider-specific, and possibly institution-specific, barriers as they relate to the assessment of sexual dysfunction. More specifically, 2 approaches are discussed to address the potential barriers of time constraints, providers’ feelings of embarrassment and fear, and assumptions about patients’ level of interest in sexual health concerns or potential reactions to sexual health discussions. By addressing these particular barriers, providers might feel more encouraged to not only assess patient’s organ function as it relates to sexuality after cancer but also to actually address sexual problems with patients in a more confident, competent, and holistic manner. The 2 approaches described include the implementation of a paper-and-pencil screening of symptoms self-report survey during routine clinic visits, and a reference guide to starting the conversation about sexual health with patients with and survivors of cancer based on established frameworks for discussing this topic. Paper-and-pencil screening tools are available to effectively obtain a first-level assessment of sexual function concerns in patients with cancer. These tools vary in length and psychometric properties, and recommendations are
provided in this section as to when these instruments could be used. Adequate screening for sexual concerns in patients with cancer patients, however, likely includes talking about sexuality with patients, which can seem a daunting task especially for untrained health providers. Therefore, 2 extensively referenced frameworks for discussing sexual problems with patients are described in this section with the aim at addressing cognitive and emotional barriers to having these discussions in a manner that feels safe and effective for both providers and patients.

**Paper-and-pencil tools for screening**

Paper-and-pencil screening tools are available to briefly and preliminarily assess sexual function in patients with cancer and help determine which patients may require further specialized assessment and intervention. A brief, psychometrically sound tool should be incorporated as part of routine review of symptoms during patient visits. For providers who are pressed for time, feel more vulnerable to screening based on individual assumptions (ie, older patients surely are not interested in discussing sexuality), or feel embarrassed by bringing up sexuality directly with patients, paper-and-pencil screening tools that patients can complete while waiting to see the provider can be particularly useful. Providers can swiftly review patient’s responses and, when necessary, further assess and address any concerns by using the starting the conversation strategies included later. For providers who feel already more comfortable having a discussion with patients about sexuality, the questions in these tools may serve as a guide to review symptoms that might be present after cancer treatment. Three instruments that have been widely established and can be easily accessible to providers are reviewed later. These instruments are the University of California Los Angeles Prostate Cancer Index, the International Index of Erectile Function, and the Female Sexual Function Index. We discuss the psychometric properties, benefits, and limitations for each of these measurements. It is important to note, however, that in recent years efforts have been made to expand the tools available for assessing sexual problems in patients with cancer to include measures other than specific organ function, and research studies on these tools continue to be underway.

**The Female Sexual Function Index (FSFI)**

The FSFI is a 19-item self-report measure originally developed to assess female sexual function in women of any age, including premenopause and postmenopause, in the general population. The FSFI takes approximately 15–20 minutes to complete and assesses function “over the past 4 weeks” in the following specific domains relevant to female sexuality: desire, arousal, lubrication, orgasm, satisfaction, and pain. The FSFI has sound psychometric properties (internal consistency α = 0.89 to 0.97 and reliability coefficient ≥ 0.79) and the ability to differentiate between clinical and nonclinical populations. The FSFI has been used and validated in studies on patients with and survivors of cancer and can be accessed along with instructions for implementation and scoring at [www.FSFIquestionnaire.com](http://www.FSFIquestionnaire.com). Although the FSFI only takes a few minutes to complete, a recently developed shorter version of the measure is also available and further improves the likelihood of utilization. The FSFI 6-item version takes approximately 3 minutes to complete, has good specificity and sensitivity values, and the ability to discriminate between clinical and nonclinical populations. However, the shorter version comes with the trade-off of measuring sexual function following a largely one-dimensional conceptualization of dysfunction, as compared with the longer, multidimensional, original FSFI. Moreover, the FSFI 6-item version has not been yet validated with patients with and survivors of cancer.

**The International Index of Erectile Function (IIEF)**

The IIEF is a 15-item self-report measure developed to assess erectile function in men in the general population. The IIEF is available in many languages and has been extensively used in studies with patients with and survivors of cancer, in particular with patients with prostate cancer. The IIEF measures function “over the past 4 weeks” in the following domains relevant
to male sexuality: erectile function, orgasm, desire, intercourse satisfaction, and overall satisfaction. This measure has adequate psychometric properties (internal consistency $\alpha \geq 0.73$ and reliability coefficient $\geq 0.64$) as well as adequate construct and discriminant validity.373 This is a brief measure that can be easily implemented in routine care with low patient and provider burden. However, shorter versions of the IIEF are also available. Of these shorter versions, the IIEF 5-item version (IIEF-5 also known as the Sexual Health Inventory for Men/HIM374) has also been validated and used in patients with and survivors of cancer.370 The IIEF-5 is limited to measuring erectile function and intercourse satisfaction in men. However, this instrument might be particularly valuable in settings where time constraints are highly significant.

The University of California, Los Angeles (UCLA) Prostate Cancer Index—Sexual Function Sexual Bother (PCI-SF SB)375

The PCI-SF SB is a 20-item self-report measure of health-related quality of life, developed specifically for men with localized prostate cancer. The measure includes items that assess function and bother relevant to urinary, sexual, and bowel domains. The PCI-SF SB takes approximately 20 minutes to complete and has been translated and validated in languages other than English, including Spanish, Dutch, and French. The PCI-SF SB has sound psychometric properties (internal consistency $\alpha > 0.78$ and reliability coefficient $\geq 0.65$) and has been extensively used in health-related quality-of-life research with patients with and survivors of prostate cancer.370

Instrument selection

As mentioned before, there are a number of sexual function measures in addition to the FSFI, the IIEF, and the PCI-SF/SB that have been or continue to be developed and validated, and a review of several of these tools can be found in Jeffery et al. When making a decision as to which measure to use, the validity and reliability of the measure as well as the time it takes to complete and the breadth of the assessment are crucial factors. Although the FSFI, the IIEF, and the PCI-SF/SB are the most widely used measures of sexual function in research, only a few studies are available that directly compare these measures.376 Therefore, at least for the time being, the decision to use 1 measure over the other will ultimately be of the practitioner’s, and will be likely based on time exigencies and potential benefit of using a more comprehensive (vs a shorter) measure of sexual function.

Starting the conversation and the purpose of assessment

Paper-and-pencil tools help facilitate an invaluable first step in the assessment of sexual problems after cancer. However, these tools should not replace a more thorough clinical assessment of patient’s concerns, particularly for those patients who indicate sexual problems during screening. Providers might feel unprepared, embarrassed, and even afraid of discussing sexual problems with their patients. However, there are several structured models of clinical inquiry that providers can use to guide their discussions about sexual function with patients. Two of the most commonly referenced models used to discuss sexuality with patients are discussed in this section and include the BETTER model and the PLISSIT model.

The BETTER model

This model stands for B ring up the topic of sexual health during consults, E xplain to the patient that sexuality is a part of cancer care and can be discussed during consults, T ell the patient that resources are available to address their concerns, T ime discussions and emphasize that patients can bring the topic up at any time, E ducate the patient about the possible changes in sexuality that can be brought by treatment, and R ecord the discussion in the patients’ chart.377 For instance, then, a conversation with patient who has completed therapy and returns for follow-up could be framed by the providers using the BETTER model as follows: “Mr. Z, as part of your routine visit today I would like to also discuss a common side effect of treatment, which is sexual dysfunction (B ring up the topic). Many of our patients have sexual health
concerns, and I would like to offer a safe venue for you (and your partner) to discuss any concerns you may have or changes you may have noticed as a consequence of treatment (Explain sexuality is part of care and can be discussed). There are many resources we could guide you toward (Tell the patient about resources), and even if you were not concerned at this particular time, I would like you to feel free to bring these concerns up at any time now or in the future (Time the needs). Some of the concerns that we are aware are low libido, difficulty with arousal, and difficulty with climax (Educate about possible changes in sexuality). I will make a note in your chart for my reference that we have discussed this here today, and will make sure to follow-up with you regarding any concerns during future visits (Record discussion in patient’s chart).

The PLISSIT model

The PLISSIT model offers another framework to effectively raise the topic about sexual concerns relevant to cancer and its treatment. PLISSIT stands for asking Permission to talk about sexuality, offering Limited Information to address sexual concerns, providing Specific Suggestions based on the patient’s presentation, and referring for Intensive Therapy as needed. A provider who uses the PLISSIT model could frame a conversation with a patient as follows: “Ms. A, I would like to discuss a very common possible side effect of the treatment you will be receiving and which could impact sexuality and intimacy. Would it be okay with you if I provide you with some specific information? (Permission). You might experience symptoms of premature menopause, including a very common one which is vaginal dryness (Limited Information). I would like you to know that if during or after treatment you find yourself having this side effect I could provide you with a list of moisturizers that could help manage this symptom (Specific Suggestion). If you find yourself having any other sexual health concerns besides the one I am telling you about, I may also be able help directly or in making sure you find a specialized resource that can provide you with further recommendations (Intensive Therapy).

Established models for discussing sexual problems, such as the BETTER and PLISSIT models, present providers with specific tools to help manage feeling unprepared to initiate conversations about sexuality with patients, and with a guide to discuss sexuality in a way that is effective and not terribly time consuming and can be recorded and referenced to in a patient’s chart as part of routine care and as recommended by practice guidelines.

Levels of intervention: Considerations beyond organ function

The utilization of integrative conceptual models for understanding sexuality in the context of cancer care, and the implementation of assessment models that incorporate a discussion of sexuality as a complex issue rather than as a mere organ function problem, should translate into the provision of interventions that address patient’s sexual problems in a comprehensive manner. However, similarly to the problems encountered with assessment, barriers to adequate intervention continue to be documented, and therefore addressing these barriers should represent both a research and clinical priority. In this section, 2 levels of intervention (or models of care) varying in depth of involvement are discussed. We believe that based on resources available to providers (eg, time and institutional and financial support) at least one of the following levels of intervention should prove feasible for implementation and adequate in addressing patient’s sexual health needs.

Level I—Developing a referral network and competency to address sexual problems

Referral networks

Following the establishment of routine practices for screening and assessment of sexual problems during and after cancer treatment, providers should be prepared to facilitate referral services to appropriate resources relevant to each patient’s particular concern. For patients who
present with functional sexual problems (e.g., erectile dysfunction and vaginal dryness), referrals to specialized medical providers such as gynecologists, urologists, and endocrinologists are crucial. For patients who present with psychological and relational concerns relevant to sexuality and intimacy after cancer, a referral to support groups or counseling should be facilitated. Providers may find specialized sex therapy and counseling providers through the American Association of Sexuality Educators, Counselors and Therapists (AASECT) website's listing of certified sex therapists and through patients' medical insurance listings of mental health providers. Moreover, practitioners should develop a referral network of consultants (medical, mental health, and rehabilitation providers) who are aware, knowledgeable, and skillful in addressing sexuality concerns particular to cancer survivorship. Providers should also refer patients to resources with general information on sexuality and cancer available through reputable sources such as the American Cancer Society and the Livestrong Foundation.

**Competencies required to address sexual problems**

Some of the barriers identified as preventing providers from addressing sexual problems with patients include time constraints, lack of training, feelings of embarrassment, attitudes and beliefs about patients' sexuality, and the potential perceived risks involved in discussing such a topic. These barriers are not surprising, given that sexuality is a complex topic that may evoke difficult cognitive and emotional processes and may therefore result in providers limiting their clinical inquiry. However, many patients expect that providers will or should address sexual problems with them and facilitate resources that can help them ameliorate their suffering. Therefore, ultimate intervention success (including those that are limited to organ function) might depend greatly on provider's level of competency in addressing sexual health concerns with their patients. As such, providers might benefit from pursuing training relevant to developing the competencies required to effectively and sensitively discuss sexual health concerns with patients. The model for developing multicultural competency in counseling, through the development of awareness, then knowledge, and then skill may be most helpful in guiding providers when seeking opportunities for training in addressing sexual health with patients. More specifically, providers should first consider trainings that focus on deepening their own awareness of barriers to addressing sexual problems with patients by participating in trainings that focus on self-evaluation and processing of attitudes and beliefs relevant to sexuality. Developing such self-awareness is likely to not only deepen the provider's understanding of barriers but also develop the competencies necessary to more effectively relate to and understand patient's concerns and develop positive rapport that can facilitate sensitive discussions. Providers may also continue developing their knowledge relevant to sexuality and cancer through reviews of the literature and attending continuing education opportunities that focus on this topic. Finally, providers might greatly benefit from developing a set of skill through shadowing and supervision from practitioners who have expertise in conducting sexual histories and providing interventions to address sexual problems. Providers who are able to develop the awareness, knowledge, and skills necessary to competently address sexual problems after cancer should find that patients' concerns would be addressed effectively, safely, and sensitively.

**Level II—Development of sexual health clinics in cancer centers**

In recent years, several cancer centers around the world have developed sexual health clinics housing multidisciplinary teams of providers that can assist patients in addressing sexual problems holistically. One such development has been described by Barbera et al where a multidisciplinary team (oncology, gynecology, nursing, psychology, social work, sexology, and administration) was involved in planning the clinic and developing a proposal for its operation. Part of the planning involved working with the gynecology oncology clinic at the institution to promote a referral pathway to the clinic and setting criteria for referrals. The authors also described the clinic's approach to assessment and discussion of patient concerns using a standardized assessment tool and the PLISSIT model, as well as to the development of resource
packages to be provided to the patients based on their needs. Patients at the clinic were able to access consultations with the specialized providers (ie, nurse and physician) for a functional assessment and discussion of appropriate intervention strategies. The authors found that the development of the clinic required strong leadership support, but was also feasible regarding implementation, and ultimately required a relatively small investment. For institutions interested in the development of such clinics, it is recommended that this article is reviewed in further detail.

Summary

In this article, we provide a review of sexual problems commonly experienced by patients with and survivors of cancer, address strategies for assessment and clinical inquiry relevant to sexual dysfunction, and propose 2 levels of intervention and models of care to adequately manage sexual problems in cancer settings. The area of sexuality and cancer has gained much deserved attention in the past several years, and advances in the understanding of this complex element of human experience have been made. However, many gaps in the literature still exist and should become a research priority in the coming years. Some of these gaps include the development of prevalence and intervention studies that more consistently incorporate a conceptual framework of sexuality as a comprehensive experience that reaches far beyond organ function and the design and evaluation of provider training that focuses on the development of competencies needed to effectively, safely, and sensitively address sexual health needs with patients.

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