Predicting and Treating the Sexual Difficulties of Gynecologic Cancer Survivors

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Women treated for gynecologic cancer represent approximately 45% of cancer survivors. Many report significant sexual difficulties during follow-up, and data suggest these difficulties are direct consequences of their cancer treatments. Health care providers can identify at the time of initial therapy those women who will be at greater risk for problem development. Clinical observations are provided on the development of sexual problems for these women as they attempt to resume sexual intercourse, and the psychologic and behavioral therapies that can be used for treatment are discussed.

Introduction

Approximately 5.7 million Americans alive today are cancer survivors. Almost three times as many women as men are survivors after cancer treatment (4.1 vs 1.6 million, respectively), and in women treated for gynecologic cancers, endometrium and cervix represent the second and third most prevalent sites for survivors. When endometrial and cervical cancer survivors are combined, they surpass breast cancer survivors as the largest number of survivors for a specific site (1,701 survivors vs 1,332 survivors per 100,000 population, respectively).[1] Among the medical concerns for these women include long-term/late effects of therapies (eg, recurrence, second malignancies),[2] emotional distress (eg, mood disturbance, traumatic stress), disrupted interpersonal relations,[3] sexuality concerns,[4] and employment and occupational difficulties.[5,6]

An evaluation of changes in quality of life following gynecologic cancer indicates that sexuality issues undergo the greatest disruption. Difficulties often begin with the signs and symptoms of the disease and continue as attempts are made to resume activity following treatment. For some women, the physical difficulties or the emotional sequelae are so disruptive that all sexual activity with the partner ceases. Other data suggest that these sexual difficulties can have a "ripple effect" that leads to negative feelings regarding self-confidence, self-esteem, and the view of herself as a woman. Younger women of reproductive age who are treated also must face the reality that their childbearing years are probably over. For these reasons, this article focuses on sexuality and emotional adjustment in gynecologic cancer survivors and offers suggestions for preventing or remediating morbidity.

Who Is at Risk for Developing Sexual Difficulties?

Schag et al[7] have noted the importance of identifying characteristics of women at risk for psychosocial distress. In a test of predictors for women with breast cancer, significant concerns were found 12 months after diagnosis in the areas of psychologic distress, communications with spouses, negative body images, and sexuality for women identified at diagnosis as being at moderate to high risk for problem development.

Medical Risk Factors

![Medical Risk Factors Diagram](image.png)
Medical factors such as the extent of disease and the magnitude of treatment appear to play significant roles in determining sexual outcomes for women with gynecologic cancer. Thus, at our institution, we have formulated a model for disease and treatment pathways that can yield differential levels of risk for sexual morbidity (Figure). [8] Variables are introduced according to disease progression, since disease-relevant events provide a meaningful framework to understand psychologic adjustment to gynecologic cancer. The occurrence of disruptive signs and symptoms at the onset of cancer is considered. The first point of psychologic and behavioral morbidity occurs when the disease is detected and produces sexual disruption. This early change is included because of its role in increasing a woman's emotional distress and in alerting her to the potential for subsequent life changes.

The model indicates that extent of disease and extent of treatment are major indicators of risk. The disease and treatment status is summarized into routes of "limited" or "extensive," based on supporting medical endpoint data (ie, five-year survival rates across sites are 89%, 54%, and 20% for localized, regional, and distant gynecologic disease, respectively). [9] The extent of disease is then considered in the context of the magnitude of treatment. For example, women with localized or regional vulvar cancer often receive the same disfiguring surgical treatment - radical vulvectomy - and might differ only in the provision of radiotherapy or additional surgery for the groin nodes in the case of regional disease. The correlation between the magnitude of disease/treatment and the psychologic/behavioral endpoints is supported across cancer sites.

For women whose therapy cannot be modified, the availability of risk-reducing medical interventions is then considered. For those with extensive disease and treatment, the availability of such interventions might reduce the level of risk from high to moderate. Examples of rehabilitative medical efforts include vaginal reconstruction for pelvic exenteration patients or labia preservation for vulva cancer patients. Although not panaceas, these interventions result in significantly better psychologic, behavioral, and sexual outcomes for those patients who have undergone such interventions. [10-12] For those with limited disease and treatment, medical interventions could reduce their risk to approximate that of healthy individuals undergoing related experiences (ie, the base rate). For example, some women experiencing a surgical menopause following treatment for localized cervical cancer can be treated with hormonal replacement therapy in the same way as healthy women who experience a natural menopause with its attendant difficulties. [13]

The final contributors to risk are new health problems such as hormonal changes or continuing stressors resulting from the disease and treatment. Consideration of "hormonal changes" includes the issues of induced menopause and infertility. The majority of women who were premenopausal prior to developing gynecologic cancer become postmenopausal following treatment, either because of ovary removal and/or the inability to be treated with estrogens. Menopausal changes produce significant sexual effects. [14] Also, ovary removal and sterilization may end childbearing - a potential stressor for the young woman with cancer. Continuing stressors, which can be heterogeneous, include chronic fatigue or nausea and vomiting from toxic or lengthy chemotherapy regimens, as well as late morbidities from treatments (eg, a bowel fistula following pelvic irradiation). If such problems arise, the model considers the availability of effective treatments. Multiple pathways can lead to a high or moderate risk of morbidity, but women who are hypothesized to have the lowest risk are only those who have limited disease and treatment and who have no new or continuing problems.

Psychologic and Behavioral Risk Factors

In addition to medical contributors, sexually relevant psychologic factors can predict risk for sexual morbidity. The model begins with "baseline" psychologic and behavioral factors. In addition to the individual difference variable described below, straightforward predictors include age, sexual status (active or inactive), and prior frequency of important sexual activities such as intercourse. These factors are important predictors of sexual activity in studies of healthy individuals as well as individuals with chronic conditions and illnesses. [15,16]

We explored the concept of body image in an effort to identify a sexually relevant individual difference variable, since body image may be relevant to sexuality for not only healthy women, [17] but also for women with cancer. [18] However, our studies found weak theoretical notions of the construct and poor measures of reliability and validity. [19] We also found in empirical tests that measures could not predict outcome either in breast cancer patients [20] or in multiple samples of women with gynecologic cancer. [19] This led us to a more central perspective - a woman's view of herself as a sexual person.

A woman's sexual self-schema (self-concept) is a cognitive view about sexual aspects of herself; it derives from past experiences and manifests in current experience, and it guides the processing of domain relevant sexual information. [21] It includes two positive aspects (an inclination to experience romantic/passionate emotions and a behavioral openness to sexual experiences and/or relationships) and a negative aspect that appears to be a deterrent to sexual expression (embarrassment and/or conservatism). The construct is related to intrapersonal and interpersonal aspects of sexuality. A woman with a low sexual self-concept appears to be at greatest risk for sexual difficulties, and she has more difficulties because she generally is less romantic/passionate in her emotions, less open to sexual experiences, and more likely to have negative feelings about her sexuality. Thus, in the context of cancer - with disease or treatment factors causing direct changes to the sexual body or sexual responses - we have found that women with low sexual self-schemas are at greater risk.

An intervention would be particularly important for the woman with a more negative view of her sexuality. While it would provide specific strategies for managing her sexual difficulties, an intervention would challenge the woman's typical self-view by providing strategies for enhancing her sexual self-schema (ie, how to become more arousable, open to sexual experiences, and less inhibited or embarrassed). A process model of sexual activity and sexual response cycle problem development among women with gynecologic cancer has been developed that details the differences between dysfunctional and nondysfunctional response patterns. [22]

Psychologic Interventions

Interventions can reduce distress, hasten resumption of routine activities, and improve social outcomes for groups at high risk for quality-of-life morbidity, such as those with disseminated or recurrent disease, as well as those at low or moderate risk. [23] When controlled studies were reviewed, effective therapy components included an emotionally supportive context to address fears and anxieties about the disease, information about the disease and treatment, behavioral coping strategies (eg, role-playing difficult discussions with family or the medical staff), cognitive coping strategies, and relaxation training to lower "arousal" and/or enhance one's sense of control. While data are insufficient to choose among components, the literature suggests an emphasis on relaxation, coping, social support, and disease-specific components. [23,24]

While no intervention studies have focused on sexuality, three have included minor sexuality components, and two of these studies included women at low morbidity risk. Capone et al. [25] provided a brief, crisis-oriented intervention. For sexually active women, a sexual-therapy component included information and methods to cope with and reduce anxiety when resuming sexual intercourse. Fifty-six women were diagnosed with gynecologic cancer at stage I-III. A nonequivalent control group was formed by recruiting previously treated women. There were no differences in measures of emotional distress between groups or within the intervention group. A trend in the percentages of women returning to work favored the intervention participants compared with the control group (eg, 50% vs 25% at three months, respectively). Substantial differences were found between the women in the resumption and frequency of intercourse across all posttreatment assessments (eg, 16% of the intervention group vs 57% of the control group reported less or no sexual activity at 12 months following treatment). The second quasi-experimental investigation [26] involving 32 women (14 with intervention and 18 as control) used a peer-counseling model. Interventions were delivered in telephone contacts and booklet descriptions of the coping strategies. Analyses indicated no differences between groups at any time. Only one study [27] of moderate-risk gynecologic cancer patients compared individual
Psychologic and Behavioral Causes of Sexual Dysfunction

We devised a clinical formulation of the development of significant sexual dysfunction for women with gynecologic cancer.[22] We considered the processes from the point at which couples attempt to return to their prior sexual routines. Our longitudinal data indicate that from the beginning, couples make few changes to accommodate for the fact that the woman has had cancer. The only accommodation that usually is made is waiting - and usually not long enough - to resume sexual intercourse. The frequency declines significantly during the early posttreatment recovery period and remains at this lowered level at 12 months posttreatment. This reduction in frequency has been replicated across gynecologic and breast patients, although the reductions are more extreme (sexual intercourse occurs rarely or never) for women receiving the most radical genitlal surgeries. [10,11]}

We also know that global behavioral disruption usually does not occur; when couples engage in sexual intercourse, albeit less often, they continue the same pattern of sexual behaviors used prior to cancer diagnosis. While this suggests that no "prompting" of the sexual behavior repertoire is needed, it also shows that couples do not vary their sexual behavior spontaneously. Couples continue to engage in the same range and type of sexual activities, perhaps unadvisedly, even when the result is significant sexual disruption or even pain during intercourse for the woman.

Approximately 50% of women will be diagnosed with a sexual desire disorder during the early posttreatment period. [28] Half of these cases will resolve during the first posttreatment year; however, a comparable number of new, late cases will occur by one year following treatment. The higher rate of problems of sexual desire early in the posttreatment year may be due in part to the emotional crisis surrounding diagnosis and treatment, which suggests that interventions to reduce affective distress might enhance sexual desire.

Of all the phases of the sexual response cycle, sexual excitement (including cognitive, affective, behavioral, and physiologic responses) undergoes the greatest disruption.[28] This disruption involves a dysfunctional self-image, lowered arousability, and reduced awareness of physiologic signs of arousal (eg, body/pelvic warmth and lubrication). The lowered arousability is specific to foreplay and sexual intercourse, [28] suggesting that woman's ability to focus on erotic cues is significantly impaired. Women also may experience dyspareunia (pain during sexual intercourse) - a significant, distracting sensation to sexual arousal. In addition, women also report negative body cognitions, with negative thoughts and evaluations for the body part (ie, the genitals) that has undergone change.[19]

In view of these difficulties, it is not surprising that the frequency of orgasmic dysfunction increases from pretreatment to posttreatment (from 7% to 25%, respectively).[28] Orgasmic difficulty for women produces moderate distress and provides a salient indicator to women that their sexual responses are significantly impaired. The high level of dyspareunia is a probable contributor to orgasmic dysfunction.

The resolution phase also is disrupted.[28] Women may experience residual pain following sexual intercourse. They also may believe that their sexual life is significantly worse, and our data again indicate that this evaluation worsens with the magnitude of disease and treatment. For women with cervical, endometrial, ovarian, or breast cancer, this evaluation is "below average," [29] for women with vulvar disease, the evaluation is "inadequate," [11] and for women treated with pelvic exenteration, the evaluation is "poor."[10]

These problems are most severe in the earliest posttreatment months, [28] and they begin as soon as intercourse is resumed. Further, the development of sexual problems for the man (particularly delayed ejaculation) may be a sequel to the woman's problems. Our longitudinal data for couples who abandoned sexual activity indicated that, typically, they would resume intercourse in the early months, experience significant sexual problems, and then forego future attempts. Thus, for both the woman and her partner, the sexual interaction is initially problematic, can become more difficult, and may worsen with the lack of knowledge or failed efforts to change. Thus, they may avoid subsequent sexual opportunities after these initial difficult experiences. The avoidance can then result in a further reduction in the frequency of sexual activity.

**Intervention Strategies**

Selection of therapeutic techniques and content can be guided by the literature on psychosocial intervention research with cancer patients [23] and behavioral sex therapy techniques. Many of the same principles and techniques of sexual therapy that have documented effectiveness with healthy individuals also can be applied to the sexuality problems of an intervention, [30,31] since many of the problems are common (eg, anticipatory concerns about resuming sexual activity following abstinence, arousal deficits, and orgasmic dysfunction). However, other problems are unique (eg, dyspareunia due to radiation-induced vaginal atrophy or stenosis), more severe (eg, orgasmic dysfunction due to nerve and/or vascular disruption/removal rather than a skills deficit), or more difficult to overcome (eg, permanent body disfigurement).

Thus, although the basic principles of social learning interventions are important, such as graduated assignments and the development of an undemanding performance environment, new techniques may be necessary. Finally, while a preferred strategy for conducting a sexual intervention involves the participation and interest of both partners, significant gains also can be achieved by treating the individual, whether the woman has cancer [32] or is healthy. [33]

**Components of an Effective Intervention**

Our interventions for women with gynecologic cancer include six components:

1. **Coping with cancer and its potential physical impact.** Information on the specific disease, treatment modality, and changes (anticipated or actual) for body parts and functions must be provided to the patient. Therapy sessions can include discussions of the woman's feelings regarding the didactic information, problem-solving for immediate concerns (eg, recuperating from surgery, coping with menopausal symptoms, and addressing the fear of recurrence), and role-playing of communication skills for facilitating problem-solving and soliciting the support and assistance of others.

2. **Considering the context for physical and sexual changes and enhancing physical and sexual self-esteem.** Information can be provided that reviews the bodily changes resulting from treatment with an emphasis on women's sexual anatomy and physiology (coverage of the sexual response cycle and expected changes). Patients also can be provided with information on sexual activity as a natural function, and they can be helped to identify as well as relabel pain/discomfort or other difficult-to-control symptoms that can occur following treatment, as well as learn about one's body through touch. Homework components are often helpful and can be individualized depending on the disease site and treatment. Typically, they include self-exploration of the body in the bath or shower, a clinical look at the genitals and breasts, and Kegel (vaginal) exercises.

3. **Broadening the contexts for sexual activity, as well as facilitating and enhancing sexual communication.** Therapy sessions can address optimal timing for sexual activity given current health status, consideration of broadening the behavioral repertoire (eg, sexual activities in lieu of sexual intercourse, alternative intercourse...
(4) Managing dyspareunia or other disruptive symptoms and signs during sexuality. Informational sessions can include discussion of the specific and general causes of the sexually disruptive symptoms and signs with regard to the disease/treatment. For vaginal pain, a multimodal strategy can be used with behavioral strategies, including the use of vaginal dilators (to gauge pain and to determine the advisability of intercourse) and artificial lubricants. For women with severe vaginal atrophy or stenosis, a regimen of dilator usage may be necessary. Homework sessions can include use of these treatments and aids, as well as vaginal Kegel exercises.

(5) Discovering the partner's sexuality and communicating sexual concerns and needs. Informational sessions can include discussions of the man's anatomy and physiology and his anticipated reactions to the woman's illness, body changes, and sexual changes. Therapy sessions can include not only discussing the woman's concerns about her partner's reaction to disease, illness, and changes in health and sexuality, but also role-playing of discussions with her partner on topics of concern. Women without partners can discuss strategies for sharing information about her cancer and treatment.

(6) Enhancing arousal and orgasm and keeping in touch. Information for the final sessions can include reviews of the previous information, additional strategies to facilitate desire and arousal, and approaches such as additional manual stimulation to facilitate orgasm if it has been disrupted with treatment. Therapeutic efforts can continue to encourage women to experiment with alternative sexual activities and experiences to maintain interpersonal intimacy.

Conclusions

Treatign difficulties after they have developed is a common strategy for providing psychosocial services for cancer patients. However, longitudinal data suggest that preventive interventions following a cancer diagnosis but prior to the resumption of sexual activity posttreatment are more effective than rehabilitation interventions during recovery or later, because sexual difficulties arise as soon as intercourse is resumed. Intensive intervention during the early posttreatment period would provide a woman with an educated perspective for understanding the sexual changes and the knowledge to modify her activities to reduce the likelihood of sexual difficulties. Conversely, intervention after the complete recovery process might be facilitated by other factors such as lowered emotional distress rather than the emotional lability that characterizes the diagnosis/treatment period[28] and the stabilization of most of the treatment side effects. Yet, by one year after treatment, sexual difficulties may be significant and some women may have abandoned sex. In either case, the sexual concerns of women with gynecologic cancer need to be addressed.

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References

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