Altered Sexuality and Body Image after Gynecological Cancer Treatment: How Can Psychologists Help?

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Abstract

Once medical treatment for gynecological cancer is completed, what happens to patients’ sexuality and body image? Due to the delicate nature of the cancer site, treating this cancer typically affects sexual functioning and body image adversely, making it critical to identify the concerns of these patients and do so in a manner less restrictive than paper-and-pencil assessment. To gain a deeper understanding of the phenomenological experiences in question, we interviewed nine gynecological cancer patients and seven cancer-free women. After implementing a relaxation protocol, we asked each woman to describe her feelings and thoughts on her sexuality and body image in one-on-one interviews. A variety of themes emerged on patients’ attitudes and perspectives concerning sexuality and body image following diagnosis and treatment of the cancer. The themes that were considerably different from those of the cancer-free women included decreased sexual functioning and body image, abrupt shifts in self-identity due to loss of physical integrity, and distancing in intimate relationships. Several implications of these findings for clinical practice are discussed, as well as the need to train medical professionals to properly assess these patients’ alterations in sexuality.

Keywords
Gynecological oncology; cancer; sexual dysfunction; body image

Introduction

What does a psychologist need to know when presented with a patient who was treated for gynecological cancer? The answer to this question is complex, as a woman’s sexuality can be influenced by a variety of factors. The sexual issues integral to the experience of gynecological cancer form a fundamental and yet still neglected aspect of psychologists’ understanding of patients’ quality of life (Butler, Banfield, Sveinson, & Allen, 1998). Unfortunately, gynecological cancer tends to result in negative changes in sexual
functioning due to the adverse impact of its medical treatment (Anastasia, 1998). Additionally, a cancer diagnosis and corresponding treatment often impact body image, and hold the potential to diminish feelings of positive sexual identity (Juraskova et al., 2003). In clinical practice, there is a need for enhanced knowledge of the effects of gynecological cancer treatment on sexuality and body image from the unique viewpoint of the patients who have undergone it. In order to explore this understudied topic, we investigated these patients’ perspectives on the aspects of their sexuality and body image that were most important to them following medical treatment. We compared such perspectives to those of women living without cancer, and implemented a qualitative inquiry method to provide a channel for all women to best express themselves on these sensitive issues. Once armed with comprehensive knowledge of such topics, psychologists could contribute to enhancing the quality of life of gynecological cancer patients in several ways. For instance, as discussed later, they could collaborate with both patients and medical professionals (a somewhat challenging task, for a variety of reasons) to facilitate client-medical provider communication. They could also improve the quality of the clinical assessment of these patients’ sexual concerns through training of medical professionals in the identification of sexuality alterations in need of therapeutic amendment.

Effects of gynecological cancer and its treatment on sexuality and body image

Gynecological cancer includes cancer of the cervix, fallopian tubes, ovaries, uterus, vagina and vulva. In the U.S., among the cancers of the reproductive system, endometrial cancer alone affects 7 of every 1 million women (National Cancer Institute, 2005). Types of treatment for gynecological cancer vary in severity and modality. Specialized surgical procedures, e.g., radiation therapy and chemotherapy, are typical treatment regimens for this cancer. Technological advances have increased the likelihood of surviving it; thus, clinicians should be prepared to target these patients’ key quality of life issues such as their sexual health and the rehabilitative aspects of their treatment (Butler et al., 1998). Overall, the prevalence of sexual problems for women living with a medical condition is very high, with estimates ranging between 45 and 90 percent (Bray, DeFrank, & Wolfe, 1981; Mattson, Petrie, Srivastava, & McDermott, 1995; Newman & Bertelson, 1986). Gynecological cancer patients in particular often endure significant and potentially detrimental alterations in both their sexuality and body image (Juraskova et al., 2003; Lagana’, McGarvey, Classen, & Koopman, 2001). For instance, treatment side effects including pain, nausea, vaginal dryness, and fatigue tend to result in negative psychological reactions that, in turn, may affect desire and libido (Anastasia, 1998).

Researchers have discovered that gynecological cancer can have a negative impact on all four stages of women's sexual response (e.g., Lagana’ et al., 2005), i.e., sexual desire, excitement, orgasm, and sexual resolution (Kaplan, 1974). Harris, Good, and Pollack (1982) found that these patients frequently experience decreased sexual satisfaction due to the cancer. According to Juraskova et al. (2003), women with cervical and endometrial cancer often express fears and insecurity regarding both future sexual interactions and long-term side effects of treatment, which often impact their perceived sexual desirability. Yet, many of them still feel the need to provide their intimate partners with sexual intercourse.

Medical treatment for cancer of all types is destructive by its very nature, often involving loss of body parts and/or challenging adjustments to functional limitations (White, 2000). In a qualitative study of how breast cancer treatment impacts sexuality, Wilmot (2001) found that surgery is often perceived by women as an assault on a key aspect of their sexual identity: “The body part assaulted had nourished their children and also had defined them as a woman” (p. 280). Similarly, medical treatment of gynecological cancer typically affects
body parts associated with womanhood and femininity, causing considerable body changes that are likely to alter body image. After this treatment is completed, gynecological cancer patients are often left with the residual effects of surgery and/or various medical procedures, such as radiation and chemotherapy. Such residual effects include hair loss, infertility, premature menopause, weight gain, scarring, and/or disfigurement of their genital organs caused by treatment (Anastasia, 1998; Butler et al., 1998; White, 2000) that can impact the reproductive organs as well as the abdomen/stomach area. At times, treatment may even require removal of portions of the vaginal walls, in addition to the ovaries and uterus, with adverse consequences for physical and emotional well-being (Ofman, 1995). The physical and emotional trauma suffered from such experiences can be substantial (Juraskova et al., 2003). Considering the sensitive nature of the body parts in question, the fact that reconstruction of the vagina and vulva can restore pre-cancer levels of sexual satisfaction in women with vulvovaginal cancer (Lai & Chang, 1999) shows remarkable resilience in this patient population.

The need to assess gynecological cancer patients' sexual health beyond coital frequency

It is important to note that gynecological cancer and its treatment often evoke sexually-related concerns other than disruption of coital activity patterns. For this reason, some researchers targeting post-treatment sexual adjustment have advocated a broader view of sexuality extending beyond coital frequency (e.g., Juraskova et al., 2003). Butler et al. (1998) found that sexual functioning contributes to a woman’s concept of her sexuality, but that her perception of the latter is not limited to this one dimension of functioning. Researchers such as Juraskova et al. (2003) discovered that satisfactory sexual experiences among gynecological cancer survivors are associated more with expressions of intimacy (such as disclosure, support, and sensuality) than with coital aspects of sexual relationships. Furthermore, Andersen, Woods, and Copeland (1997) explored the idea of sexual self-schema as a component of sexual self-concept that may be a determinant of sexual activity following onset and treatment of gynecological cancer. They found that women with a more negative self-schema not only have lower levels of arousability and ultimate sexual activity, but also lower likelihood of resuming any kind of sexual activity following cancer treatment.

The research findings summarized above highlight the importance of investigating gynecological cancer survivors’ sexual satisfaction beyond coital frequency post-treatment. To this end, the present qualitative study was designed to explore women’s intimate experiences surrounding their sexuality and body image once they complete medical treatment of gynecological cancer.

The exploration

Sixteen women comprised our sample. Recruitment occurred at the end of a quantitative treatment outcome study on a cancer support group (N=21). This psychosexual intervention targeted changes in sexual functioning and mood among gynecological cancer patients (Caldwell et al., 2003). In the initial phase of this larger study, participants were referred by two primary care physicians and one non-profit organization that offers free psychosocial support to cancer survivors and their families. Respondents were first contacted by mail. Each woman then received a follow up e-mail and/or phone call in order for us to answer any of her questions about the study and ensure that she met all inclusion criteria before being interviewed. A total of 22 women were recruited; one patient dropped out of the cancer support group (after her second meeting), stating that it was not what she had anticipated. The other 21 patients completed the intervention and were very satisfied with the outcomes of the cancer support group. Once the treatment outcome study ended, these
patients were personally contacted and invited to participate in the present qualitative research. Nine out of 21 accepted: they comprise this study’s clinical group. They were all 18 years or older, English speaking, and able to document that they had received surgical, radiation and/or chemotherapy treatment for gynecological cancer (i.e., endometrial, ovarian, uterine, vaginal, fallopian tube or cervical cancer). This group included women at all stages of the illness; such a broad inclusion criterion favored generalizability over specificity. In addressing the primary research question of the study, this heterogeneity allowed the composition of our sample to be indicative of the variety of women in the general population who have survived gynecological cancer.

For the purpose of gathering a control group, each patient, upon completion of her interview, was asked to refer to us a friend or acquaintance without cancer. Seven additional women agreed to be in this study: they were 18 years or older, English speaking, and had not received or ever needed any medical treatment for gynecological or breast cancer. Adding breast cancer as an exclusion criterion was motivated by the fact that, similarly to gynecological cancer, it could result in sexuality and body image problems, due to the very delicate nature of its site (Wilmoth, 2001). The logic underlying the comparison case sampling was that lessons could be learned about differences between the two groups. These lessons could illuminate relevant and important patterns of experience that were present in one group and absent in the other (Patton, 1990).

Using a qualitative inquiry approach, the first author conducted open-ended, one-on-one interviews exploring respondents’ various aspects of sexuality and body image. All 16 research participants were asked the same questions during the interviews, but from a different perspective. The gynecological cancer patients were asked to share their thoughts and feelings surrounding body image and sexuality as gynecological cancer survivors, and the women in the cancer-free group as women. This approach is consistent with that of Rogers (1993), who documented the importance of listening for the True-I in interviews—the voice of the woman “who knows and describes her experience through a full range of feelings, who can tell the story of her life and her relationships in detailed transparency (p. 291)”.

Interviews with each cancer survivor took place either at respondents’ homes, in a quiet private practice office in Palo Alto, California, in a Stanford University conference room, or at a location near their place of residence or work. It was important that such interviews be conducted in a place where respondents felt comfortable and secure. During the procedure, each woman was told that the interview would not be a two-way conversation, as the interviewer did not want to influence the quality or content of the answers. Individual interviews with the women in the control group were conducted via telephone, since the majority of referrals from the gynecological cancer patients were for women who lived outside of the state of California. Interviews with women in both the cancer survivor group and the control group were audiotaped with the active consent of each participant. Additionally, all respondents completed a demographic questionnaire.

**Relaxation protocol**

We administered a relaxation protocol first, to put all respondents (both cancer patients and cancer-free women) at ease. A guided visualization is a type of mindful relaxation that can have a powerful impact on the ability to expand one’s awareness of life experiences (Kabat-Zinn et al., 1992). In preparing each woman for the interview, the first author described the specific assessment procedure and then led her on a guided visualization by asking her to picture herself in a field: “Close your eyes. Take three deep breaths, letting out all the tension in your body. Start by relaxing all the muscles in your face. Then relax your arms...
and legs. Allow them to feel limp, warm, and heavy. Relax your stomach. Allow it to feel soft and warm. Now picture yourself in a beautiful field, a place that you find comfortable and safe. Slowly walk into the field and find a place to lie down in the grass, maybe under a tree, or in a spot in the sun. And once you have found it, stretch out and take in the beauty of the day, the smells of the grass, the sounds of birds or of a soft breeze rustling in the trees, or the feeling of your body pressed into the ground. And next to you, you see a large rock and there is a quote engraved on it by Thomas Moore”. The topic of sexuality was introduced within an artistic context in order to set the appropriate tone for the interview. The following quote by Moore (1998, p. 8) was then read to each woman: ‘‘Nature’s beauty, not just her functioning organs, is the essence of sexuality…if you want to know what sex is, think long and hard about a flower, especially its beauty and its appeal to the senses. Then think about all of nature and your own place in it. Whatever makes a flower glow with enchantment is the essence of your own sexuality”. The intent of using this quote was to remind the women of the sacred nature of this intimate aspect of their lives and to invite them to discuss sexuality in a way that was not shaming or humorous.

At the end of the reading, once the participant was ready to proceed, she was given a copy of the interview question to view. The latter was then read out loud to her slowly: “As we take a moment to look at your experience with gynecological cancer/as a woman in a compassionate light, what salient or relevant aspects particular to your body and your sexuality stand out for you? Consider your emotions, your thoughts, your physical body, your relationships with self and with others, your motivations, and your spirituality. This could be an issue that you have worked with or through. This could be an issue that has transformed over time. This could be an issue that came up in a support group or something that seems to resurface again and again. This could be something that has remained unspoken. In this interview I am wondering what is coming up for you as a salient issue that has transformed over time and/or remains there for you, something that stands out when you reflect on your experience of body image and sexuality as a gynecological cancer survivor/as a woman”. If a woman’s response required further clarification, the interviewer paraphrased what the participant voiced and, whenever needed, solicited more information by using phrases such as “What do you mean by that?”, “Say more about that,” “Can you give me a specific example?”, or “How was that for you?” If serious concerns surfaced as a result of this procedure, a referral for psychological treatment was provided. In addition, a referral list of local practicing sex therapists was handed out to participants on an as-needed basis.

Data coding and brief summary of the findings

Once completed, the interviews were transcribed and reviewed both audibly and visually as part of a content analysis by the first author, and then again by a co-researcher; these two women are trained researchers who had worked clinically with this patient population. Use of co-researcher control was employed to minimize systematic biases in the coding procedure. Consensus as to the emergent themes was established between the raters, in that they identified the same themes based on the responses provided by the research participants. All the protocols were thematically evaluated to determine any common elements of the sample’s experiences, focusing on identifiable patterns and themes of behavior and/or living. This is a commonly used interpretive strategy in the understanding of health and illness (Benner, 1985). Data analyses included organizing groups of related concerns and issues, as well as identifying sexual and body image themes on residual issues experienced by gynecological cancer patients. In some cases, a theme was categorized further and reorganized into sub-themes. Subsequently, the themes and sub-themes of the gynecological cancer patients were compared and contrasted with those of the women in the control group.

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The age range of the gynecological cancer group was 28 to 58 years, and the mean age was 44. Eight women were European-American and one was Asian-American. Five of the nine patients had an intimate partner. Seven of them were heterosexual, one self-identified as lesbian, and one as bisexual. One of the nine women had a child. This was a well-educated group, as most respondents had completed 4-year degrees. The majority of this group reported either part-time or full-time employment. Length of time since diagnosis ranged from 31 to 72 months; the mean was 4 years and 2 months. The majority of them had ovarian cancer, one of the most fatal gynecological cancers because its symptoms are usually vague and non-specific until the tumor is large and the disease is advanced (Basson, 1994). Attrition was a potentially limiting factor; to minimize it, the interviews were conducted in as timely a manner as was possible. Most of the patients had endured both surgery and chemotherapy. Length of time since end of treatment ranged from 21 to 65 months; the mean was 3 years and 3 months. The age range of the cancer-free group was 36 to 52 years, and the mean age was 43. Five women were European-American, one Mexican-American, and one Asian-American. They all had an intimate partner; most of them had a 4-year degree and were employed. Table 1 displays the themes that emerged from the data analyses, a sample quotation per theme, and the percentage of women who mentioned each theme.

Before we discuss our findings from a practice viewpoint, it should be noted that several issues limit their generalizability. Our results need to be corroborated in larger and more diverse studies, as we gathered a sample of modest size and little diversity, with respondents being primarily European-American, of relatively high social status, and almost exclusively heterosexual. We did not collect specific information on prognosis, although the length of time since diagnosis and since the end of treatment could be viewed as prognostic to a certain extent. Also, no information was available about pre-existing sexual problems or body image difficulties of the cancer patients, making future studies necessary before any conclusions can be definitely drawn. The quote by Thomas Moore about sexuality and the concept of beauty (used in the relaxation protocol) could be viewed as potentially leading material that might have encouraged cancer patients to focus on the loss of integrity of their intimate body parts. These women had participated in a psychosexual support group for gynecological cancer patients, thus they might have been more verbal about and aware of their sexual problems than women without this group experience. The cancer-free women were of similar age, SES, employment status, and educational background, but recruiting cancer patients’ friends and acquaintances adds a potential confound. The control group was still not a perfect match in terms of presence of children or partner status, and the majority lived outside of California (a fortuitous occurrence); this has implications for potential differences in access to health care services and geographic cultural norms. Moreover, the control participants, unlike the cancer group, were not given the interview question to view prior to this question being read to them, and were not interviewed in person. Individuals may tend to provide more confidential and sensitive information in a phone interview than in face-to-face interviews, therefore differences between the two groups should be interpreted with caution. Finally, the consensus in the application of codes was not statistically assessed. We have relied on the clinical expertise of the two raters, as well as on lengthy discussions and iterative consensus building in both the creation and application of the codes. Nevertheless, it is important to acknowledge the value of formally assessing inter-rater reliability when coding qualitative data.

A selection of clinically-salient themes and related practice implications

Due to space limitations, to optimize the between-group comparisons, the following discussion covers only the themes that best illustrate patterns of experience that were different in each of the two groups (please see Table 1 for all the themes that surfaced via
the qualitative data analyses). Having sexual concerns was a common theme for both groups. Several members of the control group stated that sexuality was not discussed in their homes when they were growing up. For others, it was a topic that was overtly addressed, and this open communication made them feel comfortable and supported in the process of their sexual development. Such a finding suggests a high prevalence of sexual development concerns that arise during adolescence and a common desire to discuss them. The theme in question was an ongoing problem for the gynecological cancer survivors, who reported that they had recently endured sexual difficulties, well beyond reduction of coital frequency. Interviews with these women revealed a negative and abrupt shift in sexuality triggered by the diagnosis and treatment of their illness. Such patients faced not only the side effects of medical treatment (such as scars, lack of libido, loss of fertility, and changes in body shape), but also the physical and emotional consequences of premature menopause (typically without help from their medical providers, as discussed later).

While cancer-free women conceptualized their body image and sexual experiences historically (referring to a gradually maturing body and sexuality that evolved over time), gynecological cancer survivors viewed them in terms of pre- and post-cancer. Diagnosis and treatment of cancer was the defining moment in the sexual history of cancer patients, as it dramatically changed how they experienced their sexuality and body from that moment on. This finding fits well within the existing pertinent literature that contains clinically-relevant information of potential use to psychologists. For instance, Juraskova et al. (2003) found that emotions and fears about sexual concerns are rarely discussed or communicated by either the cancer survivor or her partner. Also, many gynecological cancer survivors avoid questioning their health professionals about issues of sexuality because this is an embarrassing topic or is perceived as secondary (Molassiotis, Chan, Yam, Chan, & Lam, 2002). Those interviewed by Butler et al. (1998) reported feeling that sexuality is not a medical concern, leaving them and their partners to adjust in isolation, with little information and no support. Physical discomfort is an area of particular concern, as it usually inhibits the sexual activity of gynecological cancer survivors (Molassiotis et al., 2002). In this regard, Juraskova et al. found that, for some patients, fear of intercourse due to physical discomfort is so significant that they became emotionally detached when they first resumed it. If gynecological cancer patients report experiencing such a detachment, psychologists should carefully address this clinical issue as soon as feasible.

Another common theme for both groups was intimate relationships. The majority of the women without cancer reported a positive impact of such relationships on their experiences of sexuality and body image. Only one of them mentioned a feeling of self-consciousness that led to inhibition in her intimate relationships. In contrast, all cancer patients stated that their experiences of sexuality and body image post-diagnosis and post-treatment had negatively impacted their intimate relationships. Of the nine cancer patients interviewed, five had current partners; these women reported a feeling of distancing from them, both emotionally and physically. Those who were not in a relationship spoke of fear or doubt that inhibited them from forming relationships. Although none of the cancer patients reported a change in relationship status from time of diagnosis to post-treatment, the present findings suggest that the diagnosis and treatment of cancer typically have a negative impact on intimate relationships, consistent with prior empirical evidence (Juraskova et al., 2003; Molassiotis et al., 2002). It may take months or even years for gynecological cancer survivors to re-establish a comfortable equilibrium within intimate and social relations, as “almost every woman who has had gynecological cancer must grapple with tremendous feelings of loneliness and isolation” (Auchincloss, 1995, p. 2120). Auchincloss further pointed out that these women may struggle to eventually discuss their feelings with family and friends, only to find that the people within their support network are often unable to understand much of their experiences and are uncomfortable with such discussions.

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Psychologists servicing this patient population should address these relational difficulties and feelings of isolation.

In contrast to the cancer-free women, loss was an overarching theme for the cancer survivors. Among other losses, they reported loss of: maternal opportunities, wholeness, sexual desire, sexual pleasure, social/peer groups (feelings of isolation/social alienation), and identification with female athletes. One woman explained “We found out about my cancer when we were trying to have children. So I am kind of left without the ‘kids getting’”. Others stated “My sex drive is almost all gone. And I had a really strong sex drive before, and that is what I am grieving for.” and “I feel like I went from age 25 to age 65, and I did not have that transition.”

All the women in this study reported confronting issues of low self-esteem and poor body image. Respondents in the cancer-free group spoke of feeling inadequate and/or dissatisfied with their bodies at some point in their lives relative to societal standards. This is not surprising, given that much of women's sexuality is shaped by social and cultural norms of age, appearance, and childbearing ability. Any deviation from these norms could cause anxiety about self-worth in these areas. The teenage years can be especially challenging because, during that time, there is often strong pressure to change one's body rather than appreciate it and accept it, a pressure that has increased in recent years (Feingold & Mazzella, 1998). Later on in life, menopause (whether naturally occurring or consequent to medical/cancer treatment) is often coupled with psychological and physiological changes associated with decreased estrogen levels such as alterations in mood, sleep, and cognitive functioning, which can impact sexual desire and responsiveness adversely (Bachman & Leiblum, 2004). In contrast with the responses of healthy women, all cancer patients were unsatisfied with their bodies in different and more profound ways, as they felt “maimed, damaged, asymmetrical, (and/or) incomplete” due to some of the consequences of medical treatment. Understandably, because gynecological cancer and its treatment often have a negative impact on appearance (White, 2000), many of these patients experience a negative change in their body image (Bukovic et al., 2003). Some of them contend with feelings of being physically flawed for years after treatment (Auchincloss, 1995), and many have lifelong body alterations reminding them of their cancer (Juraskova et al., 2003). All these issues should be adequately addressed in a psychotherapeutic setting.

**Challenges related to addressing gynecological cancer patients’ sexual concerns**

There is an obvious need to take better care of the sexual and body image difficulties of gynecological cancer survivors. Even finding adequate support services or groups is typically more difficult for them because, compared to breast cancer, there are fewer clinical groups for patients with gynecological cancer (Auchincloss, 1995). Yet, high-quality interventions for these women are available and are highly effective (e.g., Brotto et al.’s 2008 brief psychoeducational intervention targeting these patients’ sexual arousal disorder). It is reasonable to expect that medical care providers would acknowledge these patients’ sexual concerns and provide them with a referral to a mental health professional when needed, but this seldom happens (as elaborated later). However, even if a referral is made, or patients pursue psychological services independently, the following issues could complicate the clinical picture. Psychologists, upon conducting a thorough assessment of the psychosexual needs of these women, could discover that at times immediate treatment is not feasible. This could be due, at least partially, to medical/cancer-specific issues needing to be addressed first, for instance the need to prescribe medications to decrease severe vaginal dryness before starting psychosexual treatment protocols.
A major obstacle is that, as found in our study, gynecological cancer survivors often do not feel comfortable talking about sexual issues with their medical care providers. Their reluctance to bring up sensitive sexual issues with medical professionals is often paralleled by the avoidance by such professionals to address patients’ sexual functioning. As a result, the physical complications of gynecological cancer and its treatment are often left unaddressed. Efforts should be made to improve this situation, in the best interest of the patients. Ideally, these neglected issues should be conceptualized from an integrated perspective viewing physical and sexual changes, as well as related psychosocial reactions, as critical factors to be targeted in a holistic manner. Psychologists, with their unique skills and training, could play a significant role in helping cancer survivors cope with the above-mentioned losses associated with a gynecological cancer diagnosis. They could also focus on becoming better informed about this cancer, its treatment, as well as the psychosocial and sexual concerns faced by these patients. Training in couples work could be particularly valuable, given that all the cancer patients in our sample indicated that their intimate relationships became more distant as a function of their illness and treatment.

One possibility to consider is for psychologists skilled at addressing the challenging issues in question to pursue collaborations with hospital and oncology medical providers. Professional psychologists could contact cancer treatment facilities and market themselves as psychosexual specialists for women with gynecological and other types of cancer. These efforts could also lead to the needed addition of a psychologist on cancer patients’ medical teams. Because positive, supportive interactions between gynecological cancer survivors and professionals are invaluable, it would be helpful for psychologists to clearly and comprehensively instruct patients on how to best discuss medical issues affecting sexuality and body image with their medical care providers.

As an example of the link between medical, sexual, and relational concerns, physical discomfort during sex could be related to vaginal atrophy and changes in the thickness of vaginal walls (possibly due to chemotherapy; Anastasia, 1998). If not properly addressed, this physical condition could precipitate sexual problems, with a significant increase in discomfort being paralleled by a decrease in sexual interest. Unless a patient has comprehensive information on these medical issues from reliable sources, how would she know that the thickness of her vaginal walls would eventually increase, and discomfort during intercourse would likely decrease? On the contrary, she could assume that the initial physical discomfort would not change, thus becoming resistant to engaging in sexual interactions again for fear of pain. In turn, this situation could negatively affect the quality of her intimate relations. Sadly, there seems to be little awareness of the critical role of health care providers. Are these professionals trained to assess patients’ problems related to altered sexuality? Investigating this topic, Humphery and Nazareth (2001) sent a questionnaire to 218 general practitioners; 133 of them completed it and sent it back. The findings of the survey show that only 46 of these physicians were trained in sexual history taking, 45 in diagnosing sexual difficulties, 49 in the management of patients’ sexual problems, 39 in psychosexual counseling, and 24 were trained in all these areas. These results evidence the limited training of medical doctors in sexual health assessment.

Oncology doctors and nurses are in a unique position. They could significantly assist cancer patients in obtaining needed support and assistance with their sexual problems. Yet, Stead, Brown, Fallowfield, and Selby (2003) found that, among 27 doctors and 16 nurses treating women with ovarian cancer, although most respondents thought that the majority of women with this cancer would experience a sexual problems, only 25% of the doctors and 19% of the nurses discussed sexual matters with such patients. Reasons for not discussing these issues included embarrassment, as well as lack of: knowledge and experience, perceived responsibility for patients’ failure to bring up sexuality, and resources to provide help if
needed. These findings indicate that, in spite of awareness of sexual concerns, oncology nurses and doctors typically do not initiate discussions about sexuality that would offer cancer patients the opportunity to express their concerns and obtain a referral to support groups or individual counseling/psychological services. Concerning nurses in particular, in a study on specialist nurses attending a communication skills training program, 18% of 129 nurses reported that discussing sexual matters was their most difficult communication problem (Fallow, Saul, & Gilligan, 2001). Moreover, hospital nurses often perform inaccurate evaluations of gynecological cancer patients’ overall quality of life, failing to estimate the severity of the symptomatology of those undergoing chemotherapy (Zhao, Kanda, Liu, & Mao, 2003). Zhao and colleagues suggested that nurses should undergo training to learn how to conduct proper assessments of cancer patients’ critical dimensions of quality of life such as their sexual health. This training could reduce the frequent discrepancy between clients’ reports of sexual problems and nurses’ diagnoses of negative changes in patients’ sexual functioning. Professional psychologists comfortable with addressing the complicated psychosexual issues in question could impart such training to oncology/medical professionals working at medical centers, hospitals, and/or clinics servicing this patient population, as well as to medical and nursing students undergoing training at academic institutions.

Conclusions

Several residual effects of gynecological cancer treatment on body image and sexuality appear to augment the general discomfort experienced by gynecological cancer survivors. Most of the cancer patients in our sample felt alone in dealing with their sexual difficulties, and could have used professional help from health care providers capable of addressing such concerns or, at least, of making a needed referral to a psychologist specializing in these clinical issues. The cancer survivors in the present study still had interest in sexual activities, despite experiencing significant side effects of medical treatment, feelings of separateness, and/or fears associated with pursuing or maintaining intimate relationships. Our findings could serve as hypotheses-generating for future quantitative and/or qualitative studies. They suggest that gynecological cancer patients needed an opportunity to articulate the complexity of their feelings and experiences. Many of them would have found it very beneficial to work through sensitive psychosexual issues in a psychotherapeutic setting. Psychologists working with this patient population should delicately initiate discussions of potential sexually-related concerns. This would allow gynecological cancer survivors who are too embarrassed to start these discussions to finally obtain needed information and validation, as well as get a chance at significantly enhancing their sexual and relational functioning. Moreover, psychologists could adopt several helpful roles, including patients’ educator on client-physician/nurse communication and on the psychosexual consequences of cancer, as well as trainer of oncology/medical nurses and physicians to enhance the assessment skills of these medical care providers in the area of sexual health.

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References


Biographies

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### Table 1

Summary of themes that emerged in the two groups

<table>
<thead>
<tr>
<th>Themes</th>
<th>%</th>
<th>Sample of described experiences for each theme</th>
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<tr>
<td><strong>a) Cancer patients’ themes</strong></td>
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<tr>
<td>Loss of potential maternal opportunities</td>
<td>33</td>
<td>“It is a rewarding experience in life that I will not be able to have”</td>
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<tr>
<td>Loss of wholeness</td>
<td>56</td>
<td>“Until I had enough hair (again), to kind of, pull it back into something, I did not feel like a whole person”</td>
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<tr>
<td>Intimate relationships negatively impacted</td>
<td>100</td>
<td>(see quotes below)</td>
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<tr>
<td>Women with partners: distancin in intimate relationships and feelings of guilt</td>
<td>56</td>
<td>“And you would think that with all this trauma that I would feel closer to my husband, but I do not”</td>
</tr>
<tr>
<td>Women without partners: discomfort, fear, self-consciousness, and doubt</td>
<td>44</td>
<td>“The way my body was left uneven. It bulges on one side. And so that is a big issue around going out and finding a partner”</td>
</tr>
<tr>
<td>Loss of sexual desire</td>
<td>67</td>
<td>“Those feelings, that drive is a foreign emotion to me . . . like it is a capacity I do not have anymore”</td>
</tr>
<tr>
<td>Body image negatively impacted</td>
<td>89</td>
<td>“I feel like I have not been able to regain my physical physique that I once had”</td>
</tr>
<tr>
<td>Loss of sexual pleasure</td>
<td>33</td>
<td>“But if you lose the craving for it, it does not matter if you eat it. It does not do anything for you”</td>
</tr>
<tr>
<td>Feelings of isolation/social alienation</td>
<td>44</td>
<td>“You read so much in our culture . . . . Sex is there all the time in the movies. I do not fit”</td>
</tr>
<tr>
<td>Dramatic and abrupt shift in self-image due to loss of physical integrity</td>
<td>67</td>
<td>“I was in my best physical shape before, and that really bothers me, and it affects that whole self-image . . . I guess and somewhat that desirability, of being desirous”</td>
</tr>
<tr>
<td>Loss of identification with women athletes</td>
<td>22</td>
<td>“This is another thing that is changed, where I used to work out all the time, I was always doing my hour-a-day thing. I have not done that for 4 almost 5 years now”</td>
</tr>
<tr>
<td>Sexuality as a fundamental aspect of quality of life</td>
<td>22</td>
<td>“. . . Your sexuality, that is what makes you human . . .”</td>
</tr>
<tr>
<td>Reluctance to initiate discussions about sexual concerns</td>
<td>67</td>
<td>“And I think if I asked for a referral, I think they would look at me like I was nuts. I do not want to bring that up—that I have a low sex drive”</td>
</tr>
<tr>
<td>Lack of focus by health care professionals on sexual health</td>
<td>22</td>
<td>“I just feel like the whole sexuality part of cancer is not well addressed by the medical establishment”</td>
</tr>
<tr>
<td>Heightened Negative Emotions</td>
<td>100</td>
<td>“Anyway….but there is a lot of emotion around it with me. I am grieving at this point because I realize that nothing is going to fix it and put it back the way it was”</td>
</tr>
<tr>
<td><strong>b) Cancer-free women’s themes</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Natural menopause</td>
<td>42</td>
<td>“The transformation from being a healthy womb to, you know, not being able to conceive”</td>
</tr>
<tr>
<td>Sexuality defined historically</td>
<td>86</td>
<td>“What stands out for me is the change from adolescence to now”</td>
</tr>
<tr>
<td>Gradually maturing body image and sexuality</td>
<td>86</td>
<td>“And as I have grown and developed physically and spiritually, it becomes a lot more, a lot bigger. It becomes less comparison and more introverted and you know like a flower blooming, and it opens up”</td>
</tr>
<tr>
<td>Negative impact of idealized image</td>
<td>56</td>
<td>“I was always trying to live up to some sort of idea that really came from outside of me: externally, not internally”</td>
</tr>
<tr>
<td>Themes</td>
<td>%</td>
<td>Sample of described experiences for each theme</td>
</tr>
<tr>
<td>--------------------------------------------</td>
<td>----</td>
<td>---------------------------------------------------------------------------------------------------------------</td>
</tr>
<tr>
<td>Ever feeling awkward or uncomfortable</td>
<td>100</td>
<td>“And with this [in the past,] I have moments of thinking I am too fat. I am too this. I am too that”</td>
</tr>
<tr>
<td>Positive impact of intimate relationships</td>
<td>100</td>
<td>“I think that how they react to your body is a big part of feeling good about yourself as well. If you have someone that embraces all of you and your flaws as well, just who you are . . . He embraces me at my most ugly or at my most beautiful”</td>
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