



Evaluation and management of sexual difficulties should be a standard part of the clinical care of women treated for breast cancer.

Adrian Deckbar. *Inner Reflection*. Oil, 28" × 42". Courtesy of the Hanson Gallery, New Orleans, Louisiana.

Sexual Functioning in Breast Cancer Survivors

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Background: A growing body of evidence suggests that sexual dysfunction may be among the more common and distressing symptoms experienced by breast cancer survivors.

Methods: This report reviews studies in which sexual functioning in breast cancer survivors has been investigated. Included are reports on the prevalence and nature of sexual difficulties, the relationship between specific breast cancer treatments and sexual difficulties, and the treatment of sexual dysfunction following completion of breast cancer treatment.

Results: A review of the literature suggests a wide range of rates for the prevalence of sexual problems in breast cancer survivors. Factors that may affect prevalence rates include the methods used to determine prevalence and the demographic and medical characteristics of the patients studied. With regard to treatment effects, evidence suggests that breast cancer patients who undergo chemotherapy are at high risk for sexual dysfunction after treatment. In contrast, there is little evidence of a link between type of surgical treatment (eg, lumpectomy vs mastectomy) or treatment with tamoxifen and sexual functioning outcomes.

Conclusions: A growing body of evidence suggests that sexual problems can be a long-term side effect of breast cancer treatment. Oncology professionals should initiate communication about sexual difficulties, perform comprehensive assessments, and educate and counsel patients about the management of these difficulties.

Introduction

Breast cancer is the second most common cancer among women and the second leading cause of cancer deaths in women.¹ It should be noted, however, that breast cancer mortality declined in the 1990s by the largest amount in over 65 years, with the 5-year survival rate now reaching 97% for women diagnosed at an early stage of disease.¹ Given these gains in survival time, it is increasingly important to study the long-term effects of breast cancer and its treatment. Along these

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lines, a growing body of evidence suggests that difficulties with sexual functioning may be among the more common and distressing problems experienced by breast cancer survivors.^{2,5}

For the purpose of this review, the term “survivors” refers to women who have completed surgery, chemotherapy, and/or radiation therapy for the treatment of breast cancer. Topics covered include the prevalence and nature of sexual difficulties in this patient population, the relationship of specific breast cancer treatments to sexual difficulties, and the treatment of sexual dysfunction following completion of breast cancer treatment.

Prevalence of Sexual Problems in Breast Cancer Survivors

A wide range of rates for the prevalence of sexual problems in breast cancer survivors has been reported. Among recent studies, rates range from a low of 15% for reduced physiological arousal⁶ to a high of 64% for reduced sexual desire.⁷ This variability can be attributed largely to differences in study methods. Among the factors to consider are the approach used to assess and define sexual difficulties, the timing of study assessment(s), and the demographic and medical characteristics of the patients studied.

A variety of approaches have been used to assess sexual difficulties in breast cancer survivors. Open-ended interview methods, in which women are asked general questions about their sexuality and the responses are categorized by the investigators, have been used in a number of studies. In an example of this approach, one group of investigators⁸ analyzed responses to a single question, “What, if anything, has changed the most about your sexuality since your diagnosis?” Responses to the question were then classified into “themes” using content analysis procedures. Although this method has the advantage of allowing for individualized assessment of each patient, its reliability may be limited.

Another common approach has been to develop a study-specific self-report instrument to assess sexual functioning. For example, Barni and Mondin⁷ developed a questionnaire to assess sexual dysfunction in their sample of breast cancer survivors. This questionnaire included items designed to assess changes in sexual functioning since the diagnosis of cancer as well as items assessing satisfaction with sexual functioning. One problem with this type of measure is that its psychometric characteristics are relatively unknown. A better approach is to use a measure with established reliability and validity as well as published norms. Two

of the more commonly used measures of sexual functioning in research with breast cancer survivors are the Sexual History Form⁹ and the sexual summary subscale of the Cancer Rehabilitation Evaluation System (CARES).¹⁰ The Sexual History Form was developed by Schover and Jensen⁹ and is composed of 27 multiple-choice questions assessing sexual functioning, frequency, and satisfaction with sexual activity. This questionnaire has been standardized and norms from a healthy community sample are available for comparison purposes. Reliability and validity, however, have not been established.¹¹ The CARES is a quality-of-life instrument that includes an 8-item subscale measuring sexual interest and sexual dysfunction. The CARES has been shown to have adequate reliability and validity, and normative scores are available for cancer patients.¹⁰

In addition to heterogeneity in assessment approaches, a variety of research designs have been used to study sexual difficulties in breast cancer survivors. Among the most common designs is a cross-sectional approach in which a sample of breast cancer survivors is assessed at a single point in time. An example of this method is a study by Schover et al⁶ in which the Sexual History Form was administered on one occasion to breast cancer survivors who were an average of 4 years postsurgery. This approach is limited in that it does not provide an opportunity to determine whether sexual difficulties improve or worsen over time in breast cancer survivors. To address this issue, it is necessary to use a longitudinal design in which the same group of breast cancer survivors is studied at multiple time points following completion of breast cancer treatment. An example of this method is research by Wyatt and Friedman.¹² In this study, questionnaires were administered to breast cancer survivors at 1 week, 6 weeks, 3 months, and 6 months after surgery. Although an improvement on the cross-sectional approach, this longitudinal approach still does not provide a way to determine the degree to which the observed sexual difficulties are due to breast cancer or its treatment.

Three other approaches can be used, either alone or in combination, to address this issue. One method is to recruit a comparison group that is matched on relevant demographic factors to the sample of breast cancer survivors. To the best of our knowledge, this particular approach has not been used to date to study sexual functioning in breast cancer survivors. A second method is to compare the responses of breast cancer survivors to published data. In one example of this approach, Ganz et al² compared scores on the CARES sexual functioning subscale¹⁰ and the Watts Sexual Functioning Questionnaire¹³ for their sample of breast cancer survivors with those reported for women of similar age randomized to a control group in a clinical trial of estrogen replacement

therapy. Although the use of published norms provides a useful frame of reference, it generally does not allow for direct matching of survivors and comparison subjects on relevant demographic characteristics (eg age, partner status). A third method is to ask women with breast cancer to provide retrospective ratings of their sexual functioning prior to diagnosis and compare these ratings with those for one or more time periods following diagnosis. This approach was used by Barni and Mondin.⁷ Subjects who were at least 12 months post-surgery were asked to rate their sexual functioning both currently and before their diagnosis with breast cancer. Although there are advantages to using this approach, there are also concerns as to the potential for retrospective bias. That is, the possibility exists that recollections of sexual functioning before cancer diagnosis may be biased either positively or negatively by the patient's experiences since the diagnosis of breast cancer.

Another factor contributing to the observed variability in prevalence rates of sexual difficulties is differences across studies in patients' demographic and medical characteristics. A variety of demographic characteristics (eg, age, partner status) are known to be associated with reports of sexual difficulties in the general population.¹⁴ To the extent that these characteristics differ among samples of breast cancer survivors, variability that may be unrelated to breast cancer or its treatment is introduced into reports of the prevalence of sexual difficulties. This issue is particularly important to consider in evaluating studies that seek to compare the prevalence of sexual difficulties in women who have received different forms of cancer treatment. The presence of differences in background factors associated with sexual functioning may seriously confound attempts to identify how different types of breast cancer treatment affect sexual functioning. As described below, evidence suggests that there are treatment-related differences in the sexual difficulties of breast cancer survivors. Thus, another source of variability in prevalence rates is differences across studies in the types of treatments (surgery, chemotherapy, radiotherapy, and hormonal therapy) that breast cancer survivors received.

Relative Frequency of Specific Sexual Problems in Breast Cancer Survivors

Attempts to determine the relative frequency of specific sexual difficulties in breast cancer survivors are affected by many of the same methodological challenges described above. With this in mind, we will focus on describing the relative frequency of specific sexual difficulties in a recent study that included a comprehensive measure of sexual functioning administered to a well-defined sample of breast cancer survivors.

In this study, Barni and Mondin⁷ administered a questionnaire about sexual functioning to 50 breast cancer survivors. In order to be eligible for the study, the women approached were required to be between 20 and 65 years of age, have had surgery performed at least 12 months previously, and be disease-free. Subjects were a median of 48 years old (range 38-63 years). Most were married and/or in a partnered relationship (98%) and sexually active at the time of assessment (96%). Fifty-eight percent of the women in the study were treated with mastectomy and 42% with lumpectomy. After surgery, 88% were treated with chemotherapy, 46% were treated with radiotherapy, and 4% were treated with hormone therapy. The authors constructed the questionnaire in a multiple-choice format based primarily on Diagnostic and Statistical Manual of Mental Disorders (DSM-IV) criteria for sexual dysfunction.¹⁵ A retrospective recall design was used, in which subjects reported not only current sexual functioning, but also their recollection of their sexual functioning before treatment for breast cancer. The authors found that prior to treatment, 64% of subjects judged their sex life to be good, 30% judged it to be fair, and 6% judged it to be poor. For current functioning, 28% reported having a good sex life, 48% reported having a fair sex life, and 24% reported having a poor sex life. One or more sexual problems were present in 96% of participants. In terms of specific sexual difficulties, the most common current symptoms were absence of sexual desire (48%), reduced sexual desire (64%), anorgasmia (44%), lubrication difficulties (42%), and dyspareunia (38%). These findings suggest that a variety of sexual problems are present in breast cancer survivors. Certain problems appear to be related to the desire stage of sexual activity (eg, loss of interest in sex), while others appear to be related to the arousal stage (eg, lubrication difficulties) and the orgasmic stage (eg, anorgasmia).

Relation of Specific Forms of Breast Cancer Treatment to Sexual Difficulties

In this section, we briefly review research examining the relation of specific forms of treatment to sexual difficulties in breast cancer survivors. The review is limited to studies that have sought to identify differences in sexual functioning related to the type of surgery performed (ie, lumpectomy vs. mastectomy), administration of chemotherapy, and administration of hormonal therapy.

The literature on sexual functioning in breast cancer survivors includes numerous studies in which the impact of type of surgery on sexual functioning has been examined. Investigators had theorized that more extensive surgery would lead to poorer sexual out-

comes.¹¹ However, results have been equivocal. Kiebert et al¹⁶ reported that results from 7 of the 11 studies they reviewed showed no differences in the sexual functioning between women treated with lumpectomy vs mastectomy. Since then, several investigators have reported advantages related to body image but not sexual functioning for lumpectomy patients. Mock¹⁷ found that body image, as measured by a visual analogue scale, was significantly more positive for their conservative surgery group vs women treated with either mastectomy or mastectomy plus reconstruction. Subjects in this study were diagnosed with stage I or II breast cancer and were assessed an average of 14 months posttreatment.

Ganz and colleagues¹⁸ found that women treated with mastectomy experienced more difficulty with clothing and body image (as measured by subscales from the CARES) than women treated with breast conservation. Subjects in this study were diagnosed with stage I or II breast cancer and were assessed at 1 month, 7 months, and 13 months postsurgery. Both surgical treatment groups showed improvements over time in their clothing and body image scores. Wapnir et al¹⁹ compared women treated with mastectomy or lumpectomy and found no differences in ratings of intimacy and sexual satisfaction. However, there were differences in items related to body image (eg, the impact of surgery on use of bathing suits and comfort with nudity) as well as sexual drive. Specifically, women treated with mastectomy believed that their surgery had a greater impact on these factors than did women treated with lumpectomy. Subjects in this study were assessed between 13 months and 84 months postsurgery. Schover and colleagues⁶ compared women who had partial mastectomy to women who had immediate breast reconstruction after mastectomy. They found advantages for the partial mastectomy group in terms of pleasure and frequency of breast caressing during sexual activity. Subjects in this study were diagnosed with stage I or II breast cancer and were assessed an average of 4 years after surgery. Dorval et al²⁰ compared women treated with mastectomy and lumpectomy. They did not find differences between the groups in sexual satisfaction, satisfaction with type of surgery, or ratings of the appearance of their surgical scars. Subjects in this study were assessed an average of 8 years after treatment.

Taken together, these recent studies suggest that differences in sexual functioning based on type of surgery are subtle, with the most consistent finding being that women treated with mastectomy experience greater problems with body image. This conclusion is supported by a recent meta-analysis of studies of the psychosocial consequences of surgery for breast

cancer.²¹ In this analysis, modest effects were found for the impact of type of surgery on sexual functioning. In contrast, body image showed a much larger effect size, indicating better outcomes for women treated with lumpectomy.

The use of adjuvant chemotherapy for breast cancer has increased dramatically since the 1980s,²² and many investigators have examined the effects of adjuvant chemotherapy on sexual functioning. For example, Young-McCaughan²³ compared sexual outcomes in breast cancer survivors with and without a history of treatment with adjuvant chemotherapy who were an average of 7 years postdiagnosis. Compared to women who were not treated with adjuvant chemotherapy, women treated with adjuvant chemotherapy were 5.7 times more likely to report vaginal dryness, 3 times more likely to report decreased libido, 5.5 times more likely to report dyspareunia, and 7.1 times more likely to report difficulty reaching orgasm. Likewise, Ganz et al² found that among women 1 to 5 years posttreatment, sexual problems (as measured by the CARES and the Watts Sexual Functioning Scale) were more common in women who had received chemotherapy. Lindley and colleagues²⁴ reported an interaction between age and chemotherapy in that the greatest negative change in sexual functioning (as measured by a series of questions that included items measuring sexual satisfaction and interest) occurred in premenopausal women who experienced chemotherapy-induced amenorrhea.

In contrast, Joly et al²⁵ did not find differences in sexual functioning (as measured by the European Organization for Research and Treatment of Cancer [EORTC] QLQ-C30) related to chemotherapy status in their sample of breast cancer survivors. Subjects in this study were an average of 10 years posttreatment and had been enrolled in a randomized trial comparing cyclophosphamide, methotrexate, and fluorouracil (CMF) to no adjuvant chemotherapy. The results from this study suggest that the negative effects of chemotherapy on sexual functioning may diminish over time. This issue should be directly addressed by conducting research on sexual functioning in which women who have received different forms of cancer treatment are followed over extended periods of time.

Tamoxifen, an antiestrogenic agent, has also been hypothesized to have a negative impact on sexual functioning in breast cancer patients.²⁶ In three recent studies that examined this issue in breast cancer survivors,^{23,26,27} none found differences in sexual functioning in breast cancer survivors related to tamoxifen use. In one of these studies, Young-McCaughan²³ compared stage I-III breast cancer sur-

vivors who were an average of 7 years postdiagnosis and were treated with chemotherapy and/or hormonal therapy or no pharmacological treatments. Results showed that when administration of chemotherapy treatment was controlled for statistically, women treated with hormonal therapy did not experience significantly different levels of sexual dysfunction (as measured by the Derogatis Sexual Functioning Inventory) than women not treated with hormonal therapy. Ganz and colleagues²⁶ examined the relation of tamoxifen use to sexual functioning in breast cancer survivors who were 1 to 5 years postdiagnosis and over the age of 50. Findings indicated no difference in sexual functioning (as measured by the CARES) between women treated with or without tamoxifen. Finally, Mortimer et al²⁷ assessed sexual functioning using the Sexual History Form in breast cancer survivors treated with tamoxifen for 2 to 24 months previously. Levels of sexual dysfunction for this sample were found to be comparable to those in a normative sample of healthy women. Taken together, these studies suggest that tamoxifen use does not contribute to problems in sexual functioning in breast cancer survivors.

Treatment of Sexual Difficulties in Breast Cancer Survivors

Interventions to address sexual functioning difficulties can be classified into educational efforts, pharmacological methods, and psychotherapeutic methods.

In regard to education, several researchers^{8,28} have suggested that patients and health care providers alike could benefit from specific, clear, and knowledgeable information about the sexual functioning difficulties breast cancer patients may face following diagnosis and treatment. These authors have also suggested that education and support from the patient's cancer care team may enhance the patient and her partner's sexual relationship following diagnosis and treatment. Along these lines, the health care providers should attempt to stress that sexual problems are common among breast cancer survivors.²⁶

Pharmacological interventions have also been proposed as possible treatments for sexual functioning difficulties. The use of hormone replacement therapy (HRT) or estrogen replacement therapy (ERT) to alleviate menopausal symptoms has long been debated. In a recent review, Pritchard²⁹ concludes, based on results from long-term studies of healthy women and a recent meta-analysis, that there is a relative risk of 1.3 or 1.4 for breast cancer associated with ERT/HRT use, particularly over the long-term. In terms of its use in women previously diagnosed with breast cancer, the author cites sev-

eral ongoing randomized trials of HRT and ERT and states "until results from these randomized trials are available it would seem foolhardy to believe that there is no risk related to ERT/HRT in this setting." Several alternatives to ERT/HRT were suggested, including the use of megestrol acetate and venlafaxine for hot flashes, and a vaginal lubricant (eg, KY Jelly, Replens) or an estradiol vaginal ring (eg, Estring) for vaginal dryness.

Psychotherapy approaches to sexual functioning difficulties have also been reported. Breast cancer patients with problems of sexual desire and difficulty achieving orgasm may benefit from psychotherapy to tease out physical, psychological, and interpersonal factors contributing to the problem.³⁰ It has also been recommended that breast cancer survivors participate in a culturally diverse group format to openly discuss issues of sexual functioning.³¹ Behavioral recommendations include specifying sexual practices for health promotion purposes compared to those for pleasure or arousal, use of other sources of stimulation (ie, videos, literature, or vibrators) for pleasure, and use of relaxation techniques to help alleviate sexual difficulties.³¹

Despite the growing body of research documenting the presence of problems in sexual functioning among breast cancer survivors and the aforementioned suggestions for treatments, few formal studies of means to ameliorate these concerns have been conducted. A recent publication by Ganz and colleagues³² represents one of the first randomized, controlled studies of an intervention designed to improve sexual functioning in breast cancer survivors. The primary aim of the study was to test the efficacy of a comprehensive menopausal assessment (CMA) intervention program in relieving common menopausal symptoms and improving quality of life and sexual functioning in breast cancer survivors. To be eligible for the study, potential participants had to be between 8 months and 5 years postdiagnosis of stage I or II breast cancer, disease-free, peri- or post-menopausal, and experiencing at least one of the three target symptoms (hot flashes, vaginal dryness, or stress urinary incontinence) at a moderate to severe intensity. Seventy-six women meeting these criteria were randomly assigned to either the CMA intervention or a usual care condition. The CMA intervention, which was delivered by a nurse practitioner, focused on symptom assessment, education, counseling, and, as appropriate, specific pharmacological and behavioral interventions for each of the three target symptoms. The intervention took place over a 4-month period, with outcome measures administered to all participants at baseline and at a 4-month follow-up assessment. Of particular interest is the effect of the intervention on sexual functioning as measured by the CARES Sexual Functioning Scale.

Results indicated that sexual functioning was significantly improved in the intervention group relative to the usual care group. Moreover, additional analyses indicated that the intervention group improved significantly on each of the eight items comprising the CARES scale (sexual attractiveness for self and partner, interest in sex for self and partner, frequency of sex, arousal, lubrication, and orgasm). In contrast, the usual care group demonstrated significant improvement on only two items (arousal and orgasm).

Due to the multicomponent format, it is difficult to identify the specific components that were responsible for the effectiveness of the CMA intervention in improving sexual functioning. One possibility is suggested by previous research by this investigative team, which has shown that vaginal dryness is one of the strongest predictors of sexual dysfunction in breast cancer survivors.³³ Accordingly, the authors speculate that encouragement of the use of lubricants and vaginal moisturizers to relieve vaginal dryness may have been an essential component of the intervention's efficacy. Improvements in this symptom may have contributed to better arousal and stimulation which, in turn, may have enhanced sexual functioning in a more global manner. Discussions of the use of lubricants and moisturizers occurred in the context of a discussion of the patient's sexuality that took into account her unique physical, psychosocial, and partnership situation. These discussions may also have played an important role in improving sexual functioning by "normalizing" the difficulties each woman was experiencing and suggesting specific solutions.

The results of this study have important implications for clinical practice and can be used to offer suggestions for the evaluation and management of sexual difficulties in breast cancer survivors. As with the CMA intervention, any attempt to address sexual difficulties in breast cancer survivors should begin with a comprehensive assessment. Along these lines, it is important to identify the specific nature of the sexual difficulty. The DSM-IV¹⁵ lists criteria that can be useful in distinguishing whether the disorder reflects the presence of an aversion or is due to problems with desire, arousal, achieving orgasm, or pain during intercourse (ie, dyspareunia or vaginismus). Accurate diagnosis can be helpful in treatment selection. For example, vaginal dryness associated with normal aging and/or discontinuation of hormonal therapy appears to be a common cause of sexual difficulties in breast cancer survivors. In women for whom this contributes to painful intercourse or lack of arousal, use of vaginal moisturizers (eg, Replens) or lubricants (eg, Astroglide) can be helpful in improving sexual functioning. In cases where the etiology of the sexual problem appears to be primarily

of an intra- or inter-personal nature, behavioral or psychotherapeutic intervention may be helpful. Individual or couples therapy for sexual dysfunction is best conducted by a mental health professional with specialized training in an empirically-supported form of sex therapy. Clinicians working with breast cancer survivors should seek to identify professionals with such expertise and make referrals as appropriate.

Oncology professionals play an essential role in ameliorating problems in sexual functioning among breast cancer survivors. Due to the sensitive nature of the topic, many patients are reluctant to discuss sexual difficulties with health care providers or to seek help for these problems.^{2,7} Clinicians cannot assume that sexual functioning is adequate if patients do not voice their concerns and should take the initiative in raising this issue during follow-up visits. This process should begin at the initiation of treatment and should be continued as treatment is completed.³⁴ The "PLISSIT" model³⁵ provides a guide for addressing sexual concerns. This model consists of four steps for addressing the sexual concerns of cancer patients: "Permission," "Limited Information," "Specific Suggestions," and "Intensive Therapy." In the first step of this model (permission giving), the health care provider legitimizes sexual concerns and invites the patient to disclose issues of concern. Communicating that sexual difficulties are both common and treatable often results in patients' describing heretofore unreported problems. Once problems are identified, oncology professionals need to be able to educate and engage in brief counseling with patients about the management of their sexual difficulties.³⁶ This incorporates steps 2 and 3 of the PLISSIT model — limited information, in which patients are given general information about their condition and descriptions of possible treatments, and specific suggestions about expected changes and ways to achieve acceptable sexual function. The study by Ganz et al³² suggests that a combination of both written materials and brief counseling can be effective in encouraging women to accept further help for the difficulties they are experiencing. In some cases, commonly where there is a history of sexual or relational problems prior to diagnosis, the final step intensive therapy may be required. At this point referral for psychological or sexual therapy is appropriate.

Conclusions

Although much remains to be learned, the current body of empirical research offers strong support for the view that evaluation and management of sexual difficulties should be a standard part of the clinical care of women treated for breast cancer.

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