



The Research Connection

The Psychosocial & Nursing Advisory Board to
the New Jersey Commission on Cancer Research

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The Joint Psychosocial & Nursing Advisory Group to the New Jersey Commission on Cancer Research (NJCCR) was appointed to advise the NJCCR of special research needs pertaining to nursing, psychology, sociology, and related disciplines for the purpose of addressing gaps in vital areas of cancer research and cancer care in New Jersey.

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Nurses and Social Workers: Facing the Topic of Sexuality with Your Patients

by
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While there are several important topics for practitioners to address with any individual facing a new diagnosis of cancer, among those topics least discussed (probably *the* least discussed) is the potential impact of cancer and its treatments on sexual interest and sexual and intimate function.

Very often, patients withdraw from emotional intimacy from their partner, as they fear discussing their desires, their concerns and fears for the future. Paradoxically, it is the couples' discussion of such matters that has been shown to have a positive impact on sexual functioning.

A cancer diagnosis and its treatments can dramatically affect sexual function. The negative influence on sexuality in the case of cancer may be multifactorial with the diagnosis itself and the iatrogenic impact of treatment among the issues playing a role. Both the physical and emotional effects of chemotherapy, for instance, may leave the

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cancer patient feeling less sexually attractive and may actually impact the patient's sexual libido. Much has been written in the literature on the negative impact of chemotherapy on sexual function - from desire to arousal to orgasmic capacity. Patients often speak of this decreased or lost interest in sexuality being akin to a general lessening of joy they experience in life overall with the cancer diagnosis.

With some cancer diagnosis and surgery comes an external change in body presentation. There has been conjecture that "physical change" has been the main impactor of sexuality, based on body image changes. That has not been shown to be the case consistently. For instance, much of the research on breast cancer belies that the body image issue is the cause of sexual difficulties. Lumpectomy and mastectomy patients fare about evenly in sexual function.

Cancer-related fatigue, a better understood effect of both chemotherapy and radiation therapy is often cited by cancer patients as lowering their interest in the sexual domain. Many cancer patients have conveyed in these words or others: *"Think about when you are so bone tired you have no desire to move... How much interest do you have in sex at that time?"*

It's very clear that cancer and its treatments can play havoc with sexual interest and function in even the healthiest of relationships. The best and most caring practitioners play a vital role by creating an interactive environment where discussing sexual issues is treated as normally as discussing any other aspects of the cancer patient's experience on which the patient must be queried and educated. A practitioner's avoidance of the topic of sexuality is regarded by many authorities as one of the largest obstacles to sexual rehabilitation for patients with cancer. In research on breast cancer, sexuality continually appears as one of the most neglected topics of discussion for doctors and their patients.

Nurses and social workers can often serve as advocates, encouraging patients to discuss these matters with their physicians. They may also encourage patients and their partners to reach out to their local unit of the American Cancer Society, where brochures and pamphlets are available on this important subject. While there are many disease site-specific books on the topic of sexuality and cancer for the layperson (more on breast cancer than other sites), there is one *non-site-specific* book that patients relate over and over again as finding very helpful. [Sexuality and Fertility After Cancer, Leslie Schover, New York: Wiley 1997]. Nurses and social workers would do well to read this book as well. Many who have read it noted that they feel so much better prepared to introduce this topic with patients after they have read this helpful overview.

For those patients ready to discuss their concerns about sexuality further, the following resources might be helpful. The American Association of Sex Educators, Counselors and Therapists (www.aasect.org) and The American Association for Marriage and Family Therapy (www.aamft.org) are two national groups that certify practitioners. [However, before adding a therapist to your referral list, a conversation regarding their background in and knowledge of the interface between information on sexuality and cancer is warranted].

Practitioners are encouraged to offer to discuss this issue with your patients. While the research on who should raise the issue of sexuality with a cancer patient is limited, patients have shown that they want their health care practitioners to introduce the topic first. As you speak with your patients, please remember that they will most likely look for you to bring these issues forward. They will rely on you to have some good recommendations on how they can obtain information so they might reclaim this important aspect of their lives as soon as is reasonably possible.

Sexual Adjustment to Breast Cancer in Unmarried Women

by

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Background: Breast Cancer is a significant health problem among women. Despite advances in the diagnosis and treatment, the incidence of the disease is growing. According to the National Cancer Institute (2003), it is estimated that one out of eight women in the United States will be diagnosed and treated for breast cancer at some point in her lifetime. Although breast cancer often is diagnosed early, permitting options for less disfiguring surgery than in the past and follow-up treatment that allows for control of side effects, the experience of a life-threatening disease such as breast cancer still can have a profound impact on many aspects of a woman's life. These women often journey through a maze of treatment alternatives with a wide array of physical, emotional, interpersonal, social, as well as sexual implications.

Breast cancer strikes all kinds of women, regardless of present relationships or family situations. Although attention has been given to the impact of breast cancer within a family framework, the family of a woman with breast cancer often is conceptualized in terms of a married couple or partner dyad (Lewis, 2004, Northouse, Templin, & Mood 2001). Although there is growing

evidence that women with supportive husbands seem to adjust reasonably well to breast cancer (Hoskins, et al., 2001), little is known about the impact of breast cancer among unmarried women. Some speculate that single women, widows, and divorcees may view their treatment as a serious deterrent to social and sexual activities, especially if they do not have a strong supportive partner (Dow, & Lafferty, 2000; Shain, 1995). Although unmarried women with breast cancer may have special adjustment needs, the literature is sparse regarding sexual adjustment to breast cancer among women with primary support systems other than the traditional married relationship.

Purpose: The purpose of this study is to describe the impact of breast cancer on sexual aspects of life among unmarried women during the late postoperative recovery phase. The following research question will be answered: (1) How do unmarried women describe the impact of breast cancer on the sexual aspects of their lives? (2) Is there a relationship between symptom distress and sexual adjustment to breast cancer? (3) Are demographic and medical variables associated with sexual adjustment? The finding presented here are part of a larger study designed to determine the relationships among primary treatment alternatives, symptom distress, perceived social support and psychosocial adjustment to breast cancer in unmarried women (Budin, 1998).

Unmarried women with breast cancer are defined as women not presently in a traditional married relationship or with a regular live-in partner. This includes women who are single-never-married, divorced, or separated, or widowed. The late post-operative recovery phase is defined as six-eight weeks post-definitive surgery. This is a particularly vulnerable time when the women continues recuperation from the initial treatment and begins extensive reorganization and resumption of previous activities and roles. At this time many women also begin adjuvant therapy.

Methods: A descriptive correlational design was used. Participants were selected from the practices of breast surgeons at major medical centers in the NY/NJ metropolitan area. To be included women had to have a single breast lesion with a diagnosis of early stage breast cancer, no previous history of cancer or other life threatening or serious chronic illness and had to be able to read and speak English. Data were collected from 101 unmarried women during the late post-operative recovery phase through means of a mail survey. Participants completed a questionnaire, consisting of a demographic information sheet, the Psychosocial Adjustment to Illness Scale (PAIS) (Derogates, 1983), and the Symptom Distress Scale (SDS), (McCorkle & Young, 1978). The

PAIS is a 47-item self-report pencil and paper instrument designed to assess the quality of an individual's psychosocial adjustment to a current medical illness or its residual effects. Items are scored on an ordinal scale from 0-3 with a higher score reflecting poorer adjustment. The tool contains seven domains: Health Care Orientation, Vocational Environment, Domestic Environment, Extended Family Relations, Social Environment, Psychological Distress, and Sexual Relations. The Sexual Relations Domain is defined as "changes in the quality of sexual behavior or relationships attributable to breast cancer or its aftermath." The Symptom Distress Scale (SDS) is a paper and pencil tool describing reactions to a variety of common side effects or symptoms to treatment for cancer. Each item is rated on a 5-point scale with a higher score reflecting more distress. Symptoms assessed include nausea, insomnia, fatigue, concentration, skin changes, appetite, pain, bowel, appearance, and mobility.

Sample Characteristics: Of the 101 unmarried women in the sample, a little more than half ($n=58$) of the women completed the sexual adjustment items. Ages ranged from 28-80 years ($M = 48.3$, $SD = 10.4$). Thirty six percent were single-never-married, 47% were divorced or separated, and 17% were widowed. Most were White (74%), followed by African-American (17%), Asian (5%), and Hispanic (4%). More than half (69%) were college educated and employed (66%) full- or part-time in a wide variety of professional and semiprofessional occupations. Slightly more than half (55%) had no children and lived alone (55%). Lumpectomy or Wide Excision was selected as the primary treatment alternative by 40% of the participants. The remaining participants had non-breast – conserving surgery, which included modified radical mastectomy (36%) or modified radical mastectomy with reconstruction (24%). A little more than half (57%) were receiving chemotherapy and 24% were receiving radiation therapy.

Results: There were 6 items in the Sexual Relations Domain. The range of scores for the total Sexual Relations Domain was 0 – 18 with a higher score indicating more problems or greater impact on sexual adjustment as a result of breast cancer. The mean score for this sample 5.9 ($SD = 6.1$) indicates that overall, the women were experiencing low to moderate levels of sexual adjustment problems.

The 1st item assessed change in relationships with a partner. It read as follows: "Sometimes having an illness can cause problems in a relationship. Has your illness led to any problems with your partner?" 14% percent reported moderate to serious problems in relationships, while 86% reported no change in relationship.

The 2nd item stated "Sometimes when people are ill they report a loss of interest in sexual activities. Have

you experienced less interest since your illness?” 39% reported marked loss or no sexual interest.

Item 3 stated: “Illness sometimes causes a decrease in sexual activity. Have you experienced any decrease in the frequency of your sexual activities?” 32% reported a marked decrease or no sexual activity.

Item 4 asked: “Has there been any change in the pleasure or satisfaction you normally experience from sex?” A quarter of the sample (25%) reported a marked decrease or no sexual pleasure.

Item 5 stated: “Sometimes an illness will cause interference in a person’s ability to perform sexual activities even though the person is still interested in sex. Has this happened to you, and if so to what degree?” Whereas most (88%) reported no change or only slight problems, 12% reported that their illness caused constant sexual performance problems or total inability to perform sexually.

Item 6 read: “Sometimes an illness will interfere with a couples normal sexual relationship and cause arguments or problems between them. Have you and your partner had any argument like this and if so to what degree?” Only 7% reported frequent or constant arguments, resulting form interference in normal sexual relationships.

The possible range of scores for the Symptom Distress Scale was 12 – 60 with a higher score reflecting a higher level of distress associated with side effects or symptoms of treatment. In this sample total scores ranged from 12-35 with a mean score of 22.8 (SD = 5.7). This is slightly lower than the mean score reported in other studies (26.7, 23.4) (McCorkle & Young, 1978).

Symptoms that participants rated as particularly distressful included fatigue, insomnia, and ability to concentrate.

To answer the research question “Is there a relationship between symptom distress and sexual adjustment to breast cancer,” a Pearson correlation was performed. The Pearson correlation coefficient of $r = .535$, $p = .000$. indicates that, the more distress from side effects or symptoms associated with treatment for breast cancer the higher the level of problems in sexual relationships. No other demographic or medical variables were related to sexual adjustment.

Implications: It cannot be assumed that unmarried women are not sexually active or have no sexual concerns. Assessment of all women with breast cancer needs to be comprehensive including level of functioning in all facets of life, including sexual relations. Practitioners are encouraged to discuss sexual issues with all of their patients. There is a need for nurses and other health care professional to not only assess symptom distress and sexual adjustment but also find useful, cost-effective intervention strategies that address both symptom distress and sexual adjustment needs of unmarried women during the late post-operative recovery phase. Health care professionals can play a vital role by creating an environment where discussing sexual issues are treated as normally as other aspects of the breast cancer experience.

References for this article are available by contacting the NJCCR at 609-633-6552 or njccr@doh.state.nj.us.



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