

Psycho-education for Breast Cancer Patients and Survivors— A Powerful Tool for Healthcare Providers

Sharon L Bober, PhD¹ and Veronica Sanchez Varela, PhD²

1. Director, Sexual Health Program; 2. Psychology Research Fellow, Perini Family Survivors' Center, Dana-Farber Cancer Institute

Abstract

Due to increased early detection and improved treatments, the number of breast cancer survivors is steadily increasing. However, it is now clear that breast cancer patients and survivors frequently face a difficult set of challenges as a result of their treatment. Many of these challenges can also be enduring over time, such as sexual dysfunction and fertility-related distress, and continue to disrupt daily functioning and affect quality of life. It is imperative to assess quality of life changes both during and after breast cancer treatment—specifically, psychosocial adjustment, sexuality and fertility concerns, and lifestyle change—in order to help patients access appropriate education, support and resource materials. Fortunately, there has been an enormous increase in available resources to breast cancer patients and survivors in recent years. This article will outline current advances in patient education with regard to these challenges.

Keywords

Breast cancer, psycho-education, quality of life

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Correspondence: Sharon L Bober, PhD, Dana-Farber, Cancer Institute, Dana 321, 44 Binney Street, Boston, MA 02115. E: sharon_bober@dfci.harvard.edu

Although breast cancer is still the most common cancer diagnosis among women, long-term survival rates have been steadily increasing since 1990, and there are currently over 2.5 million breast cancer survivors in the US.¹ However, now that the majority of breast cancer patients are surviving for longer, there has also been increasing clarity and concern around the long-term consequences and quality of life issues facing breast cancer survivors, including emotional distress, sexual dysfunction, and changes in lifestyle. Fortunately, patient education resources for breast cancer survivors have increased dramatically in recent years. This article will outline current advances in breast cancer patient education in terms of three primary areas: psychosocial education, sexual rehabilitation, and fertility-related concerns, as well as lifestyle interventions (e.g. diet and exercise). Various patient education resources will be underlined and cultural barriers to patient education will be discussed.

Patient Education

There are an increasing number of educational resources available to address the needs of breast cancer patients and survivors. Various educational interventions have been shown to have significant benefits on quality of life as well as on a range of symptoms, from lowering anxiety about cancer recurrence to helping women manage changes in lifestyle after breast cancer.^{2,3}

Educational interventions have been delivered to patients using a variety of methods including individual, group, and couples counseling and

psycho-educational support via print, telephone, and/or the Internet. Although the majority of educational interventions over the past 30 years have been aimed at women who are being treated, increasing numbers of interventions are now also being developed for the transition from treatment to survivorship.²

The main reason that most cancer patients call cancer-related hotlines is to obtain information and education about their disease and treatment.^{4,5} Similarly, it has been shown that interventions that are specifically educational in nature seem to meet the largest proportion of needs among breast cancer patients.⁶ Education and information are available to patients through various modalities. Recent research has highlighted the need to develop patient education that is easily disseminated and economically feasible within diverse patient populations.⁷

There has been a veritable explosion of online educational resources for breast cancer patients, representing a double-edged sword for patients, with the potential to be empowering and beneficial as well as confusing and even misleading. Appropriate Internet materials can be particularly valuable in settings where resources are limited or where specialized oncology care is not offered. Examples of high-quality Internet-based resources are websites such as the National Cancer Institute (NCA; www.cancer.gov), the American Cancer Society (ACS; www.cancer.org), the Susan G Komen Foundation (www.komen.org), and the Lance Armstrong Foundation (www.laf.org).

In addition to providing educational materials, these sites make available more specialized referral services, for example to support groups and complementary cancer therapies, such as acupuncture and chiropractic treatment. Furthermore, there are breast cancer patients who may need more targeted interventions (e.g. nutritional guidance, sexual rehabilitation counseling) or more intensive interventions such as individual counseling or group support for depression or anxiety.

Psychosocial Challenges Following Cancer Diagnosis

Approximately 50% of cancer patients receive a psychiatric diagnosis, with about two-thirds representing adjustment disorders related to the effects of the illness.⁸ Cancer patients begin to feel the burden of their life-threatening illness on quality of life from the time of diagnosis, when physical, psychological, and social realities are immediately altered. Indeed, the majority of cancer patients report feeling worried and sad at some point during their treatment, and over 80% of breast cancer survivors express worry about disease recurrence.⁹ For most breast cancer patients, the bulk of ‘normal distress’ does not significantly impair daily functioning and will be limited to the duration of their treatment.¹⁰ However, there is a subset of survivors who struggle with major depression^{11,12} and survivors for whom the effect of this illness remains present many years after the completion of treatment.¹³ In addition, some breast cancer survivors report feeling pain,¹⁴ symptoms of post-traumatic stress,¹⁵ and cognitive impairments.¹⁶

Access to appropriate interventions for psychosocial problems after breast cancer treatment depends on a number of factors, including financial barriers, patient motivation, adequate physician access, and mental health referrals. An ongoing challenge for clinicians is to identify which women need further support and what kind of intervention is appropriate. For clinicians who are unsure whether a patient’s level of distress falls within the limits of normal distress, a first step may be to either utilize a universal screening instrument for distress or to make a referral to a mental health practitioner who can screen the patient and see the patient for counseling or facilitate another clinical referral if necessary. For the bulk of patients who are struggling with psychological and quality of life changes that may be normal but are nevertheless distressing, it may be helpful to direct patients to some kind of supportive educational counseling.

Recent developments in intervention research have shown that options such as telephone-delivered therapy and moderated online support groups are effective, far-reaching, and convenient.¹⁷ One example of this kind of resource is the Virtual Wellness Community (www.thewellnesscommunity.org), which offers moderated online support groups that are educational and informational in nature, as well as webcasts, podcasts, and other interactive educational materials. It is notable that support groups are not ideal for every woman who is diagnosed with breast cancer and are most beneficial for women who feel isolated or who are not satisfied with their social and emotional support network. For those who are interested, face-to-face support groups for women with breast cancer are often available in oncology and community settings.

Another frustrating matter for many breast cancer patients is ‘chemo brain’ or ‘chemo fog,’ i.e. complaints of cognitive impairment after treatment. It is important to assess the factors that may be involved in a patient’s cognitive decline beyond cancer treatment, such as nutritional deficits, anemia, medications, or a metabolic process such

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as hormonal change. Recent developments in pharmacological and behavioral strategies, as well as advances in formal cognitive rehabilitation counseling, have begun to yield promising results. There are also a growing number of resources for patients that discuss both the etiology and management of cognitive decline after breast cancer. Such resources include the websites of the Oncology Nursing Society (www.cancersymptoms.org) and the American Society of Clinical Oncology (ASCO; www.cancer.net).

Lifestyle Changes

Although many patients often experience notable lifestyle changes after undergoing breast cancer,¹⁸ it has been shown that patient education can have a positive effect on improving the health behaviors of cancer patients.¹⁹ Common lifestyle-related challenges for many breast cancer patients revolve around managing weight gain, fatigue, and diet after treatment. These matters are frequently inter-related. Cancer treatment is a time during which positive health behaviors such as exercising may decrease and performing negative health behaviors such as eating foods of low nutritional value often become more common.¹⁹ It is not unusual for cancer patients to experience and report appetite disturbance. Some patients develop food aversions secondary to treatment-related nausea, while others, including breast cancer patients, experience changes in their metabolism, placing them at risk for weight gain.²⁰

In light of growing epidemiological evidence that weight gain is implicated in risk for breast cancer recurrence as well as decreased survival, numerous interventions have been developed for women to help change their diet and lose weight.¹⁸ Research has shown that nutritional counseling and education have proved to be greatly beneficial in improving the eating habits of breast cancer patients.²¹ In addition, studies that have focused on physical activity as the main predictor of weight loss have demonstrated the multiple quality of life benefits that additionally come from exercise beyond the reduction of bodyweight.²² For instance, regular exercise has been shown to have a positive influence on anxiety, depression, general mood, and self-image.²³

Cancer patients are also likely to experience pain and cancer-related fatigue, symptoms that greatly influence their ability to remain

physically active. It has been found that almost 40% of patients report cancer-related fatigue²⁴—an often vexing problem for many cancer survivors that can be severe enough to impair life functioning.²⁵ Breast cancer patients may benefit from receiving education on behavioral and psychological interventions to alleviate cancer-related fatigue.¹⁶ Along with weight loss, a number of research studies have found that physical exercise can improve fatigue²⁶ and decrease inflammatory markers in breast cancer patients.^{27,28}

Exercise regimens may be self-directed and home- or group-based, and it is important that patients are encouraged to find a regimen that is manageable. It may be helpful to refer a patient to a physiatrist or physical therapist as a way to get started with an exercise rehabilitation

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plan that is realistic. Furthermore, it is notable that other lifestyle behaviors such as cigarette smoking, caffeine intake, and other recreational substance use may increase when a patient is feeling most distressed.¹⁹ Many cancer patients believe that these symptoms are fated, and therefore may be hesitant to discuss them with their providers,²⁹ but these symptoms can also be effectively targeted with educational, behavioral, and psychological interventions. It is important for clinicians to adequately assess patients for these symptoms and provide them with education on how to improve their quality of life.

Sexuality and Fertility

One of the most common challenges for breast cancer patients is sexual dysfunction following treatment.³⁰ The majority of premenopausal breast cancer patients find themselves facing menopause within the first year of diagnosis and treatment.³¹ Sudden, early menopause often results in severe and long-lasting vasomotor symptoms (e.g. hot flashes, night sweats) and urogenital symptoms (vaginal dryness, dysparenia, urinary urgency). For women who have already undergone menopause, adjuvant hormonal therapy (e.g. tamoxifen or aromatase inhibitors) can also cause these symptoms. It is well-documented that such symptoms can have a direct and negative impact on quality of life, sexual functioning, body image, and self-esteem.³²⁻³⁴ Although hormone therapy is very effective in relieving these symptoms, hormone replacement therapy is generally contraindicated for breast cancer survivors, and many survivors find themselves at a loss about how to manage these potentially severe and distressing menopausal symptoms.

Studies of non-hormonal pharmacological treatments of menopausal symptoms have generally shown mixed results, with a substantial placebo effect being observed in numerous interventions.³⁵ In

addition, currently used pharmacological treatments such as gabapentin, clonidine, and selective serotonin re-uptake inhibitors (SSRIs) are also commonly associated with a wide range of side effects, such as insomnia, dizziness, and sexual dysfunction.³⁶

More recently, a few studies have demonstrated promising results with various behavioral, non-pharmacological approaches to menopausal symptom management and sexual function after breast cancer.³⁰ Such approaches include psycho-education about sexual functioning and cancer treatment, instruction for sensate focus exercises to ease the transition back to sexual functioning, information and coaching regarding the use of non-hormonal therapy for urogenital symptoms such as water-based lubricants and vaginal moisturizers, and sexual rehabilitation counseling.³⁷

Some women may also find it helpful to be referred to a counselor who specializes in sexual therapy or sexual rehabilitation counseling. Another helpful option for many breast cancer survivors who are experiencing pain during intercourse due to estrogen depletion and loss of elasticity in the vaginal tissue is pelvic physical therapy. Physical therapists can help treat breast cancer survivors with a variety of options such as biofeedback to re-educate and relax pelvic floor muscles and self-treatment using vaginal dilators or a directed exercise program that helps lightly stretch the tissue and pelvic floor muscles.

Finally, it is also imperative to note that although the majority of younger women with breast cancer want to be well-informed about fertility, recent studies have shown that perhaps one-quarter of breast cancer patients do not get the information that they need.³⁸ Furthermore, many women may have questions about fertility long after treatment ends, as well as infertility-related distress that often goes unaddressed.³⁹

There also may be significant misinformation about fertility after breast cancer treatment. For example, breast cancer chemotherapy can have a severe effect on ovarian reserve and, even when

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menstruation resumes after treatment, young survivors are still at high risk for premature ovarian failure and infertility. Resumption of menses is often misunderstood as a sign that fertility has been regained when, in fact, loss of ovarian reserve may still be profound and the effects of chemotherapy are underestimated.⁴⁰

It has been suggested that the impact of infertility can be devastating for a young woman who has had to already deal with a life-threatening disease. Certainly, it is critical for women not only to be

informed about fertility preservation options before treatment, such as *in vitro* fertilization before chemotherapy in order to cryopreserve embryos or potentially oocytes, but also to have information about available options after cancer, such as having a gestational carrier or traditional surrogacy. One national advocacy organization dedicated to providing reproductive information and support to cancer patients and survivors is Fertile Hope (www.fertilehope.org).

Cultural Awareness and Other Considerations

Although there is a significant amount of literature on the psychological effects of breast cancer, diagnosis and treatment assumptions based on the available literature must be made with caution. Most of the data available on post-treatment symptoms in this population, as well as psycho-educational and psychosocial interventions to address their needs, have been gathered from largely Caucasian samples.⁴¹ Consequently, assumptions currently made regarding psychological challenges after breast cancer may not apply to racially and ethnically diverse or underserved patients. Moreover, the Institute of Medicine (IOM) and the ACS have identified racial and ethnic disparities in access to early diagnosis and treatment of breast cancer, with patients who belong to ethnic minority groups often being diagnosed at later stages of the disease and having significantly worse treatment outcomes.⁴² Therefore, the careful consideration of these disparities is pivotal in order to implement culturally competent mechanisms that assess and address the psychological needs of underserved populations.

Another important consideration is that although a minority of breast cancer survivors will be diagnosed with full psychiatric disorders such as major depression or post-traumatic stress disorder, research studies have found that a large number of survivors are likely to experience subclinical levels of psychopathology.^{13,43} However, subclinical levels of psychological distress may also result in survivors experiencing some form of life impairment. Therefore, the careful evaluation of the quality and severity of psychosocial distress in cancer patients and survivors is

of paramount importance for conducting appropriate psychosocial and psychiatric follow-up referrals.

Conclusion

There have been significant gains made not only in increasing breast cancer survival, but also in developing effective patient education and intervention that is directly related to improving quality of life. For many patients, the challenge is finding the appropriate venue or opportunity to access such resources. The clinical encounter that takes place between a patient and her primary care physician or gynecologist in many ways offers an ideal opportunity to begin addressing needs for psychosocial patient education and intervention after breast cancer. Patients are eager for more information and education and clinicians can be assured that patients are generally relieved and appreciative when clinicians take the initiative to inquire directly about matters such as mood, sexuality, and lifestyle changes after treatment. ■



Sharon L. Bober, PhD, is a Clinical Psychologist and Director of the Sexual Health Program in the Perini Family Survivors' Center at the Dana-Farber Cancer Institute in Boston. Her clinical and research interests center on sexual health after cancer, cancer risk, and developing psychoeducational interventions for cancer survivors. Dr Bober also studies the challenges that primary care physicians face in the context of caring for long-term cancer survivors, including how to address patient education.



Veronica Sanchez Varela, PhD, is a Psychology Research Fellow at the Perini Family Survivors' Center of the Dana-Farber Cancer Institute in Boston. She provides psychosocial services to cancer patients and conducts research studies on the psychological wellbeing of cancer survivors. Dr Sanchez Varela completed her pre-doctoral training at the Center for Multicultural Training in Psychology at Boston University School of Medicine, and has a special clinical and research interest in the provision of culturally competent psychosocial services to underserved minority cancer survivors.

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