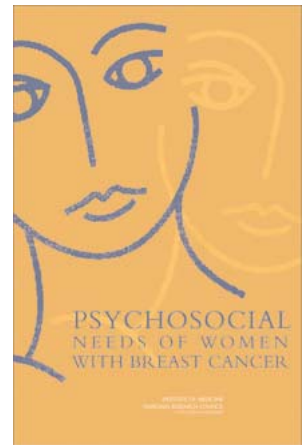


MEETING PSYCHOSOCIAL NEEDS OF WOMEN WITH BREAST CANCER

Over a quarter of a million women will hear the diagnosis of breast cancer every year, and breast cancer will kill about forty thousand women each year. Naturally, when faced with this news, women will variously experience fear, shock, sadness, disbelief or other feelings of psychosocial distress. Most women, with or without psychosocial support, will cope with psychological problems associated with living with breast cancer and successfully adjust to and manage their disease and survivorship. A small proportion, however, perhaps as many as 30 percent, will experience episodes of persistent psychosocial distress and would likely benefit from interventions designed to support them emotionally, psychologically, socially, or spiritually. For these women, psychosocial distress interferes with their ability to cope with cancer treatment and can extend along the continuum from common feelings of vulnerability, sadness, and fear, to problems that are disabling, such as true depression, anxiety, panic, and feeling isolated or in a spiritual crisis.

In *Meeting Psychosocial Needs of Women with Breast Cancer*, the National Cancer Policy Board of the Institute of Medicine examines the psychological consequences of the cancer experience. The report focuses specifically on breast cancer in women because this group has the largest survivor population (over two million) and is the most extensively studied cancer from the standpoint of psychological effects. The report:

- Characterizes the psychosocial consequences of a diagnosis of breast cancer;
- Describes psychosocial services, how they are delivered, and evaluates their effectiveness;
- Assesses the status of professional education and training and applied clinical and health services research; and
- Proposes policies to improve the quality of care and quality of life for women with breast cancer and their families.



Breast cancer will kill about forty thousand women each year.

Over a quarter of a million women will hear the diagnosis of breast cancer every year. As many as 30 percent of these women will experience persistent psychosocial distress due to this diagnosis.

Meeting a patient's psychosocial needs can provide significant benefits in quality of life and success in coping with serious and life-threatening disease for cancer patients and their families.

Box 1: Common Psychosocial Concerns of Women with Breast Cancer

- Fear of recurrence
- Physical symptoms, such as fatigue, trouble sleeping, and pain
- Body image disruption
- Sexual dysfunction
- Treatment related anxieties
- Intrusive thoughts about illness/persistent anxiety
- Difficulty with marital/partner communication
- Feelings of vulnerability
- Existential concerns regarding mortality

Because cancer of the breast is likely a good model for cancer at other sites, recommendations for this cancer should be applicable to the psychosocial care provided generally to individuals with cancer. For breast cancer, and indeed probably for any cancer, the report finds that there are significant psychosocial needs and that meeting them can provide significant benefits in quality of life and success in coping with serious and life threatening disease for patients and their families.

PSYCHOSOCIAL NEEDS ALONG THE DISEASE TRAJECTORY

For most women with breast cancer, coping strategies focusing on realistic expectations can facilitate adaptation to their illness over time. For others however, adaptation and coping may be extremely difficult and intervention may be needed. Box 1 above lists some of the most common psychosocial concerns reported by women with breast cancer.

The breast cancer experience has distinct phases with varying psychosocial concerns. These phases include diagnosis, primary treatment, special issues related to non-invasive breast cancer, genetic risk and its psychological management, completing treatment and re-entry to usual living, survivorship, recurrence, and palliation for advanced cancer.

Oncologists and other primary care providers must plan for and be prepared to evaluate and help patients with the range of psychosocial issues that arise along the breast cancer treatment continuum. The psychosocial impact of breast cancer must also be understood in the context of other issues that affect women's coping, quality of life, and well being—for example, socioeconomic and cultural factors, social support, access to health care, comorbidities, or other life crises.

This report reviews eight instruments that have been used to measure psychosocial distress and to estimate distress prevalence in American women with breast cancer. Unfortunately, most of these instruments were developed for research purposes and have not been rigorously tested and validated as

practical tools for assessment and screening for clinical use. Consideration of risk factors, such as age, pregnancy, responsibility for dependent children, concern about infertility, sexual dysfunction, pre-existing mental illness or psychological morbidity, physical comorbidities, and inadequate social support, is another way to predict the prevalence of distress. Little is known from prospective studies of the likelihood of psychosocial distress at the different points along the cancer trajectory or how levels of distress may vary for a given individual by phase of disease or treatment. Responsible clinicians need to be alert to and use the tools and information practically available to them to identify and manage or refer psychosocial distress in their patients with breast cancer.

The first and essential level of psychosocial services is basic social and emotional support from health care providers (Box 2 below), although such support can also be provided by peers, clergy, and support groups.

More formal interventions from specific professionals include psycho-educational, cognitive, and behavioral approaches, and psychotherapeutic (group and individual), psychopharmacologic, and complementary therapies. These can be delivered by oncology and specialized nurses, psychiatrists and psychologists, social workers, pastoral and specialized counselors, and psychosocial oncologists, among others. Optimally, a patient's providers work collaboratively to meet her psychosocial needs.

EVIDENCE FOR THE EFFECTIVENESS OF PSYCHOSOCIAL INTERVENTIONS

Over the past fifteen years, increasing resources have been devoted to evaluating the effectiveness of psychosocial interventions in women with breast cancer. Although a trial published in 1989 suggested that supportive-

Box 2: Steps Providers Can Take to Support "Normal" Levels of Psychosocial Distress

- Clarify and ensure understanding of diagnosis and treatment options and side effects
- Advise that distress is normal and expected and can increase at transition points
- Build trust
- Mobilize resources and direct patients to educational materials and local resources
- Consider medication for symptoms
- Ensure continuity of care
- Monitor and re-evaluate for referral to more specialized services if needed

Source: Modified from NCCN, Distress Management Guidelines, 2003

Optimally, a patient's providers work collaboratively to meet her psychosocial needs.

expressive group therapy might confer a survival advantage to women with metastatic breast cancer, that result has not been replicated. Thus, current trials are focusing on the psychological status and quality of life of women and on identification of interventions that favorably influence their psychological and social functioning. Most, but not all, recent reviews have concluded that there are important benefits associated with the use of psychological interventions in various cancers, including breast cancer, and some experts have urged that such interventions become an integral part of comprehensive medical care.

The report provides detailed reviews of 31 randomized clinical trials of various psychosocial interventions involving women with breast cancer, limited primarily to psychosocial outcomes, and focusing mostly on the early phases in the breast cancer trajectory (see table below). The report notes problems in some of these studies, including small numbers of subjects, short or varying follow-up, flaws in randomization, and omissions in base-line or other data; not all trials showed an effect. Despite the differences among the studies and their flaws, the majority demonstrated important psychological benefits, including improved mood, enhanced coping, reduced phobias, decreased levels of traumatic stress and severity of other psychiatric symptoms, increased vitality, and better social and role functioning and quality of life. A small sample of non-randomized studies was also reviewed; many of these less methodologically rigorous designs also yielded positive results.

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Randomized Trials of Psychosocial Interventions in Breast Cancer

Phase of Illness	Country		Type(s) of Intervention Investigated (some studies investigated more than one intervention)				
			Education *	Group Therapy†	Individual Therapy**	Relaxation/ Imagery	Other ***
“Early”** (n=24)	United States	12	1	8	10	5	11
	Canada	4					
	UK/Europe	6					
	Asia	2					
“Meta- static” (n=6)	United States	3	0	5	1	1	0
	Canada	2					
	Australia	1					
“Healthy Survivors ” (n=1)	United States	1	0	0	0	0	1
Total			1	13	11	6	2

* Educational materials provided passively to control groups not included.

** Includes telephone support, nursing intervention, cognitive-behavioral interventions, other.

*** Includes telephone screening in early breast cancer, videotapes in healthy survivors.

† Includes supportive or supportive-expressive group therapy, cognitive-behavioral interventions, peer discussion.

Although this research base needs strengthening, the evidence reviewed supports the conclusion that psychosocial interventions can be expected to reduce psychiatric symptoms and improve quality of life in routine breast cancer care.

DELIVERY OF PSYCHOSOCIAL SERVICES TO WOMEN WITH BREAST CANCER

Breast cancer care has moved from the inpatient to the ambulatory setting, mostly in private practices. In these practices, psychosocial providers are infrequent. Comprehensive breast centers and breast care programs, developed in the past decade, provide more reliable encounters with social workers, psychologists, and clinical nurse specialists who can provide psychosocial services. In addition to private practices, managed care, and cancer center breast programs, women may have available to them community-based support, American Cancer Society programs, Internet support programs, help from various not-for-profit and advocacy groups, and American Psychosocial Oncology Society backup.

Among the barriers to delivery of services are lack of health insurance, gaps in health insurance coverage, mental health service separation from physical health provision, inadequate reimbursement for mental health services, lack of referrals, stigma associated with mental illness, lack of awareness of community resources, failure to follow practice guidelines, and inadequate screening and assessment tools. The result of limitations in access is that service use is relatively low—perhaps 10 percent and at the most 30 percent of women with breast cancer.

RESEARCH IN PSYCHOSOCIAL CARE FOR WOMEN WITH BREAST CANCER

Over the past 10 to 15 years, reports of psychosocial research in breast cancer have been increasing, but remain less than seven percent of total citations for breast cancer research. This research is supported primarily through the federal Departments of Health and Human Services and Defense and also through private sponsors, such as the American Cancer Society and the Komen and Avon Foundations. Building on the current research base, much remains to be done, including determining relative benefits of different interventions, the optimal timing and duration of interventions, the patient characteristics associated with intervention benefits, the roles of nursing, peer support, and novel interventions, the needs of survivors, families, and minorities, and the value of measurement instruments and translation of research findings to community practice.

Over the past 10-15 years, reports of psychosocial research in breast cancer have been increasing, but remain less than seven percent of total citations for breast cancer research.

The report proposes policies to improve the quality of care and quality of life for women with breast cancer and their families.

These research priorities will be addressed most effectively if the psycho-oncology research community works together to ensure that future research provides clinically meaningful information. This approach may be facilitated by more widespread conduct of multi-center trials that address the issues identified above and avoid the problems of small single-center studies evaluated here and in other reviews.

RECOMMENDATIONS

The report proposes policies to improve the quality of care and quality of life for women with breast cancer and their families. These are abridged here, and more expanded recommendations with many specific examples are presented in the report:

- Continuing education at a level that recognizes its importance in psycho-oncology for oncologists, nurses, providers-in-training, and to improve clinician communication skills;
- Inclusion of graduate education in psycho-oncology for the spectrum of oncology providers;
- Incorporation in total medical care of planning for psychosocial management by breast cancer care clinicians as an integral part of treatment and assessment of distress;
- Adherence by providers of cancer care to American College of Surgeons and National Comprehensive Cancer Network standards of psychosocial care and clinical practice guidelines for the management of distress, respectively;
- Partnering of cancer organizations and professional and advocacy groups to focus on psychosocial needs of patients and community and national service resources;
- Collaboration of research sponsors, professional organizations, and advocacy groups to support enhancement of practice environments providing coordinated and compassionate care;
- Continuing research sponsor support of basic and applied psycho-oncology research; and
- A National Cancer Institute special study to ascertain the use of, and current need for, cancer-related supportive care services in the United States, including disparities by age, race/ethnicity, geography, and insurance coverage.

For More Information...

Copies of *Meeting Psychosocial Needs of Women with Breast Cancer* are available from the National Academies Press, 500 Fifth Street, N.W., Lockbox 285, Washington, DC 20055; (800) 624-6242 or (202) 334-3313 (in the Washington metropolitan area); Internet, <http://www.nap.edu>. The full text of this report will be available at <http://www.nap.edu>

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