Of the more than 250,000 women in the United States who will learn they have breast cancer this year, about 30% of them will need specialized emotional, social, psychological, or pastoral care, according to a draft report by the Institute of Medicine (IOM), which was released at the first meeting of the American Psychosocial Oncology Society in Orlando in late January.

In the report, Meeting Psychosocial Needs of Women with Breast Cancer, IOM advisers concluded that, to the extent that psychosocial services have been investigated, the interventions do reduce psychiatric symptoms in cancer patients and improve their quality of life. The report makes a series of recommendations for cancer providers and researchers, including that providers should adhere to the current National Comprehensive Cancer Network guidelines on distress, and that the National Cancer Institute should conduct a study to determine the use and need for such services as well as to identify barriers to access. Additionally, the report authors provide specific suggestions for how researchers working in the area of psychosocial interventions should improve their study designs.

Researchers have focused much of their work on breast cancer survivors, who represent about one quarter of all cancer survivors in the United States. “[The report] is on breast cancer, but I think we can truly use it as a paradigm from which to look at overall issues of psychosocial interventions in cancer patients,” said Jimmie C. Holland, M.D., professor of Psychiatry and Behavioral Sciences at Memorial Sloan-Kettering Cancer Center in New York and an editor on the report. “I think we can take the data from breast cancer and extrapolate it to other sites.”

After reviewing the relevant literature, the report authors identified 31 randomized controlled trials evaluating the efficacy of psychosocial interventions. Overall they conclude that, based on these trials, psychosocial interventions do provide valuable help to patients and improve their quality of life. Of the clinical trials evaluated in the report, 24 dealt with women early in their disease progression, six focused on women with metastatic disease, and one looked at long-term survivors.

Looking at the clinical trials, however, the authors also conclude that the research methods used in the arena of psychosocial care need to be strengthened. “There is room for improvement in studies,” said Roger Herdman, M.D., director of the National Cancer Policy Board and the study director for the report. Future research studies should include larger number of patients, be conducted at multiple centers, occur in both tertiary cancer centers and in community care settings, and be of longer duration, according to the draft report.

One chapter of the IOM report is devoted to the barriers that prevent patients from obtaining proper psychosocial care. Although it has been widely documented that patients who lack health insurance have poorer outcomes and less access to care, even for patients with health insurance, there are often gaps that make access to psychosocial services difficult. These barriers include
the separation of mental and behavioral services into a separate insurance carve-out and inadequate reimbursement for mental health services. In addition to insurance issues, the authors cite a lack of awareness of community resources, social stigma associated with mental illness, and inadequate psychosocial screening and assessment tools as further barriers for access to services. All told, only about 10% of breast cancer patients use the psychosocial services that are available.

With these obstacles identified, the report authors recommend that research funding agencies continue to support clinical trials in the area of psychosocial care and specify that such research should include not only evaluation of the efficacy of interventions but also the development and testing of assessment tools that can be readily used in a clinical setting. Additionally, the outcomes measured in intervention trials should include cost and the impact on quality of life. By including cost as an outcome measure, the medical establishment can begin to weigh whether these interventions ultimately affect medical care expenditures, the authors wrote.

The final recommendation in the draft report is that the NCI should undertake a study to determine the current use of and unmet need for cancer-related supportive care, including psychosocial services, in the United States. The results of the study could then be used as a benchmark against which to compare future care and services, including disparities of use by age, ethnicity, insurance coverage, and geography, according to the draft report.

Following on this point, Julia Rowland, Ph.D., director of the Office of Cancer Survivorship at NCI, noted that to get past the barriers to such care, researchers must demonstrate more clearly that providing such services will result in an overall decrease in the cost of medical care. This decreased cost may result from an increase in treatment compliance and a decrease in emergency room visits, for example.

Furthermore, said Rowland, the advocacy groups are going to have to get more involved with this issue to push for access. But, she cautioned, the medical system is typically reactive, and this is preventive, proactive care. That means that convincing public and private insurers that it is in their overall best interest to pay for it at an adequate rate will be difficult.

The report was based on a workshop held by the IOM and the National Cancer Policy Board in October 2002, as well as on two commissioned papers that included a clinical assessment of psychosocial distress and a literature review on the efficacy of psychosocial interventions. Details of the workshop, the commissioned papers, and the new report itself can be found on the IOM website at www.IOM.edu/ncpb.

—Rabiya Tuma