

REPORT BRIEF • OCTOBER 2007

CANCER CARE FOR THE WHOLE PATIENT: MEETING PSYCHOSOCIAL HEALTH NEEDS

For Health Care Providers

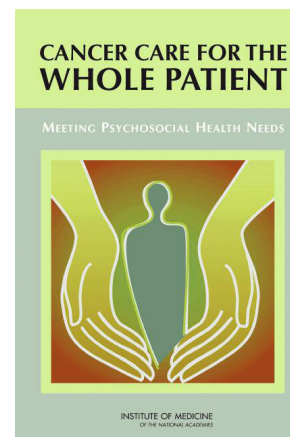
Modern cancer care is a showpiece of state-of-the-science biomedical treatment. Biomedical research aimed at improving diagnosis and treatment continues to point to ways to significantly increase the long term survival of most patients diagnosed with cancer. Over the past two decades, the five year survival rate for the 15 most common cancers has increased from 43 to 64 percent for men and from 57 to 64 percent for women.

Research findings from other fields of study also have identified ways of improving the quality of cancer care and the health of patients. A growing body of scientific evidence demonstrates that the psychological and social (“psychosocial”) problems created or exacerbated by cancer (e.g., depression, other emotional problems, or a lack of information or skills needed to manage illness) can be effectively addressed by a number of services and interventions. Other, less studied services such as transportation or financial assistance are clearly important to help support cancer patients and their families. Together, these services reduce patients’ suffering, help them adhere to prescribed treatments, and support their return to health.

THE PROBLEM

In spite of this evidence, patients, physicians and other cancer care providers tell us that attention to patients’ psychosocial health needs is the exception rather than the rule in cancer care today. Many people living with cancer report dissatisfaction with the amount and type of information they are given about their diagnosis, available treatments, and ways to manage their illness and health. Health care providers often fail to communicate this information in ways that are understandable to patients. Patients also report that their care providers do not understand their psychosocial needs; do not consider psychosocial support an integral part of their care; are unaware of psychosocial health care resources; and fail to recognize, adequately treat, or refer patients to services that could help.

A number of factors can get in the way of clinicians’ addressing psychosocial health needs. These include the way in which clinical practices are designed, the education and training of the health care workforce, shortages and maldistribution of health personnel, and the nature of the payment and policy environment in which health care is delivered. Because of this, improving the delivery of psychosocial health services requires a multi-pronged solution.



Patients, physicians and other cancer care providers tell us that attention to patients’ psychosocial health needs is the exception rather than the rule in cancer care today.



INSTITUTE OF MEDICINE
OF THE NATIONAL ACADEMIES

Advising the Nation. Improving Health.

A STRATEGY FOR IMPROVING CANCER CARE

To address this problem, the National Institutes of Health (NIH) asked the Institute of Medicine (IOM) to study the delivery of psychosocial services to cancer patients and their families and identify ways to improve it. The IOM defined psychosocial health services in this way:

Psychosocial health services are psychological and social services and interventions that enable patients, their families, and health care providers to optimize biomedical health care and to manage the psychological/behavioral and social aspects of illness and its consequences so as to promote better health.

The IOM Committee undertaking the study identified six domains of psychosocial problems and services to address them (see table). The Committee also found a number of health care providers with systems set up to address these psychosocial

Psychosocial Need	Available Health Service (examples)
Understanding of illness, treatments, and services	Strategies to improve patient-provider communication
Coping with emotions surrounding illness and treatment	Peer support groups, counseling/psychotherapy, pharmacological management of symptoms
Managing illness and health	Comprehensive self-management/self-care programs
Behavioral change to minimize disease impact	Behavioral/health promotion interventions such as smoking cessation help, patient education
Managing disruptions in work, school and family life	Family and caregiver education, assistance with Activities of Daily Living (ADLs)
Financial Assistance	Financial planning, insurance counseling, eligibility assessment for Social Security Disability Income

needs. Some of these systems are derived from theoretical or conceptual frameworks, others are based on research findings, and others have undergone empirical testing on their own. Studying these systems, the Committee identified a common framework for the effective delivery of psychosocial health services:

1. Identify psychosocial needs.
2. Link patients and families to services.
3. Support patients and families in managing illness.
4. Coordinate psychosocial and biomedical health care.
5. Follow up on care delivery to monitor the effectiveness of services.

The Committee also found that while the supply of services is not sufficient to resolve *all* psychosocial problems (such as poverty), there are untapped services available in communities across the U.S. – many of which are available at no cost to patients. However, patients are often unaware that they exist or how to access them.

Based on its extensive review of evidence, the Committee set forth a standard to guide the improvement of all cancer care (see box). What this standard means is that at the clinical level, all cancer care practices should have mechanisms in place to ensure that appropriate psychosocial health services are provided. This starts with effective communication between patients and physicians, but needs to be backed up with systemic approaches to identifying patients' needs. Once identified, the clinical practices must work with patients to create a plan tailored to their individual needs, and then link

The Standard of Care

All cancer care should ensure the provision of appropriate psychosocial health services by:

- Facilitating effective communication between patients and care providers.
- Identifying each patient's psychosocial health needs.
- Designing and implementing a plan that:
 - Links the patient with needed psychosocial services.
 - Coordinates biomedical and psychosocial care.
 - Engages and supports patients in managing their illness and health.
- Systematically following up on, reevaluating, and adjusting plans.

them to needed services. By systematizing the process, providers will ensure coordination of care and be able to follow up, evaluate and adjust services as needed. The Committee recommended that the National Cancer Institute, the Centers for Medicare and Medicaid Services, and all other organizations that set standards for cancer care should adopt this standard and incorporate psychosocial health into their research topics, policies, protocols and standards.

The Committee recognized that cancer care practices vary according to their size, internal and community resources, personnel, and ways in which work is designed. In addition to providing examples of how some oncology providers deliver care that meets this standard today, the Committee's report, *Cancer Care for the Whole Patient – Meeting Psychosocial Health Needs*, identifies approaches that all cancer care providers, including those with the fewest resources and smallest size, can use to deliver care that meets this standard of care today.

The Committee also identified actions that government and private sector institutions can take to support cancer care providers in delivering care that meets this standard. The Committee recommended, for instance, that the National Cancer Institute help providers by maintaining an up-to-date online directory of psychosocial services available nationwide and at no cost to patients. An extensive listing of such services is found in the Committee's report. Congress and federal agencies are called on to establish and fund a Workforce Development Collaborative on Psychosocial Care during Chronic Medical Illness, charged with educating doctors on the best way to serve their constituencies. Recommendations are also directed to group purchasers of health care coverage and insurers.

GOING FORWARD

Based on its findings with regard to the significant impact of psychosocial problems on health and health care, the existence of effective psychosocial services to address these problems, and the development and testing of strategies for delivering these services effectively, the IOM concludes that attending to psychosocial needs should be an integral part of quality cancer care. All components of the health care system that are involved in cancer care should explicitly incorporate attention to psychosocial needs into their policies, practices, and standards addressing clinical health care. These policies, practices, and standards should be aimed at ensuring the provision of psychosocial health services to all patients who need them.

While cancer care providers take action to meet this new standard of care, there is much more to be learned. The Committee recommends that research address the use of tools and strategies to ensure delivery of appropriate psychosocial services to

All components of the health care system that are involved in cancer care should explicitly incorporate attention to psychosocial needs into their policies, practices, and standards addressing clinical health care.

vulnerable populations, such as those with low literacy, inadequate income, and members of cultural minorities.

Psychosocial issues in cancer are palpable, important, and potentially crippling. With the systematic efforts of everyone in the chain of care — from the National Institutes of Health to the parents of a 12-year-old going through radiation therapy — these challenges can be managed effectively. All patients with cancer and their families should expect and receive cancer care that ensures the provision of appropriate psychosocial health services. Today, it is not possible to deliver good-quality cancer care without addressing patients' psychosocial health needs.

FOR MORE INFORMATION...

Copies of *Cancer Care for the Whole Patient: Meeting Psychosocial Health Needs* 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 is available at <http://www.nap.edu>.

This study was supported by funds from the National Institutes of Health. Any opinions, findings, conclusions, or recommendations expressed in this publication are those of the author(s) and do not necessarily reflect the views of the organization that provided support for the project.

The Institute of Medicine serves as adviser to the nation to improve health. Established in 1970 under the charter of the National Academy of Sciences, the Institute of Medicine provides independent, objective, evidence-based advice to policymakers, health professionals, the private sector, and the public. For more information about the Institute of Medicine, visit the IOM web site at www.iom.edu.

Permission is granted to reproduce this document in its entirety, with no additions or alterations. Copyright © 2007 by the National Academy of Sciences. All rights reserved.

COMMITTEE ON PSYCHOSOCIAL SERVICES TO CANCER PATIENTS/FAMILIES IN A COMMUNITY SETTING

NANCY E. ADLER* (*Chair*), Professor of Medical Psychology and Vice-Chair, Department of Psychiatry, University of California - San Francisco; **RONDA J. ROBINSON BEALE**, Chief Medical Officer, United Behavioral Health, Van Nuys, California; **DIANE BLUM**, Executive Director, CancerCare Inc., New York; **PATRICIA GANZ**, Professor, UCLA Schools of Medicine and Public Health and Jonsson Comprehensive Cancer Center, Los Angeles; **SHERRY GLIED***, Professor and Chair, Department of Health Policy and Management, Mailman School of Public Health, Columbia University, New York; **JESSIE GRUMAN**, President, Center for the Advancement of Health, Washington DC; **MICHAEL HOGE**, Professor of Psychology (in Psychiatry), Yale University School of Medicine, New Haven, CT; **JIMMIE HOLLAND***, Wayne E. Chapman Chair in Psychiatric Oncology, Memorial Sloan-Kettering Cancer Center, New York; **MELISSA HUDSON**, Director, After Completion of Therapy Clinic, St. Jude Children's Research Hospital, Memphis, TN; **SHERRIE KAPLAN**, Associate Dean for Clinical Policy and Health Services Research, University of California at Irvine School of Medicine; **ALICIA MATTHEWS**, Associate Professor, University of Illinois, Chicago; **RUTH MCCORKLE***, Florence S. Wald Professor of Nursing and Director, Center for Excellence in Chronic Illness Care, Yale University School of Nursing, New Haven, CT; **HAROLD ALAN PINCUS**, Vice Chair, Department of Psychiatry, College of Physicians & Surgeons, Columbia University, and Director of Quality and Outcomes Research, New York-Presbyterian Hospital, New York; **LEE SCHWARTZBERG**, Medical Director, The West Clinic, Memphis, TN; **EDWARD WAGNER**, Director, Group Health Cooperative W.A. McColl Institute for Healthcare Innovation Center for Health Studies, Seattle, WA; **TERRIE WETLE**, Associate Dean of Medicine for Public Health and Public Policy, Brown Medical School, Providence, RI.

*Member, Institute of Medicine

STUDY STAFF

ANN E. K. PAGE, Study Director and Senior Program Officer, Board on Health Care Services; **JASON F. LEE**, Christine Mirzayan Science and Technology Policy Graduate Fellow (9/06 – 12/06); **RYAN PALUGOD**, Research Assistant; **WILLIAM McLEOD**, Senior Research Librarian; **EVALYNE BRYANT-WARD**, Financial Associate.