

REPORT BRIEF • OCTOBER 2007

CANCER CARE FOR THE WHOLE PATIENT: MEETING PSYCHOSOCIAL HEALTH NEEDS

For Patients

Cancer is an all-too-common part of our lives. Today, more than 10.5 million people in this country will wake up fighting cancer, either battling current disease or hoping that an earlier illness stays in remission. All told, more than 40% of all Americans will be diagnosed with cancer at some point in their lifetimes.

The good news is that cancer is more survivable than ever. Early detection and medical innovation have made powerful strides against the most common cancers, prolonging lives and opening windows of hope where none existed before.

But even in the best situation, cancer is a heavy burden. The very treatments that prolong life and even cure certain cancers can also cause serious and sometimes long-lasting problems for patients. More than half of adult cancer patients and survivors report substantial disabilities at some point in their treatment, recovery or survivorship, and the physical toll is only half the battle. Both cancer patients and their families are at increased risk for anxiety, depression, and other mental health problems tied to the strain of both the disease – and the complicated efforts to manage that disease.

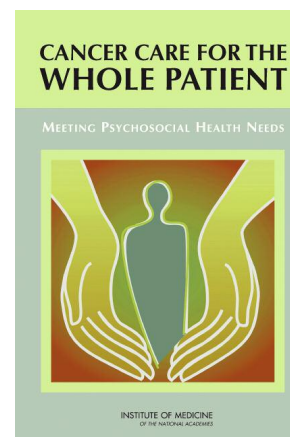
THE IMPORTANCE OF PSYCHOSOCIAL HEALTH CARE

The health care community is increasingly aware of the importance of addressing psychological and social problems in the lives of patients in order to provide good quality health care and promote better health. As a result, the National Institutes of Health (NIH) asked the Institute of Medicine (IOM) to examine how the health care system copes with cancer patients' psychological and social problems, and how "psychosocial" care can be improved.

Over the years, there has been a great deal of uncertainty about what exactly "psychosocial" care includes. The IOM Committee defined it 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.

To put it more plainly, psychosocial health care addresses the emotional challenges that can accompany a serious illness as well as the life challenges that can prevent good healthcare and patients' ability to take care of them-



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selves: inability to pay for and receive health care or medications; a lack of transportation to medical appointments; inability to perform personal care activities such as bathing or preparing meals; and lack of information, knowledge, and skills addressing how to monitor and improve their health. Many psychosocial health services are available to cancer patients to address these needs – often at no cost to the patient. A large group of voluntary, not-for-profit organizations, and other governmental and private sector organizations provide a web of psychosocial health services to patients with cancer and their families.

In spite of the availability of these services, the Committee found that health care providers often do not ask about psychosocial problems or link patients to available services – with detrimental effects on their patients. The Committee found that this care can and must be improved, if patients are to receive the care they need, and have their health care and health optimized. It further laid out recommendations about what doctors and other caregivers should do to provide patients with the support they need – and what patients should do to help ensure they get the care they deserve.

WHY DOES PSYCHOSOCIAL HEALTH CARE MATTER?

Physically, cancer and cancer treatments are tremendously challenging, often requiring a combination of debilitating treatments that can continue for months or years. But effects on mental health are also common, with depression and anxiety disorders frequently reported. In fact, recent studies have shown that cancer patients and the parents of young children with cancer sometimes meet the textbook criteria for post-traumatic stress disorder (PTSD).

These mental states can cause harmful health effects of their own, compounding the challenges of treatment and disease in a damaging, downward spiral. Patients suffering from depression, anxiety, or excessive stress can have difficulty remembering things, concentrating, and making decisions. These mental health problems can also decrease patients' motivation to complete treatment, change unhealthy practices such as smoking, and decrease their ability to cope with the demands of a rigorous treat-

What Causes Psychosocial Stress?

- Fears and worries that accompany having a life-threatening illness.
- The physical pain and exhaustion of disease and treatment.
- Not understanding about cancer, treatment options, and how to manage your illness and overall health.
- Not having family members or other people who can provide emotional support and practical day-to-day help such as performing household chores.
- Not having transportation to medical appointments, pharmacies, or other health services.
- Financial problems, ranging from concerns about health insurance to payments for treatments, or problems paying household bills during and after treatment.
- Concern for how family members and loved ones are coping.
- The challenges of changing behaviors to minimize impact of the disease (smoking, exercise, etc.).

ment process. There is growing evidence that stress can directly interfere with the working of the body's immune system and other functions.

The first line of defense for most cancer patients is their family and loved ones. But sometimes this support is unavailable. In other situations, they can be overwhelmed by the sheer volume or intensity of a patient's needs. Moreover, members of this critical support network are themselves at risk for depression and other adverse health effects. This leads to a kind of "negative feedback loop" where patients' and their families' stress can add to each other. Studies of care-givers supporting women with breast cancer found that the partners' mental health correlates directly to the anxiety, depression, fatigue, and symptom distress of the patient, and vice-versa.

MAKING A DIFFERENCE

The failure to address the very real psychosocial health needs of patients and their caregivers is a failure to effectively treat that patient's cancer, plain and simple. After all, cancer treatment is intended both to extend life and to improve the patients' *quality* of life. The health care system should explicitly recognize these needs and find ways to meet them. Patients and caregivers deserve no less.

There *are* reasons to be optimistic. In many communities, substantial support is available. But we need our health care professionals to do a better job recognizing a patient's needs and connecting them to the right services – each and every time, for each and every patient.

Cancer care is a collaborative endeavor. As a patient, or part of a support network, there are things you can do and things you should expect from your health care team. As a person diagnosed with cancer, you should expect to have:

- Satisfying communication with doctors, nurses, and others treating your cancer;
- Doctors, nurses, and others treating your cancer ask you about your needs for information and emotional and social support; and
- A health care person or team who works with you to develop and carry out a plan that:
 - links you to the information and support that you need;
 - coordinates your medical, emotional, and social care; and
 - helps you to manage your illness, treatments, and health.

If those who treat your cancer do not provide this type of care, you need to be prepared to ask for it. Tools like the Cancer Survival Toolbox (available free of charge from the National Coalition for Cancer Survivorship at www.cancersurvivaltoolbox.org) can help you to be more comfortable asking for such care and generally communicating more effectively with health care providers.

The story doesn't end with patients and their doctors. Through the IOM's ongoing work, these issues are being discussed throughout the health care industry, including the National Cancer Institute and other federal agencies, health care insurance companies and purchasers, and others.

Cancer is no simple disease, and effective treatment is not just about killing rogue cells with radiation and chemotherapy.

It's about healing the human being.

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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>.

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