

## Free Executive Summary



### **Cancer Care for the Whole Patient: Meeting Psychosocial Health Needs**

Committee on Psychosocial Services to Cancer Patients/Families in a Community Setting, Nancy E. Adler and Ann E. K. Page, Editors

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*Cancer care today often provides state-of-the-science biomedical treatment, but fails to address the psychological and social (psychosocial) problems associated with the illness. This failure can compromise the effectiveness of health care and thereby adversely affect the health of cancer patients. Psychological and social problems created or exacerbated by cancer--including depression and other emotional problems; lack of information or skills needed to manage the illness; lack of transportation or other resources; and disruptions in work, school, and family life--cause additional suffering, weaken adherence to prescribed treatments, and threaten patients' return to health. Today, it is not possible to deliver high-quality cancer care without using existing approaches, tools, and resources to address patients' psychosocial health needs. All patients with cancer and their families should expect and receive cancer care that ensures the provision of appropriate psychosocial health services. Cancer Care for the Whole Patient recommends actions that oncology providers, health policy makers, educators, health insurers, health planners, researchers and research sponsors, and consumer advocates should undertake to ensure that this standard is met.*

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## Summary

### ABSTRACT

*Cancer care today often provides state-of-the-science biomedical treatment, but fails to address the psychological and social (psychosocial) problems associated with the illness. This failure can compromise the effectiveness of health care and thereby adversely affect the health of cancer patients. Psychological and social problems created or exacerbated by cancer—including depression and other emotional problems; lack of information or skills needed to manage the illness; lack of transportation or other resources; and disruptions in work, school, and family life—cause additional suffering, weaken adherence to prescribed treatments, and threaten patients' return to health.*

*A range of services is available to help patients and their families manage the psychosocial aspects of cancer. Indeed, these services collectively have been described as constituting a “wealth of cancer-related community support services.”*

*Today, it is not possible to deliver good-quality cancer care without using existing approaches, tools, and resources to address patients' psychosocial health needs. All patients with cancer and their families should expect and receive cancer care that ensures the provision of appropriate psychosocial health services. This report recommends ten actions that oncology providers, health policy makers, educators, health insurers, health plans, quality oversight organizations, researchers and research sponsors, and consumer advocates should undertake to ensure that this standard is met.*

## PSYCHOSOCIAL PROBLEMS AND HEALTH

*The burden of illnesses and disabilities in the United States and the world is closely related to social, psychological, and behavioral aspects of the way of life of the population. (IOM, 1982:49–50)*

*Health and disease are determined by dynamic interactions among biological, psychological, behavioral, and social factors. (IOM, 2001:16)*

*Because health . . . is a function of psychological and social variables, many events or interventions traditionally considered irrelevant actually are quite important for the health status of individuals and populations. (IOM, 2001:27)*

In previous reports the Institute of Medicine (IOM) has issued strong findings about the important role of psychological/behavioral and social factors in health and recommended more attention to these factors in the design and delivery of health care (IOM, 1982, 2001, 2006). In 2005, the IOM was asked once again to examine the contributions of these psychosocial factors to health and how best to address them—in this case in the context of cancer, which encompasses some of the nation's most serious and burdensome illnesses.

## STUDY CONTEXT

### The Reach and Influence of Cancer

One in ten American households today has a family member who has been diagnosed with or treated for cancer<sup>1</sup> within the past 5 years (USA Today et al., 2006), and 41 percent of Americans can expect to be diagnosed with cancer at some point in their lifetime (Ries et al., 2007). More than ten and a half million people in the United States live with a past or current diagnosis of cancer (Ries et al., 2007).

Early detection and improved treatments for many different types of cancer have changed our understanding of this group of illnesses from that of a single disease that was often uniformly fatal in a matter of weeks or months to that of a variety of diseases—some of which are curable, all of which are treatable, and for many of which long-term disease-free survival is possible. In the past two decades, the 5-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 (Jemal et al., 2004).

Nonetheless, the diseases that make up cancer represent both acute life-threatening illnesses and serious chronic conditions. Their treatment is

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<sup>1</sup>This excludes non-melanoma skin cancers.

typically very challenging physically to patients, requiring some combination of surgery, radiation, or chemotherapy for months or years. Even when treatment has been completed and no cancer remains, the frequently permanent, serious residua of cancer and/or the side effects of chemotherapy, radiation, hormone therapy, surgery, and other treatments can permanently impair cardiac, neurological, kidney, lung, and other body functioning, necessitating ongoing monitoring of cancer survivors' health and many adjustments in their daily living. Eleven percent of adults with cancer or a history of cancer (almost half of whom are age 65 or older) report having one or more limitations in their ability to perform activities of daily living such as bathing, eating, or using the bathroom, and 58 percent report other functional disabilities, such as the inability to walk a quarter of a mile, or to stand or sit for 2 hours (Hewitt et al., 2003). Long-term survivors of childhood cancer are at particularly elevated risk compared with others their age. Nearly 20 percent of those who survive 5 years or more report limitations in activities such as carrying groceries, climbing a flight of stairs, or walking a block (Ness et al., 2005). Significant numbers of individuals stop working or experience a change in employment after being diagnosed or treated for cancer (IOM and NRC, 2006).

Not surprisingly, significant mental health problems, such as depression and anxiety disorders, are common in patients with cancer (Spiegel and Giese-Davis, 2003; Carlsen et al., 2005; Hegel et al., 2006). Studies have also documented the presence of symptoms meeting the criteria for post-traumatic stress disorder (PTSD) and post-traumatic stress symptoms (PTSS) in adults and children with cancer, as well as in the parents of children diagnosed with cancer (Kangas et al., 2002; Bruce, 2006).<sup>2</sup> These mental health problems are additional contributors to functional impairment in carrying out family, work, and other societal roles; poor adherence to medical treatments; and adverse medical outcomes (Katon, 2003).

Patients with cancer (like those with other chronic illnesses) identify a number of other problems that adversely affect their health care and recovery, including poor communication with physicians, lack of knowledge about their illness and its management, lack of transportation to health care appointments, financial problems, and lack of health insurance (Wdowik et al., 1997; Eakin and Strycker, 2001; Riegel and Carlson, 2002; Bayliss et al., 2003; Boberg et al., 2003; Skalla et al., 2004; Jerant et al., 2005; Mallinger et al., 2005). Fifteen percent of households affected by cancer report having left a doctor's office without getting answers to important

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<sup>2</sup>These mental health problems are not unique to cancer patients. Populations with other chronic illnesses, such as diabetes, heart disease, HIV-related illnesses, and neurological disorders, also have higher rates of depression, adjustment disorders, severe anxiety, PTSD or PTSS, and subclinical emotional distress (Katon, 2003).

questions about the illness (USA Today et al., 2006). The American Cancer Society and CancerCare report receiving more than 100,000 requests annually for transportation so patients can get to medical appointments, pick up medications, or receive other health services. In 2003, nearly one in five (12.3 million) people with chronic conditions<sup>3</sup> lived in families that had problems paying medical bills (May and Cunningham, 2004; Tu, 2004). Among uninsured cancer survivors, more than one in four delayed or decided not to get treatment because of its cost, and 41 percent were unable to pay for basic necessities, including food (USA Today et al., 2006). About 5 percent of the 1.5 million American families who filed for bankruptcy in 2001 reported that medical costs associated with cancer contributed to their financial problems (Himmelstein et al., 2005).

Although family and loved ones often provide substantial amounts of emotional and logistical support and hands-on personal and nursing care (valued at more than \$1 billion annually) in an effort to address these needs (Hayman et al., 2001; Kotkamp-Mothes et al., 2005), they often do so at great personal cost, themselves experiencing depression, other adverse health effects, and an increased risk of premature death (Schultz and Beach, 1999; Kurtz et al., 2004). Caregivers providing support to a spouse who report strain from doing so are 63 percent more likely to die within 4 years than others their age (Schultz and Beach, 1999). The emotional distress of caregivers also can directly affect patients. Studies of partners of women with breast cancer (predominantly husbands, but also “significant others,” daughters, friends, and others) find that partners’ mental health correlates positively with the anxiety, depression, fatigue, and symptom distress of women with breast cancer and that the effects are bidirectional (Segrin et al., 2005, 2007).

### Effects of Psychosocial Problems on Physical Health

The psychosocial problems described above can adversely affect health and health care in many ways. For example, a substantial literature has documented low income as a strong risk factor for disability, illness, and death (IOM, 2001; Subramanian et al., 2002). Inadequate income limits one’s ability to purchase food, medications, and health care supplies necessary for health and health care, as well as to secure necessary transportation and obtain relief from other stressors that can accompany tasks of everyday life (Kelly et al., 2006). As noted above, lack of transportation to medical appointments, the pharmacy, the grocery store, health education classes, peer support meetings, and other out-of-home health resources is common,

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<sup>3</sup>Asthma, arthritis, diabetes, chronic obstructive pulmonary disease, heart disease, hypertension, cancer, benign prostate enlargement, abnormal uterine bleeding, and depression.

and it can pose a barrier to health monitoring, illness management, and health promotion.

Depressed or anxious individuals have lower social functioning, more disability, and greater overall functional impairment than those without these conditions (Spitzer et al., 1995; Katon, 2003). Distressed emotional states also often generate additional somatic problems, such as sleep difficulties, fatigue, and pain (Spitzer et al., 1995; APA, 2000), which can confound the diagnosis and treatment of physical symptoms. Patients with major depression as compared with nondepressed persons also have higher rates of unhealthy behaviors such as smoking, a sedentary lifestyle, and overeating. Moreover, depression and other adverse psychological states thwart behavior change and adherence to treatment regimens by impairing cognition, weakening motivation, and decreasing coping abilities. Evidence emerging from the science of psychoneuroimmunology—the study of the interactions among behavior, the brain, and the body’s immune system—is beginning to show how psychosocial stressors interfere with the working of the body’s neuro-endocrine, immune, and other systems.

In sum, people diagnosed with cancer and their families must not only live with and manage the challenges and risks posed to their physical health, but also overcome psychosocial obstacles that can interfere with their health care and diminish their health and functioning. Unfortunately, the current medical system deploys its resources largely to address the former problems and often ignores the latter. As a result, patients’ psychosocial needs frequently remain unacknowledged and unaddressed in cancer care.

### **Cancer Care Is Often Incomplete**

Many people living with cancer report that their psychosocial health care needs are not well addressed in their care. At the most fundamental level, throughout diagnosis, treatment, and post-treatment, patients report dissatisfaction with the amount and type of information they are given about their diagnosis, their prognosis, available treatments, and ways to manage their illness and health. Health care providers often fail to communicate this information effectively, in ways that are understandable to and enable action by patients (Epstein and Street, 2007). Moreover, individuals diagnosed with cancer often 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 offer referral for depression or other sequelae of stress due to the illness in patients and their families (President’s Cancer Panel, 2004; Maly et al., 2005; IOM, 2007). Twenty-eight percent of respondents to the National Survey of U.S. Households Affected by Cancer reported that they did not have a doctor who

paid attention to factors beyond their direct medical care, such as sources of support for dealing with the illness (USA Today et al., 2006). A number of studies also have shown that physicians substantially underestimate oncology patients' psychosocial distress (Fallowfield et al., 2001; Keller et al., 2004; Merckaert et al., 2005). Indeed, oncologists themselves report frequent failure to attend to the psychosocial needs of their patients. In a national survey of members of the American Society of Clinical Oncology, a third of respondents reported that they did not routinely screen their patients for distress. Of the 65 percent that did do so, methods used were often untested or unreliable. In a survey of members of an alliance of 20 of the world's leading cancer centers, only 8 reported screening for distress in at least some of their patients, and only 3 routinely screened all of their patients for psychosocial health needs (Jacobsen and Ransom, 2007).

A number of factors can interfere with 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 multipronged approach.

## STUDY SCOPE

In this context, the National Institutes of Health asked the IOM to empanel a committee to conduct a study of the delivery of the diverse psychosocial services needed by cancer patients and their families in community settings. The committee was tasked with producing a report describing barriers to access to psychosocial services and ways in which these services can best be provided, analyzing the capacity of the current mental health and cancer treatment system to deliver such care, delineating the associated resource and training requirements, and offering recommendations and an action plan for overcoming the identified barriers. The committee interpreted "community care" to refer to all sites of cancer care except inpatient settings.

This study builds on and complements several prior reports on cancer care. First, two recent reports address quality of care for cancer survivors. *From Cancer Patient to Cancer Survivor: Lost in Transition* (IOM and NRC, 2006) well articulates how high-quality care (including psychosocial health care) should be delivered after patients complete their cancer treatment. *Childhood Cancer Survivorship: Improving Care and Quality of Life* (IOM and NRC, 2003) similarly addresses survivorship for childhood cancer. The recommendations made in the present report complement and can be implemented consistent with the vision and recommendations put forth in those reports. Second, two other recent reports address palliative care:

*Improving Palliative Care for Cancer* (IOM and NRC, 2001) and *When Children Die: Improving Palliative and End-of-Life Care for Children and Their Families* (IOM, 2003). For this reason, the additional considerations involved in providing end-of-life care are not addressed in this report.

### FINDINGS GIVE REASON FOR HOPE

In carrying out its charge, the IOM Committee on Psychosocial Services to Cancer Patients/Families in a Community Setting found multiple reasons to be optimistic that improvements in the psychosocial health care provided to oncology patients and their families can be quickly achieved. First, there is good evidence of the effectiveness of a variety of services in relieving the emotional distress—even the debilitating depression and anxiety—experienced by cancer patients. Strong evidence also supports the utility of services aimed at helping individuals adopt behaviors that can minimize disease symptoms and improve overall health. Other psychosocial services, such as transportation to health care or financial assistance to purchase medications or supplies, while not the subject of effectiveness research, have long-standing and wide acceptance as humane approaches to addressing health-related needs. Such services are available through many health and human service providers. In particular, the strong leadership of organizations in the voluntary sector has created a broad array of psychosocial support services, in some cases available at no cost to the consumer. Together, these resources have been described as constituting a “wealth of cancer-related community support services” (IOM and NRC, 2006:229).

However, it is not sufficient simply to have effective services; interventions to identify patients with psychosocial health needs and to link them to appropriate services are needed as well. Fortunately, many providers of health services—some in oncology, some delivering health care for other complex health conditions—understand that psychosocial problems can affect health adversely and have developed interventions to address these problems. Some of these interventions are derived from theoretical or conceptual frameworks, some are based on research findings, and some have undergone empirical testing on their own; the best have all three sources of support. Common components of these interventions point to a model for the effective delivery of psychosocial health services (see Figure S-1). This model includes processes that (1) identify psychosocial health needs, (2) link patients and families to needed psychosocial services, (3) support patients and families in managing the illness, (4) coordinate psychosocial and biomedical health care, and (5) follow up on care delivery to monitor the effectiveness of services and make modifications if needed—all of which are facilitated by effective patient–provider communication. Routine implementation of many of these processes is currently under way by a number of exemplary cancer care providers in a variety of settings, attest-



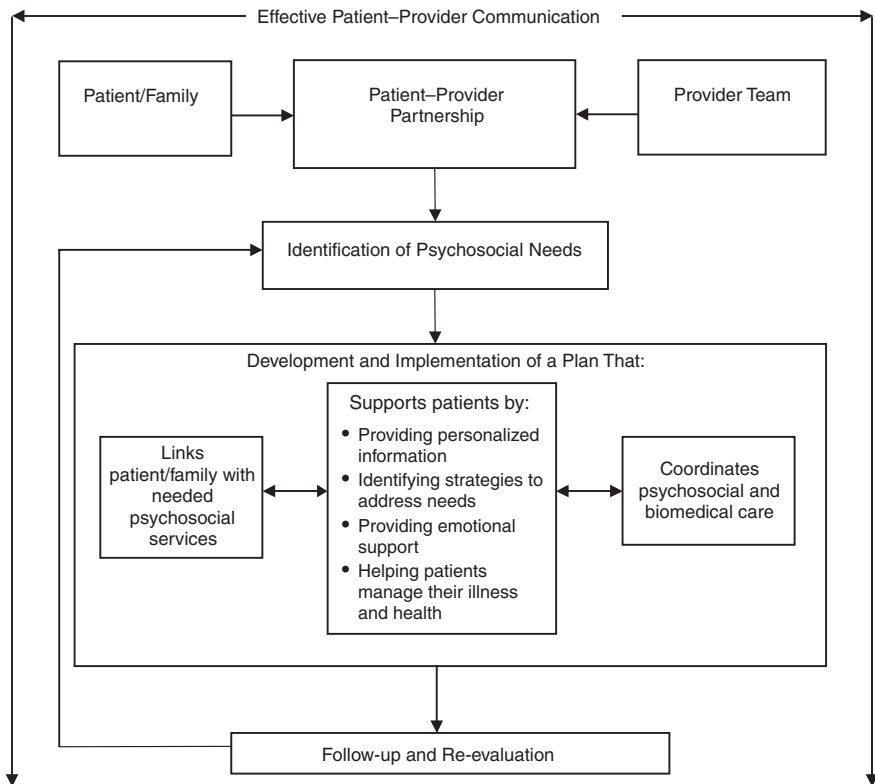


FIGURE S-1 Model for the delivery of psychosocial health services.

ing to their feasibility in settings with varying levels of resources. However, many patients do not have the benefit of these interventions, and more active steps are needed if this lack of access is to become the exception rather than the rule.

## CONCLUSIONS

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 committee 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.*

The committee defines psychosocial health services as follows:

*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.*

This definition encompasses both psychosocial *services* (i.e., activities or tangible goods directly received by and benefiting the patient or family) and psychosocial *interventions* (activities that enable the provision of the service, such as needs assessment, referral, or care coordination). Examples of psychosocial needs and services that can address those needs are listed in Table S-1. Psychosocial interventions necessary for their appropriate provision are portrayed in Figure S-1. The committee offers the following recommendations for making attention to psychosocial health needs an integral part of quality cancer care.

## RECOMMENDATIONS FOR ACTION

***Recommendation 1: The standard of care.*** All parties establishing or using standards for the quality of cancer care should adopt the following as a standard:

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

- facilitating effective communication between patients and care providers;<sup>4</sup>
- 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; and
- systematically following up on, reevaluating, and adjusting plans.

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<sup>4</sup>Although the language of this standard refers only to patients, the standard should be taken as referring to both patients and families when the patient is a child, has family members involved in providing care, or simply desires the involvement of family members.

**TABLE S-1** Psychosocial Needs and Formal<sup>a</sup> Services to Address Them

Psychosocial Need	Health Services
Information about illness, treatments, health, and services	<ul style="list-style-type: none"> <li>• Provision of information, e.g., on illness, treatments, effects on health, and psychosocial services, and help to patients/families in understanding and using the information</li> </ul>
Help in coping with emotions accompanying illness and treatment	<ul style="list-style-type: none"> <li>• Peer support programs</li> <li>• Counseling/psychotherapy to individuals or groups</li> <li>• Pharmacological management of mental symptoms</li> </ul>
Help in managing illness	<ul style="list-style-type: none"> <li>• Comprehensive illness self-management/self-care programs</li> </ul>
Assistance in changing behaviors to minimize impact of disease	<ul style="list-style-type: none"> <li>• Behavioral/health promotion interventions, such as:               <ul style="list-style-type: none"> <li>– provider assessment/monitoring of health behaviors (e.g., smoking, exercise)</li> <li>– brief physician counseling</li> <li>– patient education, e.g., in cancer-related health risks and risk reduction measures</li> </ul> </li> </ul>
Material and logistical resources, such as transportation	<ul style="list-style-type: none"> <li>• Provision of resources</li> </ul>
Help in managing disruptions in work, school, and family life	<ul style="list-style-type: none"> <li>• Family and caregiver education</li> <li>• Assistance with activities of daily living (ADLs), instrumental ADLs, chores</li> <li>• Legal protections and services, e.g., under Americans with Disabilities Act and Family and Medical Leave Act</li> <li>• Cognitive testing and educational assistance</li> </ul>
Financial advice and /or assistance	<ul style="list-style-type: none"> <li>• Financial planning/counseling, including management of day-to-day activities such as bill paying</li> <li>• Insurance (e.g., health, disability) counseling</li> <li>• Eligibility assessment/counseling for other benefits (e.g., Supplemental Security Income, Social Security Disability Income)</li> <li>• Supplemental financial grants</li> </ul>

<sup>a</sup>Family members and friends and other informal sources of support are key providers of psychosocial health services. This table includes only *formal* sources of psychosocial support—those that must be secured through the assistance of an organization or agency that in some way enables the provision of needed services (sometimes at no cost or through volunteers).

Key participants and leaders in cancer care have major roles to play in promoting and facilitating adherence to this standard of care. Their respective roles are described in the following nine recommendations.

***Recommendation 2: Health care providers.*** All cancer care providers should ensure that every cancer patient within their practice receives

care that meets the standard for psychosocial health care. The National Cancer Institute should help cancer care providers implement the standard of care by maintaining an up-to-date directory of psychosocial services available at no cost to individuals/families with cancer.

The committee believes that *all* providers can and should implement the above recommendation. Individual clinical practices vary by their patient population, their setting, and available resources in their clinical practice and community. Because of this, *how* individual health care practices implement the standard of care and the level at which it is done may vary. Nevertheless, as this report describes, the committee believes that it is possible for all providers to meet this standard in some way. This report identifies tools and techniques already in use by leading oncology providers to do so. There are many actions that can be taken *now* to identify and deliver needed psychosocial health services, even as the health care system works to improve their quantity and effectiveness. The committee believes that the inability to solve all psychosocial problems permanently should not preclude attempts to remedy as many as possible—a stance akin to oncologists' commitment to treating cancer even when the successful outcome of every treatment is not assured. Patient education and advocacy organizations can play a key role in bringing this about.

***Recommendation 3: Patient and family education.*** Patient education and advocacy organizations should educate patients with cancer and their family caregivers to expect, and request when necessary, cancer care that meets the standard for psychosocial care. These organizations should also continue their work on strengthening the patient side of the patient–provider partnership. The goals should be to enable patients to participate actively in their care by providing tools and training in how to obtain information, make decisions, solve problems, and communicate more effectively with their health care providers.

A large-scale demonstration of the implementation of the standard of care at various sites would provide useful information about how to achieve its implementation more efficiently; reveal approaches to implementation in both resource-rich and non-resource-rich environments; document approaches for successful implementation among vulnerable groups, such as those with low socioeconomic status, ethnic minorities, those with low health literacy, and the socially isolated; and identify different models for reimbursement. A demonstration could also be used to examine how various types of personnel can be used to perform specific interventions encompassed by the standard and how those personnel can best be trained.

*Recommendation 4: Support for dissemination and uptake.* The National Cancer Institute, the Centers for Medicare & Medicaid Services (CMS), and the Agency for Healthcare Research and Quality (AHRQ) should, individually or collectively, conduct a large-scale demonstration and evaluation of various approaches to the efficient provision of psychosocial health care in accordance with the standard of care. This program should demonstrate how the standard can be implemented in different settings, with different populations, and with varying personnel and organizational arrangements.

Because policies set by public and private purchasers, oversight bodies, and other health care leaders shape how health care is accessed, what services are delivered, and the manner in which they are delivered, group purchasers of health care coverage and health plans should take a number of actions to support the interventions necessary to deliver effective psychosocial health services. The National Cancer Institute, CMS, and AHRQ also should spearhead the development and use of performance measures to improve the delivery of these services.

*Recommendation 5: Support from payers.* Group purchasers of health care coverage and health plans should fully support the evidence-based interventions necessary to deliver effective psychosocial health services:

- Group purchasers should include provisions in their contracts and agreements with health plans that ensure coverage and reimbursement of mechanisms for identifying the psychosocial needs of cancer patients, linking patients with appropriate providers who can meet those needs, and coordinating psychosocial services with patients' biomedical care.
- Group purchasers should review cost-sharing provisions that affect mental health services and revise those that impede cancer patients' access to such services.
- Group purchasers and health plans should ensure that their coverage policies do not impede cancer patients' access to providers with expertise in the treatment of mental health conditions in individuals undergoing complex medical regimens such as those used to treat cancer. Health plans whose networks lack this expertise should reimburse for mental health services provided by out-of-network practitioners with this expertise who meet the plan's quality and other standards (at rates paid to similar providers within the plan's network).

- Group purchasers and health plans should include incentives for the effective delivery of psychosocial care in payment reform programs—such as pay-for-performance and pay-for-reporting initiatives—in which they participate.

With respect to the above recommendation, “group purchasers” include purchasers in the public sector (e.g., Medicare and Medicaid) as well as group purchasers in the private sector (e.g., employer purchasers). Mental health care providers “with expertise in the treatment of mental health conditions in individuals undergoing complex medical regimens such as those used to treat cancer” include mental health providers who possess this expertise through formal education (such as specialists in psychosomatic medicine), as well as mental health care providers who have gained expertise through their clinical experiences, such as mental health clinicians collocated with and part of an interdisciplinary oncology practice.

*Recommendation 6: Quality oversight.* The National Cancer Institute, CMS, and AHRQ should fund research focused on the development of performance measures for psychosocial cancer care. Organizations setting standards for cancer care (e.g., National Comprehensive Cancer Network, American Society of Clinical Oncology, American College of Surgeons’ Commission on Cancer, Oncology Nursing Society, American Psychosocial Oncology Society) and other standards-setting organizations (e.g., National Quality Forum, National Committee for Quality Assurance, URAC, Joint Commission) should

- Create oversight mechanisms that can be used to measure and report on the quality of ambulatory oncology care (including psychosocial health care).
- Incorporate requirements for identifying and responding to psychosocial health care needs into their protocols, policies, and standards.
- Develop and use performance measures for psychosocial health care in their quality oversight activities.

Ultimately, the delivery of cancer care that addresses psychosocial needs depends on having a health care workforce with the attitudes, knowledge, and skills needed to deliver such care. Thus, professional education and training should not be ignored as a factor influencing health practitioners’ practices. The committee further recommends

*Recommendation 7: Workforce competencies.*

- a. Educational accrediting organizations, licensing bodies, and professional societies should examine their standards and licensing and certification criteria with an eye to identifying competencies in delivering psychosocial health care and developing them as fully as possible in accordance with a model that integrates biomedical and psychosocial care.
- b. Congress and federal agencies should support and fund the establishment of a Workforce Development Collaborative on Psychosocial Care during Chronic Medical Illness. This cross-specialty, multidisciplinary group should comprise educators, consumer and family advocates, and providers of psychosocial and biomedical health services and be charged with
  - identifying, refining, and broadly disseminating to health care educators information about workforce competencies, models, and preservice curricula relevant to providing psychosocial services to persons with chronic medical illnesses and their families;
  - adapting curricula for continuing education of the existing workforce using efficient workplace-based learning approaches;
  - drafting and implementing a plan for developing the skills of faculty and other trainers in teaching psychosocial health care using evidence-based teaching strategies; and
  - strengthening the emphasis on psychosocial health care in educational accreditation standards and professional licensing and certification exams by recommending revisions to the relevant oversight organizations.
- c. Organizations providing research funding should support assessment of the implementation in education, training, and clinical practice of the workforce competencies necessary to provide psychosocial care and their impact on achieving the standard for such care set forth in recommendation 1.

In addition, improving the delivery of psychosocial health services requires targeted research. This research should aim to clarify the efficacy and effectiveness of new and existing services and to identify ways of improving the delivery of these services to various populations in different geographic locations and with varying levels of resources. Doing so would be facilitated by clarifying and standardizing the often unclear and inconsistent language used to refer to psychosocial services.

*Recommendation 8: Standardized nomenclature.* To facilitate research on and quality measurement of psychosocial interventions, the

National Institutes of Health (NIH) and AHRQ should create and lead an initiative to develop a standardized, transdisciplinary taxonomy and nomenclature for psychosocial health services. This initiative should aim to incorporate this taxonomy and nomenclature into such databases as the National Library of Medicine's Medical Subject Headings (MeSH), PsycINFO, CINAHL (Cumulative Index to Nursing and Allied Health Literature), and EMBASE.

*Recommendation 9: Research priorities.* Organizations sponsoring research in oncology care should include the following areas among their funding priorities:

- Further development of reliable, valid, and efficient tools and strategies for use by clinical practices to ensure that all patients with cancer receive care that meets the standard of psychosocial care set forth in recommendation 1. These tools and strategies should include
  - approaches for improving patient–provider communication and providing decision support to cancer patients;
  - screening instruments that can be used to identify individuals with any of a comprehensive array of psychosocial health problems;
  - needs assessment instruments to assist in planning psychosocial services;
  - illness and wellness management interventions; and
  - approaches for effectively linking patients with services and coordinating care.
- Identification of more effective psychosocial services to treat mental health problems and to assist patients in adopting and maintaining healthy behaviors, such as smoking cessation, exercise, and dietary change. This effort should include
  - identifying populations for whom specific psychosocial services are most effective, and psychosocial services most effective for specific populations; and
  - development of standard outcome measures for assessing the effectiveness of these services.
- Creation and testing of reimbursement arrangements that will promote psychosocial care and reward its best performance.

Research on the use of these tools, strategies, and services should also focus on how best to ensure delivery of appropriate psychosocial services to vulnerable populations, such as those with low literacy, older adults, the socially isolated, and members of cultural minorities.



Finally, the scope of work for this study included making recommendations for how to evaluate the impact of this report. The committee believes evaluation activities would be useful in promoting action on the preceding recommendations, and makes the following recommendation to that end.

***Recommendation 10. Promoting uptake and monitoring progress.*** The National Cancer Institute/NIH should monitor progress toward improved delivery of psychosocial services in cancer care and report its findings on at least a biannual basis to oncology providers, consumer organizations, group purchasers and health plans, quality oversight organizations, and other stakeholders. These findings could be used to inform an evaluation of the impact of this report and each of its recommendations. Monitoring activities should make maximal use of existing data collection tools and activities.

Following are examples of the approaches that could be used for these monitoring efforts.

To determine the extent to which patients with cancer receive psychosocial services consistent with the standard of care and its implementation as set forth in recommendations 1 and 2, the Department of Health and Human Services (DHHS) could

- Conduct an annual, patient-level, process-of-care evaluation using a national sample and validated, reliable instruments, such as the Consumer Assessment of Healthcare Providers and Systems (CAHPS) instruments.
- Add measures of the quality of psychosocial health care for patients (and families as feasible) to existing surveys, such as the Centers for Disease Control and Prevention's Behavioral Risk Factor Surveillance System (BRFSS) and CAHPS.
- Conduct annual practice surveys to determine compliance with the standard of care.
- Monitor and document the emergence of performance reward initiatives (e.g., content on psychosocial care in requests for proposals [RFPs] and pay-for-performance initiatives that specifically include incentives for psychosocial care).

For recommendation 3 on patient and family education, DHHS could

- Routinely query patient education and advocacy organizations about their efforts to educate patients with cancer and their family caregivers about what to expect from, and how to request when

necessary, oncology care that meets the standard of care set forth in recommendation 1.

- In surveys conducted to assess the extent to which oncology care meets the standard of care, include questions to patients and care-givers about their knowledge of how oncology providers should address their psychosocial needs (the standard of care) and their actual experiences with receiving such care.
- Use an annual patient-level process-of-care evaluation (such as CAHPS) to identify patient education experiences.

For recommendation 4 on dissemination and uptake of the standard of care, DHHS could report on the extent to which the National Cancer Institute/CMS/AHRQ had conducted demonstration projects and how they had disseminated the findings from those demonstrations.

For recommendation 5 on support from payers, DHHS/NCI and/or advocacy, provider, or other interest groups could

- Survey national organizations (e.g., America's Health Insurance Plans, the National Business Group on Health) about their awareness of and/or advocacy activities related to the recommendations in this report and the initiation of appropriate reimbursement strategies/activities.
- Monitor and document the emergence of performance reward initiatives (e.g., RFP content on psychosocial care, pay for performance that specifically includes incentives for psychosocial care).
- Evaluate health plan contracts and state insurance policies for coverage, copayments, and carve-outs for psychosocial services.
- Assess coverage for psychosocial services for Medicare beneficiaries.

For recommendation 6 on quality oversight, DHHS could

- Examine the funding portfolios of NIH, CMS, AHRQ, and other public and private sponsors of quality-of-care research to evaluate the funding of quality measurement for psychosocial health care as part of cancer care.
- Query organizations that set standards for cancer care (e.g., the National Comprehensive Cancer Network, the American Society of Clinical Oncology [ASCO], the American College of Surgeons Commission on Cancer, the Oncology Nursing Society, the American Psychosocial Oncology Society) and other standards-setting organizations (e.g., the National Quality Forum, the National

Committee for Quality Assurance, the URAC, the Joint Commission) to determine the extent to which they have

- created oversight mechanisms used to measure and report on the quality of ambulatory cancer care (including psychosocial care);
- incorporated requirements for identifying and responding to psychosocial health care needs into their protocols, policies, and standards in accordance with the standard of care put forth in this report; and
- used performance measures of psychosocial health care in their quality oversight activities.

For recommendation 7 on workforce competencies, DHHS could

- Monitor and report on actions taken by Congress and federal agencies to support and fund the establishment of a Workforce Development Collaborative on Psychosocial Care during Chronic Medical Illness.
- Review board exams for oncologists and primary care providers to identify questions relevant to psychosocial care.
- Review accreditation standards for educational programs used to train health care personnel to identify content requirements relevant to psychosocial care.
- Review certification requirements for clinicians to identify those requirements relevant to psychosocial care.
- Examine the funding portfolios of the NIH, CMS, AHRQ, and other public and private sponsors of quality-of-care research to quantify the funding of initiatives aimed at assessing the incorporation of workforce competencies in education, training, and clinical practice and their impact on achieving the standard for psychosocial care.

For recommendation 8 on standardized nomenclature and recommendation 9 on research priorities, DHHS could

- Report on NIH/AHRQ actions to develop a taxonomy and nomenclature for psychosocial health services.
- Examine the funding portfolios of public and private research sponsors to assess whether funding priorities included the recommended areas.

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# CANCER CARE FOR THE WHOLE PATIENT

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## MEETING PSYCHOSOCIAL HEALTH NEEDS

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Committee on Psychosocial Services to  
Cancer Patients/Families in a Community Setting  
Board on Health Care Services

Nancy E. Adler and Ann E. K. Page, *Editors*

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The serpent has been a symbol of long life, healing, and knowledge among almost all cultures and religions since the beginning of recorded history. The serpent adopted as a logotype by the Institute of Medicine is a relief carving from ancient Greece, now held by the Staatliche Museen in Berlin.

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*“Knowing is not enough; we must apply.  
Willing is not enough; we must do.”*  
—Goethe



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## Reviewers

This report has been reviewed in draft form by individuals chosen for their diverse perspectives and technical expertise, in accordance with procedures approved by the NRC's Report Review Committee. The purpose of this independent review is to provide candid and critical comments that will assist the institution in making its published report as sound as possible and to ensure that the report meets institutional standards for objectivity, evidence, and responsiveness to the study charge. The review comments and draft manuscript remain confidential to protect the integrity of the deliberative process. We wish to thank the following individuals for their review of this report:

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Although the reviewers listed above have provided many constructive comments and suggestions, they were not asked to endorse the conclusions or recommendations nor did they see the final draft of the report before its release. The review of this report was overseen by **JOHANNA T. DWYER**, Friedman School of Nutrition Science and Policy, Tufts University School of Medicine and Frances Stern Nutrition Center, Tufts-New England Medical Center and **RICHARD G. FRANK**, Department of Health Care Policy, Harvard Medical School. Appointed by the National Research Council and Institute of Medicine, they were responsible for making certain that an independent examination of this report was carried out in accordance with institutional procedures and that all review comments were carefully considered. Responsibility for the final content of this report rests entirely with the authoring committee and the institution.

## Foreword

*Cancer Care for the Whole Patient: Meeting Psychosocial Health Needs* is an important new addition to a series of Institute of Medicine reports that prescribe actions needed to improve the quality of U.S. health care. Following in the footsteps of *Crossing the Quality Chasm: A New Health System for the 21st Century*, *Improving the Quality of Health Care for Mental and Substance Use Conditions*, and other reports in the Quality Chasm series, this report takes another step forward and attends to the psychological/behavioral and social problems that can accompany serious illness. Although the report examines psychosocial health needs from the perspective of individuals with a diagnosis of cancer, the recommendations in this report are also relevant to clinicians, other health care providers, payors, and quality oversight organizations concerned with the care of individuals with other serious and complex medical conditions.

Research has amply demonstrated the significance of psychosocial factors to health and health care. Incorporating evidence from studies of psychological and social determinants of health, clinical research on the effectiveness of psychological and behavioral services, health services research on the effective organization and delivery of health care, and biologic research in fields such as psychoneuroimmunology, this report documents the consequences of failing to meet psychosocial health needs. Importantly, it translates scientific research findings into practical applications for improving the quality of cancer care.

The result is a new standard of care for cancer care, a standard that incorporates acknowledgement, treatment, and management of psychosocial



problems. While this report deals specifically with cancer patients, the lesson to improve the quality of care by focusing on the psychosocial needs of the whole patient will apply as well to many other conditions.

Harvey V. Fineberg, MD, PhD  
*President, Institute of Medicine*

## Preface

Americans place a high premium on new technologies to solve our health care needs. However, technology alone is not enough. Health is determined not just by biological processes but by people's emotions, behaviors, and social relationships. Sadly, these factors are often ignored or not defined as part of health care. Many doubt their importance and dismiss the evidence as being based on "soft science." Even when acknowledged, they are often seen as ancillary rather than central to care. High and escalating health care costs fuel the argument that addressing such concerns is a luxury rather than a necessity. These views fly in the face of evidence of the important role that psychosocial factors play in disease onset and progression, not to mention their impact on people's ability to function and maintain a positive quality of life. As this report documents, a growing body of scientific evidence demonstrates that psychological and social problems can prevent individuals from receiving needed health care, complying with treatment plans, and managing their illness and recovery. Another recent Institute of Medicine report<sup>1</sup> states that the purpose of health care is to "continuously reduce the impact and burden of illness, injury, and disability, and . . . improve . . . health and functioning." To accomplish this, good quality health care must attend to patients' psychosocial problems and provide services to enable them to better manage their illnesses and underlying health. To ignore these factors while pouring billions of dollars into new

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<sup>1</sup>IOM. 2006. *Performance measurement: Accelerating improvement*. Washington, DC: The National Academies Press.

technologies is like spending all one's money on the latest model car and then not having the money left to buy the gas needed to make it run.

This report examines psychosocial health services from the perspective of the more than ten and a half million individuals in the United States who live with a current or past diagnosis of cancer, and who reside in 1 of every 10 U.S. households. Not only are these patients affected by their illness, but so, too, are their families. Fortunately, new advances in treatment are transforming the nature of cancer as a disease. Increasingly individuals are prevailing against acute, life-threatening diagnoses and physically demanding (and sometimes themselves life-threatening) surgical, radiation, and drug treatments. They are joining a growing segment of the U.S. population—those with chronic illnesses. This has important implications for the organization and delivery of services and for health care costs. Although the recommendations in this report address the delivery of psychosocial health services to individuals diagnosed with cancer, the committee believes the model for care delivery developed for the report and the accompanying recommendations are applicable to the health care of all with chronic illnesses. Indeed, much of the evidence of the effectiveness of individual psychosocial health services and models of care reviewed by the committee comes from services and interventions designed for individuals with other types of chronic illnesses.

The committee found evidence that was both cautionary and encouraging. Both patients and providers tell us that attention to psychosocial health needs is the exception rather than the rule in oncology practice today. We noted with dismay the many recommendations over the years calling for more attention to psychosocial concerns on which there has been no action. However, there are forces at play currently that could facilitate change as a result of this report. First, the patient care tools, approaches, and resources needed to deliver effective services for those in need are already *sufficiently* (though not *ideally*) developed. Today, every individual treated for cancer can (and should) expect to have their psychological and social needs addressed alongside their physical needs. Second, this report provides an ingredient essential to all successful change initiatives—a shared vision toward which all involved parties can direct and coordinate their efforts. This report puts forth such a vision in a standard of care articulating how psychosocial health services should be routinely incorporated into oncology care. This multidisciplinary standard can provide a common framework around which clinicians, health care organizations, patients and their advocates, payers, quality oversight organizations, and all concerned about the quality of cancer care can organize and coordinate their efforts and achieve synergy.

Finally, successful change initiatives also are characterized by their strong leadership. The United States is fortunate to have strong individual

and organizational leaders who have done much to advance the quality of cancer care. This leadership is a powerful resource for change, and can do much to make the delivery of psychosocial health services a routine part of cancer care. To engage these parties in advancing the standard of care for psychosocial health services, the committee has put forth a small number of recommendations (10 in all), each targeted to key leadership—clinical leaders, advocacy organizations, health plans and purchasers, quality oversight organizations, and sponsors of research. The committee hopes that all of these leaders will join in making this new standard of care the norm—and better the health care and health of our brothers, sisters, parents, children, and ourselves—for the more than 40 percent of all Americans who will receive a diagnosis of cancer in their lifetime.

Nancy E. Adler  
*Chair*



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