

Caring for the whole patient: the Institute of Medicine proposes a new standard of care

By Patrick Young

On October 23, 2007, the Institute of Medicine (IoM) issued a report entitled "Cancer Care for the Whole Patient: Meeting Psychosocial Health Needs." The report, available online at www.iom.edu, proposes a new standard of care under which "all oncology care providers would systematically screen patients for distress and other problems; connect patients with health care or service providers who have resources to tackle these issues and coordinate care with these professionals; and periodically re-evaluate patients to determine if any changes in care are needed." To that end, the IoM recommends an evidence-based model that would ensure psychosocial health services are integrated into cancer care and provides specific steps to implement this model, across settings where resources may vary.

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*
- *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.*

Recommendation 1

Cancer Care for the Whole Patient: Meeting Psychosocial Health Needs A report of the Institute of Medicine

Ready or not, community oncology practices must confront the challenge of meeting a new psychosocial standard for patient care, one advanced by a committee of the prestigious Institute of Medicine (IoM), a part of the National Academy of Sciences. For some practices, meeting the proposed standard will mean added costs and time burdens. But not meeting the standard could become an issue, as patients and family members expect and demand psychosocial care as part of cancer treatment.

The 339-page IoM report is meant as a practical guide, particularly for community oncologists, on how to assess the psychosocial problems of cancer patients, connect them with the assistance they need, and follow up on resolving these psychosocial needs. It neither mandates nor recommends a single way to meet the standard of psychosocial care,

but provides information on different approaches so a practice can design a program that works best for it. The report also stresses the importance of doing so.

"Initially, a diagnosis of cancer causes a multitude of changes in peoples' health and in their social and psychological circumstances," said Lee S. Schwartzberg, MD, president and chief medical officer of the West Clinic in Memphis, and the sole community oncologist on the IoM panel. "It's important for everyone who deals with cancer patients to recognize that and for cancer practitioners to address. If we don't address the psychosocial aspects of cancer care at the same time we are addressing the biomedical aspects, then we are not doing an adequate job."

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The referral gap

At a meeting of committee members and stakeholders intended to outline the report and its implications, Robert T. Croyle, PhD, director of the National Cancer Institute's Division of Cancer Control and Population Sciences, emphasized the "referral gap" between the psychosocial problems of cancer patients and existing services to help them. "There has been a proliferation of nonprofit organizations and free services," he said, "but facilitating the appropriate use of these services has been a challenge. We need to increase consumer demand for these services so patients at least know to ask about what is available to them."

Several committee members and a number of patient advocates hope to create that demand by publicizing the report and educating cancer patients about their "right" to psychosocial care. "The report raises the bar for what the expectations are in terms of meeting patients' non-medical needs," said committee member Diane Blum, MSW, executive director of *CancerCare*, a nonprofit organization that aids more than 90,000 cancer patients annually.

However, the new standard could conceivably introduce an additional basis for malpractice lawsuits—"failure to effectively treat." A brief description of the report for cancer patients that the IoM posted on its Web site states: "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." Dr. Schwartzberg said the committee never meant to introduce a new malpractice issue. "That was certainly not the intent," he said. "I don't think the report itself makes any kind of statement to that effect."

The evidence-based IoM report spans the needs of cancer patients from better communications with

care providers to psychotherapy, financial aid, and assistance with problems that interfere with patients getting to treatment. For example, it lists these findings compiled from an extensive literature review:

- Although the prevalence of psychological distress varies by cancer type, time since diagnosis, impairment, and pain, 29%–43% of adult patients with the 14 most common cancers suffer significant psychological problems, including depression, anxiety, and posttraumatic stress disorder.
- Of adults with cancer, 11% report one or more limitations in performing daily activities, including bathing and eating, and 58% report other functional disabilities, such as the inability to walk a quarter-mile or sit for 2 hours.
- Among uninsured cancer survivors, more than 25% delay or decide against treatment because of cost.

Affecting survival

Psychotherapy by itself does not increase cancer survival, says noted panel member Jimmie Holland, MD, chair of psychiatric oncology at Memorial Sloan-Kettering Cancer Center. "But if you are improving treatment behavior, then you are affecting survival."

However, psychological stresses may more directly affect a patient's outcome. "Physical and emotional stressors cause our brains to generate neuroendocrine hormones that cascade to our organs and can actually accelerate the growth of cancers and affect the quality of our lives," said David B. Abrams, PhD, director of the National Institutes of Health's Office of Behavioral and Social Sciences Research. "The brain directly influences biology and gene expression, as well as the psychosocial needs of the patients."

To improve psychosocial care, the report said oncologists must screen patients for problems and improve their communications with patients.

"We know there is not adequate screening for distress," said Nancy E. Adler, PhD, chair of the IoM report committee. "For example, 33% of American Society of Clinical Oncology members report there was no screening for distress in their practices, and only 3 out of 18 members of the National Comprehensive Cancer Network (NCCN) routinely screened all patients for distress."

Moreover, according to Dr. Adler, who is a professor of medical psychology and vice chair of the psychiatry department at the University of California San Francisco, oncologists and their staffs often fail to adequately communicate with patients about their psychosocial problems. When asked, 28% of patients say their physicians do not pay attention to anything but their medical needs. "We need to focus on the critical issue of provider communications," Dr. Schwartzberg said. "We can only know about psychosocial needs if providers ask. And that goes beyond screening questions to a dialogue with patients."

Intervening effectively

In its review, the panel found five key elements that characterized programs at oncology practices with the most effective psychosocial intervention results. These practices

- identified patients with psychosocial needs likely to affect their health or healthcare and developed an appropriate plan to help them;
- linked patients to appropriate services;
- supported patients in managing their illness;
- coordinated psychosocial and biomedical health care;
- followed up on care delivery to monitor its effectiveness and determine whether any changes were needed.

"We recognize that clinical practice varies by setting, patient population, as well as by the resources available,"

said panel member Ruth McCorkle, RN, PhD, professor of nursing and director of the Center for Excellence in Chronic Illness Care at Yale Uni-

versity. “Nonetheless, the committee believes it’s possible for all providers to meet this standard in some way.”

The report provides some impor-

tant guidance for practices. For example, included are lists of regional and national groups that support psychosocial care and sample letters that

Jimmie Holland, MD

A pioneer in psycho-oncology reflects on the IoM report

PSYCHIATRIST JIMMIE HOLLAND, MD, considered the founder of psycho-oncology, has spent 3 decades at Memorial Sloan-Kettering Cancer Center in New York City investigating the psychological needs of cancer patients and urging oncologists to make psychological care an integral piece of cancer therapy. She brought a deep historical perspective to the Institute of Medicine panel. *Community Oncology* spoke with her shortly after the release of “Cancer Care for the Whole Patient.”

Is this report a turning point?

I would like to see it as such. The message is there: Psychosocial issues have to be a part of routine care, not just in cancer but in any chronic disease. When not cured of cancer, you don’t necessarily die; you are treated intermittently or continuously. That’s the big change in cancer. Increasingly, it’s becoming a chronic illness.

Why did the National Institutes of Health and the National Cancer Institute request this study at this time?

Various reports kept alluding to the fact that these needs weren’t met, but there was nothing much beyond those observations. The National Coalition for Cancer Survivorship and a few people who really felt strongly about psychosocial care got \$1 million put in an appropriation bill for the study.

How will the psychosocial care standard win acceptance?

I’m hopeful we can work on it from two sides. One, we can get all the patient advocacy groups to tell their constituents “It is your right to say to your doctor, ‘You aren’t dealing with my psychosocial problems as part of my medical care.’” Two, we can use this evidence-based report to get some performance measures. With standards and performance measures, we can get the regulatory bodies behind it. That’s what happened with pain.

What evidence shows psychosocial support benefits patients?

We looked at the range of psychological interventions, peer groups and professional groups, and the few psychopharmaceutical studies we have. All of them show they make a difference in outcome in terms of diminishing distress, making quality of life better, and affecting adherence to treatment.

When are cancer patients most likely to develop depression or anxiety?

These symptoms can occur at any time. Anxiety is high before treatment begins. Once people start treatment, they do pretty well. But there are transitions—to diagnosis, to treatment, from curative to palliative treatment, to hospice or end-of-life care—when the patient may need to readapt to what is happening. That is accompanied by a lot of distress.

Are there psychosocial care guidelines specific to community

oncologists?

The guidelines written by the National Comprehensive Cancer Network are perfectly applicable to any practice, community or otherwise.

You have previously said that oncology needs an educational campaign to inform patients that psychological care is part of their total cancer treatment. Where does that campaign stand now?

Organizations that offer education and support to different types of cancer patients and the National Coalition of Cancer Survivors are our best sources of getting this information to patients so they can put pressure on the doctors. We would not have the two-phase treatment for breast cancer had it not been for women who said about 30 years ago, “I do not wish to be taken into the operating room without knowing whether or not I have breast cancer.” What patients want is for somebody to care about them as people. That’s what everybody misses in today’s medicine.

What do you see as the future of psychosocial care?

We will never move psychosocial care forward until it is regarded as part of routine cancer care, until the treating team accepts that it hasn’t done its duty if it hasn’t asked about distress. In Canada, they’ve made pain the fifth vital sign, and they’ve made distress the sixth vital sign. That needs to be the standard practice.

physicians can use in communicating with patients. It also lists four basic approaches by which oncologists can meet the standard for the psychosocial care of patients:

- Locate and integrate psychosocial services within the practice;
- Link patients to local resources that deal with their specific problem(s);
- Use remote providers at the regional or national level;
- Combine elements of the first three approaches.

In its report, the committee also cited examples of practices that currently meet the standard, and offered guidance on how practices can make use of local and remote resource providers. “We are not recommending that every community oncologist set up a psychosocial support system in the office,” Ms. Blum said. However, whatever arrangement a practice chooses, it must screen patients for psychosocial distress and link patients with problems to a group that can help them. A number of such screening tests exist, including the Distress Thermometer,

which Dr. Holland developed and which the NCCN incorporated into its psychosocial guides for hospital-based oncology programs.

“We understand that oncologists and other cancer care providers are very busy and that their focus has to be on the biomedical aspects,” said Dr. Schwartzberg. “But one of the most important points of the report is that services are out there. What we do need is a better linkage to these services, some of which are available in every practitioner’s community.”

Reimbursement questions

Reimbursement remains the unknown. Third-party payers cover many of the psychological services needed by cancer patients, but the committee acknowledged that meeting the new standard will require some changes in reimbursement by Medicare and private insurers. Susan Pisano, vice president of communications for America’s Health Insurance Plans, said the trade group will analyze the IoM report and provide its

findings to member companies. Panel member Sherry Glied, professor and chair of health policy and management at Columbia University’s Mailman School of Public Health, noted that the report does identify a number of ways that payers can support the provision of psychosocial services, including explicitly addressing these services in their agreements with providers and incorporating psychosocial services into their pay-for-performance initiatives.

“We’re not going to get a major turnaround tomorrow,” said Ms. Blum, “but we want to overcome the obstacles that interfere with people getting their best opportunity for cure. The point we are trying to make very strongly is that for cancer, more than any other illness, there is a whole host of support services and educational material available for patients.”

To read “Cancer Care for the Whole Patient: Meeting Psychosocial Health Needs,” go to www.iom.edu and click on “Reports.”

Washington Update continued from page 746

On November 8, 2007, the FDA introduced labeling changes that clearly validate the importance of physician judgment in using ESAs. Although warning about using ESAs in cases where hemoglobin levels are 12 g/dL or higher, the revised FDA-approved labeling allows the use of ESAs at hemoglobin levels of 10 g/dL or higher—not to exceed the upper safety limit of 12 g/dL. This contrasts with the NCD, where CMS has established a treatment ceiling of less than 10 g/dL.

The labeling changes prompted the major cancer organizations, as well as the manufacturers Amgen and Ortho Biotech, to submit another round of formal reconsideration requests to CMS. According to Dr. Patrick Cobb, Chairman of the Clinical Practices

Committee of the Community Oncology Alliance, “What prompted us to ask CMS to reconsider its decision to restrict ESA use was the release on November 8, 2007, of revised FDA-approved labeling for ESAs. Unfortunately, what FDA considers safe and effective ESA use, CMS does not. As a result, our Medicare patients are not receiving the same standard of care as our younger patients.”

In the majority of reconsideration letters to the FDA, similar arguments were advanced to CMS: the NCD is not supported by scientific evidence and expert guidelines, conflicts with newly revised FDA-approved labeling, hinders physician clinical judgment to individualize treatment, and disadvantages seniors covered by Medicare. Additionally, new scien-

tific evidence was submitted demonstrating the safety and effectiveness of using ESAs to minimize the need for transfusions in cancer patients undergoing chemotherapy.

The arguments advanced in these formal reconsideration requests to CMS, supported by revised product labeling, have given the cancer community powerful arguments in enlisting the support of Congress to stop the ESA NCD. Indications are that Congress may look to move on this issue by the end of 2007, or early 2008, depending on the legislative agenda and the resolve of the cancer community in reaching out to its members of Congress.

Mr. Okon is Executive Director of the Community Oncology Alliance, based in Washington, DC.