

Institute of Medicine (IOM) Workshop

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In this issue of *The Oncologist* is an important article summarizing the key findings of an Institute of Medicine (IOM) workshop entitled “Patient-Centered Cancer Treatment Planning,” conducted on February 28 and March 1, 2011 in Washington, DC [1]. The workshop had its origins in discussions by the IOM’s National Cancer Policy Forum and was cosponsored by the IOM and the National Coalition for Cancer Survivorship. The workshop was convened to raise the awareness of health care providers of the importance of developing accurate, well-conceived, and easily understood treatment plans for their cancer patients. Further, this “treatment-plan” document should address not only the medical strategy but also the social and cultural needs of the patient and their family, thus involving everyone in a complete understanding of the planned course of treatment.

Having been actively involved in both delivering cancer care and also as the family member responsible for a cancer patient, the points raised and suggestions made by the participants in this workshop certainly resonated with my personal experiences. As physicians responsible for cancer care, we know that, in many areas of patient and family support, we often fall short of the mark. Cancer, we would all agree, is an extremely complex disease, and its treatment and management are complicated. None of us would ever question the need to spend whatever time is required to be sure our patients and their caregivers are totally informed regarding the patient’s diagnosis and the path of planned treatment. We want not only their acceptance of the plan but, as much as possible, their understanding of how this plan of care might change. The patient also needs to know what to expect in terms of treatment side effects and what to expect if the cancer progresses. All the time, the patient care team must strive to have these conversations in language that is understood and, as much as possible, does not take away the most important element of cancer treatment—reasonable hope of success.

All of this is, of course, the “ideal world” for which all phy-

sicians strive each and every day. What I could not get out of my mind as I studied the thoughtful recommendations of the IOM workshop was the gnawing question of “yes, of course” but how, in today’s health care market place with its increasing downward pressure on revenues, can we ever expect to be able to afford the added professional time and the additional staff required to achieve this goal? From whom or where will the revenues for such patient-centered support come? The discussants at this important IOM workshop certainly also recognized the challenges of creating the ideal cancer care model (see **The Challenges of Implementation**). Certainly, “cancer patients need a clinical home” and “patient navigation” and “multispecialty care,” but in today’s world they need much more.

The current demands of maintaining an oncology practice, although not specifically a part of this workshop dialogue, are well known to all cancer specialists as well as our colleagues delivering primary care. Everywhere, physicians today are faced with the anxieties of a decreasing revenue stream combined with increasing federal regulation, gatekeeping restrictions on planned care, Medicare-driven physician fee schedules, increasing exposure to government audit, and the added stress of documentation required in “pay for performance” metrics. In our very uncertain economic future, physicians are forced to take on new roles and responsibilities, advocating on behalf of patients who are increasingly overwhelmed dealing with payors as well as their disease.

Patients and their families are equally challenged in today’s economy. Many delay or do not participate in screening. An increasing number of patients cannot meet their copay obligations, particularly now that many anticancer drugs are oral and insurance plans have adopted a 25% copay for these “specialty medications.” Increasingly, patients, if not delinquent, are slow in paying out of pocket for physician services. This constant financial pressure on our cancer patients, especially those on fixed incomes, has a number of negative conse-

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quences. Some of our patients avoid reporting side effects associated with therapy or delay filling prescriptions, especially those provided for symptom management. One might say that, in many ways, providing a detailed “patient-centered cancer treatment plan” for each patient seems almost secondary in the context of the current health care state of affairs and the economic storm clouds on the horizon of cancer care.

Educating our patients and the people who provide their support starts with the diagnosis but is a continuous, evolving process—a process that is as different in its needs as the patient is unique. In my personal experience, it is not a situation that lends itself to a carefully worded specific plan that most likely runs the risk of producing unnecessary anxiety and almost certainly will need to be fairly vague in its projections of care. Patient-centered cancer treatment planning is not about one meeting or the development of one plan—written or oral. The complexity of treating cancer requires multispecialty care wherein decisions and alterations/adjustments can occur weekly, monthly, sometimes daily. The cancer patient today requires a team of specially trained coworkers available to help the patient navigate insurance bills and manage lost income, social workers skilled to counsel the patient and family, and a space away from hospital and clinics, allowing a respite from the constant reminder of the cancer they are dealing with.

The laudable goals of the workshop thus face at least three challenges: (a) the increasing economic pressures on our patients add to the office service requirements to deal with financial issues, (b) the complexity and the need for continuous patient social services support require a different and more extensive solution and staffing than a simple “plan,” and (c) the oncology practice will have to find the revenues to support providing these services within their practice business model. Let me propose that, if we are to be successful in achieving the important navigational, patient-centered care, family education, and counseling that our cancer patients increasingly require, we will need to move to a new model.

The Inova Health System’s Life With Cancer center addresses these needs in a unique way. The Life With Cancer center fills a multifaceted need going beyond the patient-

centric care plan. It provides a comprehensive set of financial, social, educational, and navigation services in a peaceful, restful separate care setting, connected virtually to oncology private practices and to the hospital in-patient facilities. The head of the center reports to the cancer center program and cancer system-wide service line in terms of program oversight and operations. The Center addresses the needs of the patient, family, and cancer survivor. Often patients are worried more about their spouse and children than about themselves. To financially support the many professionals who staff the center (<http://www.lifewithcancer.org>) requires a dedicated group of volunteers and a committed hospital partner. Our center serves an average of 3,200 patients and their families annually. The volunteers at the center—a beautiful dedicated facility—have raised >\$1.5 million each year, or about 75% of the annual budget. The cancer problem has a long-standing history of attracting well-organized, compassionate advocates who are dedicated to building programs and raising funds to support cancer patients and their families. The Life With Cancer center shows what the community can do to fill this gap for our patients.

We in cancer medicine know the challenges that lie ahead; we understand all too well that there will be fewer dollars to support patient care, increasing complexity to optimal care, more patients with cancer as the population ages, fewer physicians to provide the care, and more expensive and scarce drugs. If we accept that the means to support the intense level of ancillary services will not be forthcoming from the usual health care resources, we will need help from outside. The issues will not be solved by government funds or programs, by increased medical school training, by online computer programs, or as a part of physician licensure, but they will need multifaceted support services that evolve in partnership with oncology practices. No one recognizes the needs of our patients and families more than those who have lived the experience. Engaging our survivors, dedicated volunteers, and philanthropy provide the opportunity to raise the resources necessary to meet the challenges faced by each cancer patient.

REFERENCE

1. Balogh EP, Ganz PA, Murphy SB et al. Patient-centered cancer treatment planning: Improving the quality of oncology care. Summary of an Institute of Medicine workshop. *The Oncologist* 2011; 16:1800–1805.

See the accompanying meeting report on pages 1800–1805 of this issue.