



### Kim Thiboldeaux

Kim Thiboldeaux is President and CEO of the Cancer Support Community (CSC) ([www.cancersupportcommunity.org](http://www.cancersupportcommunity.org)), which works to support patients and families in 3 key areas. First, CSC provides direct patient and family support through face-to-face, online, and telephonic support services delivered by licensed mental health professionals. Second, CSC backs its service delivery arm with research generated by the Research and Training Institute, whose staff conducts cutting-edge psychosocial and behavioral research about the cancer patient experience. Finally, the Cancer Policy Institute at CSC unites the experience of research and direct services to educate policymakers on the core tenets of 1) access to comprehensive care for all patients, 2) quality as a central theme, and 3) research as a critical priority.

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## Caring for the Whole Patient

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We are currently witnessing an important shift in cancer care in America from a model of traditional physician and institutionally driven care toward an emerging paradigm of patient-centered care and a framework of caring for the needs of the “whole patient.” But where are we in this shift? What concrete progress have we truly made toward this new paradigm, and what remains to be done to realize and incorporate true patient-centered care?

### Background

The Institute of Medicine (IOM) released a number of reports over the past several years that address various aspects of comprehensive and integrated cancer care, including *From Cancer Patient to Cancer Survivor: Lost in Transition*<sup>1</sup> in 2005; the 2008 report, *Cancer Care for the Whole Patient: Meeting Psychosocial Health Needs*,<sup>2</sup> and the most recent report, *Delivering High-Quality Cancer Care: Charting a New Course for a System in Crisis*<sup>3</sup> in 2013. These reports consistently involve patient-centered themes and recommendations, which include advocating for approaches such as distress screening, palliative care, survivor care planning, and enhanced patient–physician communication.

The reports also address the need to better integrate and align the medical establishment with community resources to provide a comprehensive model of care for patients. For example, the 2013 report on delivering high-quality cancer care states, “The committee recommends that HHS [Department of Health and Human Services] develop a national strategy that leverages existing community interventions to provide accessible and affordable cancer care. To accomplish this, HHS should support the development of innovative programs, identify and disseminate effective community interventions, and provide ongoing support to successful community interventions.”<sup>3</sup>

These reports set out clear recommendations, but our progress in meeting them is less clear. Where have we seen measurable progress toward these and other recommendations in caring for the whole patient? Where must we continue to invest?

Arguably, one of the most significant steps forward in caring for the whole patient in cancer was the bold action by the American College of Surgeons Commission on Cancer in 2011 to adopt a series of patient-centered standards that go into effect in 2015 and will apply to the nearly 1500 cancer programs the Commission accredits. The standards include the integration of routine distress screening for patients with cancer, the incorporation of patient navigation services, and the use of survivor care plans for those completing treatment.

We have also seen the advancement of patient support and psychosocial services by ASCO through its Quality Oncology Practice Initiative (QOPI), and the Community Oncology Alliance through its medical home model. We have seen more hospitals and community oncology practices integrating psychosocial programs and services on their own and in partnership with community-based resources and organizations. In fact, several hospitals, in search of a “plug and play” psychosocial and support model, have incorporated the multipronged Cancer Support Community (CSC) program directly into the hospital site. Hospital administrations are accustomed to contracting and outsourcing for various services, and an interest seems to be emerging in contracting

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with nonprofit organizations, professional societies, and private vendors for services that help meet the burgeoning patient-centered standards in oncology.

Another positive development following the issuance of the 2008 IOM report<sup>2</sup> was the formation of the Alliance for Quality Psychosocial Cancer Care to advance the recommendations in that report. This is a national alliance of patient groups, professional societies, hospitals, and cancer centers dedicated to ensuring the integration of psychosocial care into the medical standard of care for all people with cancer.

In addition to the IOM's recommendations around patient-centered care and the emergence of new standards of patient engagement by professional societies and standard-setting organizations, recognition of the importance of empowering and engaging patients can be seen in the formation of the Patient-Centered Outcomes Research Institute (PCORI) and through the Center for Medicare & Medicaid Innovation Center (CMMI). According to the PCORI Web site, the institute is "authorized by Congress to conduct research to provide information about the best available evidence to help patients and their health care providers make more informed decisions. PCORI's research is intended to give patients a better understanding of the prevention, treatment, and care options available, and the science that supports those options."<sup>4</sup> CMMI was formed to test new care delivery and payment models to look for ways to improve quality and decrease cost. Although these funding mechanisms are thought by some to be cumbersome and not easily accessible to smaller community entities—where 80% of cancer care is being delivered in the United States—this greater focus by the federal government on patient-centered interventions and models of care is encouraging.

### Charting the Path Ahead

Despite important recent progress toward a system in which the needs of the whole person are identified and met, we still have a great deal of work to do to meet that goal. First, despite the emergence of new entities like PCORI that are focused on patient-centered research, more funding mechanisms are needed to study a wide range of psychosocial and behavioral interventions. Further, these interventions must be evaluated not only for their efficacy in improving the patient experience and quality of life, but for their cost-effectiveness as well.

Billions of dollars are invested in biomedical research, yet the funding to examine potentially high-impact, low-cost psychosocial interventions is scarce. We know that it is cost-effective to manage depression and anxiety for patients with cancer, and we have the infrastructure, partners, and mechanisms to examine this further, but the dollars for these studies are limited.

Further, if we say we value a model of patient-centered care, then we must pay for a model of patient-centered care. Currently, many of the "high touch" services we claim to value are not reimbursed by Medicare or private payors. In addition, some of the traditional care that is costing the system billions of dollars does not have the evidence to support its use. The IOM report on delivering high-quality care states, "The committee concludes that the cancer care delivery system is in crisis. Care often is not patient-centered, many patients do not receive palliative care to manage their symptoms and side effects from treatment, and decisions about care often are not based on the latest scientific evidence."<sup>3</sup>

We must chart a path ahead with a range of key stakeholders—including the medical community, policymakers, payors, advocates, and, most importantly, patients—to examine new payment models that reimburse for psychosocial services, professionals, and interventions that consider patient preferences and values and lead

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to improved quality of life and decreased cost. Just as we reimburse for biomarker tests to determine a treatment plan, we should reimburse for distress screening to determine a care plan. Just as we reimburse for antiemetics and pain medications during treatment, we should reimburse for navigators to help patients maneuver through the challenges that come with a cancer diagnosis. And just as we reimburse for posttreatment medical care and surveillance, we should reimburse for survivor care planning and support to help ease the transition from patient to survivor.

## Conclusions

We are making progress toward a medical model of patient-centered care, but much work remains. This is not a “check the box” exercise, but the emergence of a new paradigm that can help achieve 2 ultimate goals in health care: improve quality and decrease cost. But to achieve these goals, we must invest in further evaluating psychosocial and support interventions so that they can be appropriately used for the right patient in the right setting, and we must be willing to pay for these services as their effectiveness is better understood. As we anticipate the aging of millions of baby boomers who will suffer from a wide range of illnesses, now is the time to act and invest in our future.

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