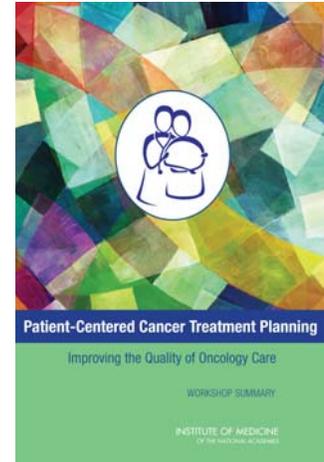


Patient-Centered Cancer Treatment Planning

Improving the Quality of Oncology Care

Summary of a Workshop



With support from the National Coalition for Cancer Survivorship (NCCS), the National Cancer Policy Forum (NCPF) of the Institute of Medicine convened a public workshop titled Patient-Centered Cancer Treatment Planning: Improving the Quality of Oncology Care on February 28 and March 1, 2011 in Washington, DC. The workshop addressed a broad range of topics, including shared decision making, communication in the cancer care setting, and patient experiences with cancer treatment. Best practices, models of treatment planning, and tools to facilitate their use were also discussed, as well as policy changes that may promote patient-centered care by enhancing a patient's understanding of the goals of treatment through a shared decision-making process with their healthcare team from the moment of diagnosis onward. While previous IOM work has focused on the challenges of cancer care planning for individuals who have completed their treatment—sometimes referred to as follow-up or survivorship care planning—this workshop focused on treatment planning for patients with cancer at the time of diagnosis.

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The Value of Treatment Planning

The life-threatening nature of cancer and the complexity of cancer treatment options, each with its own set of potential risks and benefits, make it difficult for people with cancer to make decisions about their care. Cancer care also usually involves multiple specialties, which can impede the coordination of care and the development of comprehensive treatment plans. A cancer treatment plan can provide a roadmap to help patients navigate the uncertain path

they find themselves on. As one participant noted, “Patients want to know what’s going to happen to them. Pilots don’t take off without a flight pattern, and architects don’t break ground without a blueprint.” Unfortunately though, most patients with cancer do not receive a written treatment plan, in large part because care providers currently lack the tools, time, and resources needed to efficiently and effectively prepare such plans.

The Treatment Plan

A treatment plan is a written document that describes the path of cancer care, and can be given to the patient, family, and other treating physicians in order to inform everyone about the path of care and who is responsible for each portion of that care. The treatment plan is altered when new information, such as a change in treatment response or in patient preference for treatment, dictates the need for changes.

Many speakers described typical features of a treatment plan, which can include:

- specific tissue diagnosis and stage, including relevant biomarkers;
- initial treatment plan and proposed duration;
- expected common and rare toxicities during treatment and their management;
- expected long-term effects of treatment;
- who will take responsibility for specific aspects of treatment and their side effects;
- psychosocial and supportive care plans;
- vocational, disability, or financial concerns and their management; and
- advance care directives and preferences.

However, one participant noted that a treatment plan is just the beginning, and that the “whole point of a care plan is not just to have a document, but to have a conversation. I think we will have failed if we do nothing but generate treat-

ment plans and that dialogue hasn’t occurred.”

Putting Patients at the Center of Treatment Planning

Patient-centered care has been defined as providing care that is respectful of and responsive to individual patient preferences, needs, and values, and ensuring that patient values guide all clinical decisions. A primary goal of patient-centered treatment planning is to engage patients and their families in meaningful and thorough interactions with their healthcare providers to develop an accurate, well-conceived treatment plan, using all available medical information appropriately while also considering the medical, social and cultural needs and desires of the patient and family. As one participant noted, many providers assume that women with early-stage breast cancer, for whom lumpectomy or mastectomy followed by radiation is equally effective, would prefer not to lose their breast. Yet in a study of breast cancer patients who were asked how important it was to them to keep their breast, one-third said it was not that important. As one participant noted, “We can’t make assumptions that everybody is going to feel the way that we do, so you have to ask the patient.”

The Challenges of Implementation

A number of model programs described at the workshop have attempted to make cancer treatment planning and other aspects of health care more patient-centered. These models include patient coaching programs, centers for shared decision making, enhanced discharge planning programs, accountable care systems, and self-help support groups. However, several recent studies to assess whether patient-centered cancer treatment planning is being put into clinical practice suggest there is much room for improvement. Participants at the workshop identified numerous obstacles to achieving patient-centered care

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planning in practice, including variable and often sub-optimal communication between the patient and healthcare provider that may not be culturally or personally appropriate, and information overload for the patient and family, without appropriate written documentation of treatment plans, options, and expectations that the patient and family might refer to after a visit.

Many participants also lamented the frequent lack of involvement of primary care physicians and provider teams who might know the patient and family better. Numerous factors that might contribute to that lack of involvement were noted, including poor coordination of care, a lack of time to keep up with myriad complex and rapidly changing cancer treatment regimens, and workforce shortages.

Other obstacles to care planning identified by workshop participants included the increasingly complex medical data that healthcare providers need to consider when making treatment decisions, and a lack of decision support for healthcare providers—for example, in electronic health records—to aid in managing the complexity of medical information. In addition, the current reimbursement system for health care does not compensate providers for the time it takes to develop, discuss, and document a treatment plan.

The Way Forward

Workshop participants also suggested a variety of mitigation strategies to address these many

obstacles, including improved training of physicians, nurses and other healthcare providers in the components of optimal communication with patients and families, and improved education of patients and families about how to be more proactive and assertive to optimize interactions with healthcare providers. Many participants advocated for greater use of support services, such as mental health services, social work, and nutrition counseling, as well as greater involvement of patient navigators who can help coordinate cancer care and foster communication among providers.

However, others argued that the need for patient navigators is a symptom of a broken system, and strongly advocated for more structural, systemic reforms in cancer care. For example, many participants emphasized a need to change the reimbursement and financial incentives in the system to encourage and support more patient-centered treatment planning and care. Many participants also stressed that greater use of quality improvement programs and accountable care systems could have a positive impact on the care provided to patients with cancer.

A variety of tools and online resources were also cited as potential means to improve care planning, such as electronic health records that can organize all important medical information, share it with all members of the healthcare team, utilize decision support to better assure optimal treatment recommendations for patients, and facilitate electronic input from patients into their health-



care records. In some cases, videos depicting different care options also might be useful supplements to written or verbal communication. Online tools that patients can use to educate themselves about treatment options and care planning have been developed by several organizations and federal agencies, including the American Cancer Society, the American Society of Clinical Oncology, NCCS, the National Transitions of Care Coalition, the Agency for Healthcare Research and Quality, and the National Cancer Institute.

Some speakers also suggested that more research on patient-centered cancer treatment outcomes and the value of cancer treatment plans is needed. However, cancer survivors attending the workshop also pleaded to avoid letting “the great be the enemy of the good.” They advocated for taking some concrete steps now to foster patient-centered cancer treatment planning, based on existing knowledge and evidence. As one participant noted, “I don’t want to be a patient that is left behind while you are waiting for the gold standard.”

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