



Patient-Centered Cancer Treatment Planning: Improving the Quality of Oncology Care. Summary of an Institute of Medicine Workshop

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ABSTRACT

The Institute of Medicine's National Cancer Policy Forum recently convened a workshop on patient-centered cancer treatment planning, with the aim of raising awareness about this important but often overlooked aspect of cancer treatment. A primary goal of patientcentered treatment planning is to engage patients and their families in meaningful, thorough interactions with their health care providers to develop an accurate, wellconceived treatment plan, using all available medical information appropriately while also considering the medical, social, and cultural needs and desires of the patient and family. A cancer treatment plan can be shared among the patient, family, and care team in order to facilitate care coordination and provide a roadmap to help patients navigate the path of cancer treatment. There are numerous obstacles to achieving patient-centered

cancer treatment planning in practice. Some of these challenges stem from the patient and include patients' lack of assertiveness, health literacy, and numeracy, and their emotional state and concurrent illnesses. Others are a result of physician limitations, such as a lack of time to explain complex information and a lack of tools to facilitate treatment planning, as well as insensitivity to patients' informational, cultural, and emotional needs. Potential solutions to address these obstacles include better training of health care providers and patients in optimal communication and shared decision making, and greater use of support services and tools such as patient navigation and electronic health records. Other options include greater use of quality metrics and reimbursement for the time it takes to develop, discuss, and document a treatment plan. The Oncologist 2011;16:1800-1805

Introduction

Each year ~ 1.5 million people in the U.S. are confronted with a cancer diagnosis [1] and must then decide on a course of care. The complexity of treatment options—each with its own set of potential risks and benefits—and the life-threatening nature of cancer and its emotional repercussions make it difficult for people with cancer to make decisions about their care. In addition, the fragmented nature of the cancer care system [2], in-

volving multiple specialties, providers, and locations, also presents challenges that may impede coordinated care and the development of comprehensive treatment plans.

In recognition of these challenges, the Institute of Medicine's National Cancer Policy Forum (NCPF), with support from the National Coalition for Cancer Survivorship (NCCS), held a workshop, Patient-Centered Cancer Treatment Planning: Improving the Quality of Oncology Care, on February 28

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and March 1, 2011 in Washington, DC [3]. Founded by cancer survivors, NCCS advocates for quality cancer care and provides tools to empower individuals affected by cancer to advocate for themselves. The NCPF convenes professionals from government, industry, and academia and other representatives to consider issues in science, medicine, public health, and policy relevant to the goals of preventing, palliating, and curing cancer. The NCPF explores emerging issues in cancer care through workshops that enable forum members, workshop speakers, and the public to debate and examine potential actions.

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-centeredness by enhancing patients' understanding of the goals of treatment through a shared decision-making process with their health care team from the moment of diagnosis onward. Whereas previous Institute of Medicine 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 from the time of diagnosis through completion of active treatment.

THE TREATMENT PLAN

A treatment plan is a document that describes the path of cancer care, and can be given to the patient, family, or other members of the care team in order to inform everyone about the path of care and who is responsible for each portion of that care. Many workshop participants, including cancer survivors, stressed that a cancer treatment plan can provide a roadmap to help patients navigate the uncertain path they face. One workshop participant noted:

"Pilots don't take off without a flight pattern, and architects don't break ground without a blueprint. Patients diagnosed with cancer are taking the journey of their life, literally, so the role of the cancer treatment plan in starting a conversation, in promoting comprehension and retention, in managing expectations and anxiety, and providing continuity across settings and episodes is so important."

A primary goal of patient-centered treatment planning is to engage patients and their families in meaningful and thorough interactions with their health care 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.

Components of a treatment plan, which ideally should be in electronic form, 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
- Advanced care directives and preferences.

One workshop 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 treatment 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" [4]. Promoting a partnership between a patient and his or her provider, patient-centered care enables shared decision making and ensures that communication is sensitive to the needs and capabilities of the patient. Patientcentered care also involves patient navigators, social workers, and other personnel to help in the coordination of care and the easement of health-related burdens, including psychosocial issues such as anxiety or financial stress. Some of the features of patient-centered care raised at the workshop include: the importance of patient education and empowerment; communication that involves patients, family, and friends, explaining treatment options and including patients in treatment decisions that reflect patients' values, preferences, and needs; coordination and integration of care; and the provision of emotional support as needed to relieve fear and anxiety and address mental health issues.

Breast cancer care is often used as a model to assess whether patient-centered care is occurring, because for many women with early stages of breast cancer, there are two equally effective treatment options: mastectomy and lumpectomy followed by radiation. Consequently, patient preferences and input must be solicited when making treatment decisions. However, there is some evidence to suggest that patient-centered care is not occurring as often as it should be. For example, one study suggested that only a little more than half of the patients reported hearing about both mastectomy and breastconserving therapy options, and patients reported that the pros and cons of each option were thoroughly discussed only 41% and 18% of the time, respectively. Only about half the time did patients report that their doctor asked which treatment they wanted [5]. In another analysis, only 60% of the time did patients and surgeons agree that both lumpectomy and mastectomy treatment options were discussed. Twenty-two percent of the time, the surgeon said that he or she had discussed both options, but patients only reported hearing one option. Compared with patients with more education, patients with less education more often reported that their surgeon only discussed one treatment option when their surgeon reported that both treatment options were discussed [6]. In addition, providers may incorrectly assume that women with early-stage breast cancer would prefer not to lose their breast. Yet in a study of breast cancer patients who were provided with comprehensive information about the risks and benefits of mastectomy and lumpectomy, one third of these informed women chose mastectomy [7]. Eighty-nine percent of the women who received a mastectomy did not feel strongly about keeping their breast, and women who chose mastectomy rated the values "remove breast for peace of mind" and "avoid radiation" significantly higher than those who chose lumpectomy. However, even among the women who chose lumpectomy, 32% did not feel strongly about keeping their breast. As one workshop participant noted: "We can't make assumptions that everyone is going to feel the way we do, so you have to ask the patient."

IMPLEMENTING PATIENT-CENTERED TREATMENT PLANNING

A number of model programs 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 programs, accountable care systems, and self-help support groups [8–11]. For example, the University of California, San Francisco's Carol Franc Buck Breast Care Center has a Decision Services program that offers decision aids and informational packets in advance of patient visits, planning calls to assist patients in developing questions for their providers, and note-takers to accompany patients to their medical appointments. In a survey of patients who participated in the Decision Services program, 95% reported that their provider discussed all of their treatment options and 66% reported that their provider asked them what their treatment preferences were [12].

In addition, experiences with treatment planning initiatives and survivorship care planning may inform the implementation of more widespread cancer treatment planning. For example, the Breast Cancer Registry Pilot evaluated an American Society of Clinical Oncology (ASCO) treatment plan and summary template and found that ~90% of patients and providers surveyed found that the treatment plan and summary template improved communication between patients and their providers [13]. Following the 2006 Institute of Medicine report [14] recommending that all cancer patients be provided with a survivorship care plan and treatment summary, a number of groups developed survivorship planning tools [15]. Assessments of these care plans can provide insights into the features that could be useful in the treatment planning setting.

THE CHALLENGES OF IMPLEMENTATION

However, workshop participants raised a number of obstacles to achieving patient-centered cancer treatment planning in practice, suggesting that there is much room for improvement. Some of these challenges stem from the patient and include patients' lack of assertiveness, health literacy, and numeracy, and their emotional state and concurrent illnesses. Others were a result of physician limitations, such as a lack of time to explain complex information and a lack of tools to facilitate treatment

planning, as well as insensitivity to patients' informational, cultural, and emotional needs. Many participants stressed the variable and often suboptimal communication between the patient and health care provider that may not be culturally or personally appropriate and information overload for the patient or family, without appropriate written documentation of treatment plans, options, and expectations that the patient and family might refer to after a visit. For example, recent studies found that only half of early-stage breast cancer patients knew that patients treated with mastectomy and those treated with lumpectomy have equivalent survival outcomes [16], and only 11% of patients were able to answer three questions about breast reconstruction correctly [17]. The lack of decision support tools (such as those embedded within electronic health record systems) was also cited as a barrier to cancer treatment planning, especially given the increasingly complex medical data that health care providers need to consider when making treatment decisions.

In addition, a number of system challenges were emphasized at the workshop, including a lack of financial incentives for providers to devote the time and effort required for patientcentered care planning, the costs of providing patient-centered cancer care, and the fragmentation of the health care system. Many workshop participants stressed that the current reimbursement system for health care does not compensate providers for the time it takes to develop, discuss, and document a treatment plan. Some workshop participants also questioned how the provision of patient-centered cancer treatment planning would affect the already high costs of medical care. For example, one workshop participant said it is difficult to imagine how the additional costs of supporting patient navigation will be borne, given the current economic climate: "To put a new player on the ground, you are going to have to save somewhere, and continuity of care and systems that are organized to realize those cost savings aren't out there right now." However, others suggested that patient navigation may likely reduce health care costs by averting readmissions and costly errors, and could improve the efficiency and effectiveness of the medical system by fostering low no-show rates, better adherence to treatment regimens, and timely access to medical care before major health complications develop. Several workshop participants called for the inefficiency and waste in the current health care system to be addressed so that resources could be redirected to providing better, more comprehensive, and more coordinated care to patients.

Many workshop participants noted that insufficient coordination of cancer care, which involves multiple specialties, providers, and locations, can also hamper the development of comprehensive treatment plans. A particular coordination challenge is the frequent lack of involvement of primary care providers in cancer treatment planning. The primary care team may know the patient and family better and longer than the oncology team, and may need to be kept abreast of their patient's cancer treatments because it influences how they care for a patient's concurrent illnesses and conditions. Numerous factors that might contribute to that lack of involvement were noted, including inappropriate exclusion by the oncology team, the



inability of primary care physicians to devote the time needed to keep up with myriad complex and rapidly changing cancer treatment regimens, and the lack of availability of primary care physicians resulting from workforce shortages. Referral patterns may also hamper coordination between primary care and oncology. Primary care practitioners have a number of referral options to consider when their patient is facing a cancer diagnosis, including cancer centers, community oncology practices, or general surgery, and some workshop participants noted that it can be difficult for primary care practitioners to know which option is best suited to their patient's needs. Similarly, a surgeon may refer a patient to a medical oncologist following surgery, but the patient's primary care practitioner may not be included in this process.

THE WAY FORWARD: TOOLS, PRACTICE, POLICY, AND RESEARCH

Workshop participants elaborated on a variety of possible solutions to address obstacles that may be preventing more widespread use of patient-centered cancer treatment planning, including tools and resources, changes for oncology practice and education, and opportunities for policy and research that may advance patient-centered cancer treatment planning.

Tools and Resources

Workshop participants suggested a number of tools and resources that could improve the provision of patient-centered cancer treatment planning. 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, ASCO, NCCS, the National Transitions of Care Coalition, the Agency for Healthcare Research and Quality (AHRQ), and the National Cancer Institute. For example, NCCS offers the Cancer Survival Toolbox [18], a tool that helps patients diagnosed with cancer develop skills to help navigate their cancer treatment, including how to communicate, find information, make decisions, and negotiate and stand up for one's rights as a patient. In addition, ASCO publishes an advanced cancer communication guide [19] that helps patients and their families understand their advanced cancer diagnosis, what options are available to them, and how to cope and locate support near the end of life. AHRQ provides a number of patient guides for people with various types of cancer that help empower patients, including a list of questions patients should ask their providers.

Another important tool that will advance patient-centered cancer treatment planning is an electronic medical record (EMR) that can create a checklist of key components in a treatment plan, organize all important medical information, and share this with the patient and family, as well as all members of the health care team. Decision support features of EMRs could ensure that health care providers consider practice guidelines when developing treatment plans, and make it easier to complete a treatment plan by providing autofill options with dropdown menus that may avoid errors of omission and transcription.

Sometimes verbal descriptions are not sufficient in ex-

plaining the options available to patients, and videos may be an important tool in soliciting patient preferences. In one randomized study, patients with malignant glioma were either shown a video depicting three levels of medical care (life-prolonging care, including the administration of cardiopulmonary resuscitation [CPR]; basic care, including hospitalization without CPR; and comfort care, such as symptom relief) or given a verbal narrative of these options. Patients who watched the video were much more likely to choose comfort care or basic care and not life-prolonging care than patients who received only verbal descriptions of the care options [20].

Several workshop participants suggested that screening tools, such as the Memorial System Assessment Scale and distress thermometer, can aid in symptom management and screen for mental health conditions, such as depression. Interactive voice response or automated telephone systems that elicit patients' symptoms may also be useful. One study found that such automated systems led to faster symptom response times and referrals than those that use a cognitive behavioral phone interview with a nurse [21], and another study found that patients had more discussions of symptoms and quality of life with their providers when they used computer-based patient symptom reporting [22].

Changes to Oncology Education and Practice

Many workshop participants suggested that there should be better training for physicians and other providers about patient-centered cancer care planning, including dissemination of best practices from both community care private practices and academic medical centers. One participant noted: "As we figure out the best way and tools, we absolutely also need to think forwardly about how to train people to implement them." Workshop participants suggested that training should expand beyond medical school, and that it would be helpful to provide better role modeling for practitioners with feedback on their performance in real time. Role modeling and patient-centered treatment planning could also be valuable in a variety of settings outside oncology, especially in situations in which the treatments and decision-making processes are complex. In addition, some workshop participants stressed that training should reinforce a collaborative approach to oncology care, suggesting that the many individuals who care for a cancer patient may not have shared expectations and clearly articulated responsibilities. One participant noted: "This is not beyond our capabilities, but we can't get to patient-centered care unless that's a vital part of it. It has to be a team sport."

Many workshop participants also 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 and nurse oncologists in cancer. Cancer survivors at the workshop highlighted the emotional toll that a cancer diagnosis can take, and strongly advocated for cancer treatment plans to address psychosocial issues, such as anxiety and depression, that may arise during treatment. Others emphasized the greater role oncology nurses and social workers

could play in communicating information in cancer treatment

The topic of patient navigation generated substantial discussion about how and even whether or not to make more use of patient advocates or navigators, as well as how to develop a new business model to support them. Patient navigation is defined as "individualized assistance offered to patients, families, and caregivers to help overcome health care system barriers and facilitate timely access to quality medical and psychosocial care from prediagnosis through all phases of the cancer experience" [23]. What competencies patient navigators need and how they are trained is an ongoing question, with workshop participants distinguishing between two types of navigators: peer navigators, who may have a personal experience with cancer treatment and can provide patients with some sense of the journey, and professional navigators, who may serve as clinical extenders by facilitating access to health care and linking patient needs with available resources. Some workshop participants emphasized the benefits of patient navigation in improving coordination and adherence to screening, diagnostic, and treatment regimens, and called for patient navigation to be more integrated into the health care system. To improve integration of patient navigation into the health care system, some workshop participants suggested that continued research demonstrating the cost-effectiveness of patient navigation is warranted. However, other participants asserted that the need for patient navigators is a symptom of a broken cancer care system, and strongly advocated for more structural, systemic reforms.

Policy Options and Continued Research

Many workshop participants advocated for standards of care for oncology to include patient-centered treatment planning and communication, and suggested that these standards be part of physician training and licensure. For example, one standard of care could include the need for a multidisciplinary team, using the best available evidence, to construct the initial cancer treatment plan, with the inclusion of the patient and family in decision making. The treatment-planning process could encourage second opinions to validate the initial provider's recommendations and diagnosis and ensure that the written plan is communicated to all parties. Other participants suggested that physician-patient communication should be a component of the medical license certification process.

Workshop participants stressed that financial incentives are also needed to spur implementation of patient-centered cancer treatment planning. One suggestion was for insurers to incentivize patient-centered care by reimbursing physicians only if they provide the documentation that is involved in creating a treatment plan. Workshop participants noted that congressional action may also facilitate changes to reimbursement that would incentivize providers to complete and communicate treatment plans. In an initiative led by NCCS, patient advocates lobbied for the Comprehensive Cancer Care Improvement Act, a bill that would require the Centers for Medicare & Medicaid Services to cover the cost of cancer care planning. Plans to reintroduce this legislation are under way.

Several participants suggested policies to enhance systemic health care reform that promotes patient-centered cancer treatment, including more accountable care organizations that coordinate care under a single institution and quality metrics and incentives to ensure that patient-centered care is being provided. As one workshop participant noted, "cancer patients need a clinical home that takes responsibility and is accountable for the quality of care through all the handoffs." Several participants said that ASCO's Quality Oncology Practice Initiative (QOPI), an oncologist-led practice-based quality improvement program, provides patient-centered metrics that could generate valuable feedback to practices assessing patient-centeredness. For example, within just a few months of instituting the QOPI program at a comprehensive cancer center and informing physicians of their scores on QOPI metrics, the percentage of patients receiving chemotherapy during the last 2 weeks of life decreased from 50% to 20% [24]. Many participants stressed that the greater use of quality improvement programs and accountable care systems could have a positive impact on the care provided to patients with cancer.

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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See the accompanying editorial on pages 1665–1666 of this issue.