

Shared Decision Making for Treatment of Cancer: Challenges and Opportunities

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The growing focus on patient-centered oncology care is increasing the demand on physicians' time and effort to engage patients and their families in treatment decision making. At the same time, the clinical encounter is becoming more challenging because evaluative testing strategies and cancer disease management decisions are increasingly complex.¹ Cancer treatment context is particularly challenging for patients and their families because there are multiple effective therapies that are interconnected, and there is a complex interplay between their benefits and risks. Furthermore, treatment recommendations are based on increasingly complicated clinical information that is revealed variably over time after initial diagnosis. Integrating this information into a treatment plan is challenging because different specialists direct the various treatments.²

Objectives of Shared Decision Making With Patients

Presenters at the symposium session entitled "Shared Decision Making for Treatment of Cancer – Value, Measurement, Improvement" highlighted the challenges and opportunities to improve the patient experience in the treatment decision-making process. The key objectives of shared decision making (SDM) are achieved when (1) patients are fully informed of the treatment options and the trade-offs between risks and benefits, and (2) patient values and preferences are incorporated into treatment decisions. SDM with patients has been strongly promoted for several reasons. First, it is the ethical responsibility of clinicians to facilitate patient autonomy in treatment decision making because patients and their families are ultimately subjected to the outcomes of these decisions. Second, there is strong evidence that more engaged patients are more informed, they are more likely to fully deliberate about the risks and benefits trade-offs of the different treatment options, and they are more satisfied with the clinical encounter. There is also evidence that more informed and involved patients have better psychosocial, and in some cases physical, outcomes.³

Challenges to Patients in Achieving the Goals of SDM

Presenters underscored the challenges to patients in achieving the goals of SDM in clinical encounters focused on cancer treatment decision making. Patients newly diagnosed with cancer confront a complex decision context with no prior experience to guide them forward. Thus, patient decision support

needs are high.^{4,5} Patients face the high potential of mismatch between the information they need and the information that is available and delivered. This can lead to patients getting too much, too little, or conflicting information.⁶ Time spent in the examination room can frequently be suboptimal for patients, particularly if they "freeze up" or "tune out" during the relatively brief periods of face-to-face time with clinicians.⁷⁻⁹ Another important challenge for patients newly diagnosed with cancer is a steep learning curve on collaborating with clinicians to make complex decisions about treatment.

Improving Measurement of SDM

Another key barrier to improving SDM is measuring it. Presenters highlighted the problems with proposed outcome-based SDM measures. Given the complexity and interplay between different treatment options, patients have trouble identifying the decisions that were on the examination room table in the context of the complexity and interplay between the different treatments. Patients frequently do not know what decisions are supposed to be made, let alone how they ought to be made. This problem with patient "decision awareness" can compromise measures of patient appraisal of decision making. Patient-reported appraisals of aspects of decision making such as satisfaction are also vulnerable to strong ceiling effects. This makes these measures less useful in quality improvement. There are also concerns about the validity of patient report. A number of studies have shown that patient report of aspects of communication with clinicians in the examination room correlate poorly with direct observation through audio or video recordings.

Another challenge to outcome-based measures is patient preference concordance: the alignment of an enacted patient decision with informed preferences. Current approaches are hampered by a lack of understanding of what preferences are important to patients, what structure underlies these preferences, and how are they constructed and expressed. There are important gaps in the literature about how patients construct preferences because the literature has generally focused on single decisions in contexts largely devoid of strong interpersonal inputs. This differs markedly from the treatment decision context after a cancer diagnosis, where a cascade of inter-related decisions is directed by different clinicians. This poses challenge to measuring to what extent patient preferences are elicited, understood, and incorporated into treatment decisions. Current approaches also assume a high level of conscious

deliberation that may be unrealistic given the powerful role of intuitive decision making emphasizing cognitive short-cuts and quick trade-offs. The process by which preferences for treatment are constructed does not easily surface for patients. Intuitive judgment processes dominate the construction of preferences, and these processes are largely subconscious. Heuristics such as availability bias (factoring personal experience into judgments of the probability of an event) and risk aversion can strongly influence patient's perspectives about the risk and benefits of treatment. For example, availability bias distorts knowledge about the probability of adverse effects of chemotherapy because patients weigh too strongly the experiences of others. Risk aversion can strongly influence patient's preferences for a more extensive treatment plan. Counterfactual thinking such as anticipated regret (the desire to receive all treatments available to reduce future regret if disease recurs) focuses on total recurrence and distracts patients from considering the net benefit of any given treatment. Finally, a narrow focus on preferences for treatment options fails to address patient preferences for other aspects of decision making. This includes preferences for involvement in decision making, the role of key decision support people such as family, and the role of clinicians in helping patients navigate those decisions.

The limitations to outcomes-based SDM measures motivate more attention on the advantages of process-based measures. A process-oriented approach simplifies the measurement task for patients by debriefing them on aspects of the communication they experienced and can accurately recall. Elwyn suggests questions along three constructs related to patient understanding: information provision, preference elicitation, and preference integration of their perspective into final treatment decisions¹⁰: The construct is measured via patient report of the amount of clinician effort to help a patient (1) understand the health issues, (2) listen to the things that matter most, and (3) include what matters most when choosing what to do next.^{11,12} The measure has the potential advantage of low patient burden and high practical use in a variety of medical settings.

Interventions to Improve SDM in Clinical Encounters

The final portion of the presentations was focused on interventions to improve SDM in clinical encounters. There is no doubt that patient-managed decision tools will become more important in clinical practice along with other advances in health information technology. There are many important questions to address about the content and structure of decision aids (DAs), including (1) the breadth and depth of information, (2) whether tools can be used in clinical encounters^{13,14} or whether they are best given to patients to use independently, (3) the role of preference elicitation and preference clarification exercises, and (4) approaches to improving patient engagement skills. There is also the question of how decision support can address the needs of significant others. Another critical area of investigation is how to practically and cost effectively introduce DAs into clinic work flow and integrate such tools into the rapidly evolving information technology milieu of clinical practice. The evidence, to date, suggests significant resistance to integrating DA tools into clinical practices.¹⁵

Another important development in decision support implementation research is the use of informal or formal coaches during the deliberation period. DAs may not be sufficient to optimize decision quality. Informal or formal coaching of patients could be combined with self-administered or facilitated use of decision and communication aids to maximize patient education and engagement. Patients can access and use self-administered decision tools during the short period of deliberation about treatments, but early evidence suggests that more do so in the context of coaching.^{16,17} Furthermore, DAs may have limited capability to increase patient engagement, address emotional responses to illness, and elicit preferences for aspects of the decision process and treatment options. In response, Belkora et al have developed and evaluated coaching strategies using student interns who facilitate (1) previsit, self-administered DA use to increase knowledge and engagement skills; (2) visit transcription or audio recording of the encounter; and (3) postvisit summaries for the patient and medical record. This dual approach, combining self-administered DAs with decision coaching, has been associated with increased patient satisfaction,^{18,19} knowledge,²⁰ decision self-efficacy, question asking, and recall. Physicians also endorse this method as satisfying without lengthening consultations.^{16,21} The economics of such strategies remain to be fully reported. An early study determined that patients were willing to pay \$150 and delivery costs of \$48 to \$78.^{18,19} Taken together, the presentations in this session highlighted a rich agenda in decision support and communication research to maximize patient experiences in clinical encounters about treatments for cancer.

Authors' Disclosures of Potential Conflicts of Interest

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