Shared Decision Making in Oncology Practice: What Do Oncologists Need to Know?

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LEARNING OBJECTIVES

After completing this course, the reader will be able to:

1. Outline the five steps that comprise shared decision making.
2. Identify specific tactics that can be used to engage a patient in a shared decision making process.

CME

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ABSTRACT

Background. There is growing interest by patients, policy makers, and clinicians in shared decision making (SDM) as a means to involve patients in health decisions and translate evidence into clinical practice. However, few clinicians feel optimally trained to implement SDM in practice, and many patients report that they are less involved than they desire to be in their cancer care decisions. SDM might help address the wide practice variation reported for many preference-sensitive decisions by incorporating patient preferences into decision discussions.

Methods. This paper provides a perspective on how to incorporate SDM into routine oncology practice to facilitate patient-centered communication and promote effective treatment decisions. Oncology practice is uniquely positioned to lead the adoption of SDM because of the vast number of preference-sensitive decisions in which SDM can enhance the clinical encounter.

Results. Clinicians can facilitate cancer decision making by: (a) determining the situations in which SDM is critical; (b) acknowledging the decision to a patient; (c) describing the available options, including the risks, benefits, and uncertainty associated with options; (d) eliciting patients' preferences; and (e) agreeing on a plan for the next steps in the decision-making process.

Conclusion. Given recent policy movements toward incorporating SDM and translating evidence into routine clinical practice, oncologists are likely to continue expanding their use of SDM and will have to confront the challenges of incorporating SDM into their clinical workflow. More research is needed to explore ways to overcome these challenges such that both quality evidence and patient preferences are appropriately translated and incorporated into oncology care decisions. *The Oncologist* 2012;17:91–100

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INTRODUCTION

There is growing interest by patients, policy makers, and clinicians in shared decision making (SDM) as a means to involve patients in health decisions and translate evidence into clinical practice. Fundamentally, SDM entails a model of collaboration between patients and their clinicians to reach agreement about a health decision involving multiple medically appropriate treatment options [1, 2]. SDM helps inform patients about which interventions are most effective under specific circumstances, incorporates patients’ needs and values into decisions, and aims to improve the patient–clinician dialogue about decisions [3, 4]. Many tools, such as patient decision aids, have been designed to facilitate the SDM process [2, 5, 6]. These decision aids have been found to increase patients’ knowledge, decrease their anxiety and decisional conflict, improve patient–clinician decision discussions, and, on some occasions, affect treatment decision making [2]. However, SDM is more than simply recommending or prescribing a patient decision aid. It involves collaborative conversations between patients and clinicians during which clinicians can provide input based on their clinical expertise and patients can provide input based on their symptoms, experiences, and preferences so that all involved can reach a mutually agreed upon plan [3, 4, 7].

Many national and international initiatives encourage clinicians to engage in SDM with patients. For instance, section 936 of The Patient Protection and Affordable Care Act [8] suggests that clinicians should provide patients and caregivers with information about risks, benefits, and tradeoffs among treatment options, and incorporate patients’ preferences into medical plans. Individual states, such as Washington, Minnesota, Vermont, Maine, and Connecticut, have either passed or proposed legislation to facilitate adoption of SDM into routine clinical practice. An international group recently released a Salzburg Statement calling on clinicians, patients, and policy makers to support SDM [9]. Additionally, many national organizations, such as the U.S. Preventive Services Task Force and the National Comprehensive Cancer Network (NCCN), encourage the application of SDM to many cancer-related decisions [10–12].

Although policy statements encourage widespread incorporation into clinical care, few clinicians feel adequately trained to implement SDM in practice [13–15]. In fact, there is often regional or physician-based practice variation for many preference-sensitive decisions that is not explained by regional or practice-based differences in patient populations [16–18], suggesting that patient preferences are not routinely incorporated into these decisions. This paper provides a perspective on how to incorporate SDM into routine oncology practice to facilitate patient-centered communication and promote effective treatment decisions. Oncology practice is uniquely positioned to lead the adoption of SDM because of the vast number of preference-sensitive decisions in which SDM can enhance the clinical encounter.

THE PROCESS OF SHARED DECISION MAKING IN ONCOLOGY PRACTICE

When patients are diagnosed with cancer, they are challenged with managing complex information about their diagnosis,

Table 1. Five steps in shared decision making (SDM)

1.	Determine the situations in which SDM is critical
2.	Acknowledge the decision to the patient
3.	Describe options, including risks, benefits, and uncertainty associated with options
4.	Elicit patient preferences and values
5.	Agree on a plan for the next steps in the decision-making process

Table 2. National Comprehensive Cancer Network (NCCN) categories of evidence and consensus

Category 1	The recommendation is based on high-level evidence (e.g., randomized controlled trials) and there is uniform NCCN consensus.
Category 2A	The recommendation is based on lower level evidence and there is uniform NCCN consensus.
Category 2B	The recommendation is based on lower level evidence and there is nonuniform NCCN consensus (but no major disagreement).
Category 3	The recommendation is based on any level of evidence but reflects major disagreement.

treatment options, side effects of treatment options, and the impact of treatment options on both quality and length of life [19]. At each step of the decision process, patients rely on their clinicians to support them by providing information in a clear manner, describing treatment options, and helping them manage uncertainty [4, 19, 20]. Clinicians can facilitate cancer decision making by implementing the following five SDM steps: (a) determining the situations in which SDM is critical; (b) acknowledging the decision to a patient; (c) describing the available options, including the risks, benefits, and uncertainty associated with options; (d) eliciting patients’ preferences; and (e) agreeing on a plan for the next steps in the decision-making process (Table 1). Although many oncologists recognize the importance of patient-centered communication, psychosocial support, and general principles of SDM, unfortunately, many patients still report that they are less involved than they desire to be in cancer decision making [21–23]. SDM is a process of engaging in decisions with patients, and although there are specific steps that can be followed, each step individually does not constitute SDM as a whole.

To engage in SDM with patients, clinicians’ first task involves *determining the situations in which SDM is critical*. Not all cancer decisions are preference sensitive (i.e., have multiple medically appropriate options), whereby the patient’s preferences for risks and benefits of options are key. It is readily apparent that SDM is appropriate for situations in which the level

of certainty regarding evidence falls in categories 2A, 2B, or 3 of the NCCN Categories of Evidence and Consensus as shown in Table 2 [24]. However, even within category 1, when there is high certainty about evidence, there may be a need to engage in SDM with specific patients when the evidence is less certain (e.g., patients with comorbidities who might have more toxicities from chemotherapy) or with specific individual patients who have strong preferences. For instance, examples in which SDM may play a less prominent role during clinical encounters include some patients with newly diagnosed chronic myeloid leukemia, when the only appropriate choice may be treatment with a tyrosine kinase inhibitor, and some patients with metastatic prostate cancer, for whom hormone-mediated therapy may be considered the only medically appropriate therapy. In these instances, although there may be little discussion of alternatives to these classes of therapy, choices within the class of therapy may still offer opportunities for collaboration and SDM.

Across the continuum of cancer care, preference-sensitive decisions range from cancer screening decisions (e.g., whether or not to have a prostate-specific antigen test for men aged >65 years and when to start mammography screening for women aged 40–50 years) to cancer treatment decisions (e.g., whether or not to participate in a phase III clinical trial and whether or not to have chemotherapy for early-stage cancer) and to end-of-life care decisions (e.g., when to forgo cancer-directed therapy and focus exclusively on palliative care and whether or not to participate in a phase I or phase II clinical trial). In addition to standard decisions based on uncertain evidence, there can be decisions in which it is crucial to engage in SDM because of an individual's clinical context. For instance, patients with localized lung cancer but impaired lung function may struggle with the decision between surgery and advanced radiation therapy. Other instances include treatments that entail a high side-effect burden and a modest survival benefit (e.g., the addition of erlotinib to gemcitabine for metastatic pancreatic cancer). Identifying preference-sensitive decisions is an important first step to engaging in SDM.

Once a clinician recognizes that a decision is preference sensitive, he or she must *acknowledge the decision* to a patient and *describe the available options, including the risks, benefits, and uncertainty associated with the options*. Although this task can seem straightforward, it may actually be quite difficult. Cancer decisions are highly personal and often depend on life stage, fears about the side effects of treatment or intervention options, and anxiety about cancer recurrence [19, 20, 25, 26]. Patients typically meet with numerous clinicians about a cancer diagnosis, including surgeons, medical oncologists, radiation oncologists, nurses, and others, which can complicate the communication process [19, 20]. And although many patients require time to process information about a cancer diagnosis before considering options, most feel pressure to make a decision about treatment soon after diagnosis (whether it results from system-level issues or pressure placed by the patient on him- or herself) [27, 28]. As a result of the decision complexity, communication challenges, patients' heightened emotional state, and time pressure to make a decision, many

Figure 1. Example of a pictograph often used to facilitate risk communication. In this image, risk can be described in the following way: “Our best estimate is that 25 of 100 people like you might experience nausea and/or vomiting after taking treatment A (as shown in the black-shaded rectangles), compared with 45 of 100 people who might experience nausea and/or vomiting after taking treatment B (as shown in the black-shaded and the blue-shaded rectangles). In other words, 20 additional people might experience nausea and/or vomiting after taking treatment B versus treatment A.”

patients unfortunately make decisions without fully understanding the options and associated risks and benefits [27–29]. In some cases, this lack of knowledge can lead to an underuse or overuse of cancer treatments [30, 31].

To facilitate SDM and involve patients in cancer decisions, clinicians should first describe the health condition in language that is accessible to patients, list options available to the patient (including describing possible procedures), and discuss the benefits and drawbacks of options in a balanced way [32, 33]. Efforts to communicate quantitative data available from clinical trials research can be complicated by the limited numeracy (ability to work with numbers) and health literacy skills of many patients [34]. To facilitate understanding, statistics about risks and benefits can be framed in terms of frequencies (e.g., “Our best estimate is that x of 100 people like you will have a recurrence without having this treatment, compared with x of 100 people who will have a recurrence after having this treatment”), with visual aids or graphics if available (Fig. 1). Frequencies are better understood than risks and benefits framed in terms of relative risk (e.g., “this treatment will lower your risk for recurrence by 15%”) or number needed to treat (e.g., “I have to treat 10 patients like you for one person to benefit from this treatment”) [35, 36]. Ideally, clinicians can refer patients to websites or evidenced-based decision tools [2] to review information discussed during the visit and further clarify prefer-

ences, because most patients want more time than a single visit to decide on a first course of action. However, additional visits to process the information and decide on a treatment plan are not always available given health care system constraints, the distance some patients travel to receive care from oncologists, and fears about delaying the decision. In addition, not all patients have access to, or comfort with, information provided on the Internet. Thus, having materials in the office visit to help patients understand options can enhance SDM. For instance, many clinicians use risk communication guides such as *Adjuvant! Online* [37, 38] to facilitate discussions of risks and benefits. Decision tools that help structure the clinical conversation during the visit [39–42] can provide additional guidance on decision making (e.g., values clarification and step-by-step guides to making decisions, in addition to risk communication).

For tests considered in secondary prevention planning (e.g., genetic testing for *BRCA1* and *BRCA2* gene mutations and Lynch syndrome testing) or tests to optimize primary treatment decisions (e.g., *Oncotype DX* and fluorescence in situ hybridization analysis in chronic lymphocytic leukemia or multiple myeloma), clinicians should also describe what the test measures and how the test is done, and explain the next steps recommended based on the test results [32, 33]. For example, for *BRCA1* and *BRCA2* mutation testing, the clinician can describe that the test is a blood test that can help women find out if they have a gene mutation that can make them much more likely to develop breast or ovarian cancer in the future. The clinician (or genetic counselor, when available) could describe the benefits and drawbacks of testing, and describe the possible next steps if the test is positive, negative, or indeterminate. It is also important to discuss concepts such as the likelihood of a false-positive or false-negative test result [43, 44]. For tests considered in secondary prevention planning, patients often have more time to consider the options and might feel less pressure than when making treatment decisions.

After describing the decision and options, clinicians can then help *elicit patients' preferences* and help patients to understand how these preferences apply to the available options. During the consultation, eliciting individual patient preferences using a values clarification approach refers to the process of clinicians working with patients to help them identify and/or clarify personal beliefs, goals, and opinions about options [45]. This process is different from the process in which preferences are elicited using a time tradeoff or standard gamble approach to assess health states (utilities), commonly used in macrolevel decision analysis, economic evaluations, and some patient decision aids [46]. Patient preferences cannot often be predicted and do not always correlate with sociodemographic variables like age or gender [47], so eliciting individual preferences provides the only reliable method of understanding individual values that can influence decisions. In addition, patients might not have previously formed preferences about cancer decisions because they find themselves in a new, emotional situation [4, 20, 48].

Values clarification serves to illuminate these preferences and can be approached in several ways. During consultations,

many clinicians begin by asking patients about their fears, encouraging them to express concerns, and discussing the psychosocial outcomes in addition to the physical outcomes of options. Others engage in reflective listening and shared deliberation about options, during which clinicians acknowledge that preferences can change with new information over time [48]. Finally, some clinicians supplement conversations with decision tools or decision aids (described in the next section) to more formally help patients to clarify their values. These decision tools can include interactive balance scales that list the pros and cons of a decision, allowing patients to attach their own values to each outcome [49], and personal testimonials to depict how individuals made decisions consistent with their values [50], and can provide quantitative estimates of risks, benefits, and harm that can be tailored to the individual to help patients identify preferences [51, 52]. When clinicians collaborate with patients, engage in values clarification, and deliberate with patients, this allows patients to process information and apply knowledge; these processes can lead to greater satisfaction and trust, and even bolster treatment adherence in some contexts [7, 53–57]. Explicit values clarification can help clinicians and patients better understand each other's perspectives on decision and options.

Finally, agreeing on a plan for the next steps in the decision-making or treatment process is important during oncology decisions. For instance, the oncologist and patient might agree to reevaluate a decision after several cycles of chemotherapy to determine its effectiveness and to discuss whether or not to continue with additional chemotherapy [41]. A plan for managing the possible side effects of the option(s) can also be established during this stage of decision making [4].

Although oncologists may have their own individual approaches to achieving SDM with patients, patient decision aids or decision support tools offer structured approaches to communicate knowledge, elicit values, clarify preferences, and plan for the next steps in decision making [2]. Below we describe several types of decision aids available to help during cancer decision making. Some aids help to structure the clinical visit such that SDM is more easily incorporated into practice and others facilitate decision making by supplementing the time spent during the clinical visit.

PATIENT DECISION AIDS IN ONCOLOGY PRACTICE

Some patient decision aids can be used immediately prior to a consultation, whereas others are to be used during the oncology visit to help provide knowledge and elicit patients' values about the risks and benefits of options [2, 33]. These tools can help prepare patients for decision discussions so that the conversation between the oncologist and patient can start at a higher level or so that patients can have time to review their specific questions and concerns before the visit. Some of these tools use question prompt lists or consultation planning during which a trained facilitator (any health professional who fits into the clinic structure) meets with patients and/or family members immediately prior to the appointment in which decisions are discussed [39, 40, 58–60]. A template is used to help patients and caregivers identify and plan questions or concerns

SCOPED Note Title: _____

List 3 key facts about the **SITUATION**

Fact 1: _____

Fact 2: _____

Fact 3: _____

List 3 **CHOICES** or actions that are available to you

Choice 1: _____

Choice 2: _____

Choice 3: _____

List 3 **OBJECTIVES** (goals), in order of priority

Objective 1: _____

Objective 2: _____

Objective 3: _____

List 3 **PEOPLE** who are either involved or will be affected

Person 1: _____

Person 2: _____

Person 3: _____

EVALUATE the consequences of each **CHOICE** for each **OBJECTIVE**

	<i>Objective 1</i>	<i>Objective 2</i>	<i>Objective 3</i>
<i>Choice 1</i> _____	_____	_____	_____
<i>Choice 2</i> _____	_____	_____	_____
<i>Choice 3</i> _____	_____	_____	_____

DECIDE on the Best Choice and Next Steps

Best Choice: _____

Next Steps: _____

Figure 2. Example of a decision tool used to help prepare patients for oncology visits [39, 40, 60, 61].

to discuss with the clinician (Fig. 2) [39, 40, 60, 61]. Others use strategies such as decision boards [41, 42, 62] to enhance decision communication. Decision boards employ visual displays (often poster sized) containing both text and graphics describing options and the risks and benefits of these options. They are presented to patients by clinicians to help simplify information and elicit patients’ values. Consultation planning, question prompt lists, and decision boards can be incorporated into oncology clinic visits but require planning to determine who will work through the tools with patients and how each type of decision aid can be developed and implemented for a broad range of oncology decisions.

In addition to tools used during the health care visit to structure the patient-centered decision process, many decision aids incorporate knowledge provision and values clarification to supplement the time spent during the health care visit [2, 5, 33]. Decision aids used outside the health care visit (paper based, DVDs, Web-based programs) (Fig. 3) [63] typically include background knowledge about the decisions, information about the options, risks and benefits of the options, uncertainties about the options, and structured values clarification, and

provide step-by-step approaches for patients to deliberate about options and prepare for discussions with clinicians [32, 49–52]. Like tools to structure the decision conversation, decision aids that supplement the oncology visit also require some planning to determine when and how to administer the tools. If decision aids are used prior to the oncology visit, patients might not know all the details of their cancer diagnosis and might not understand if each option presented in the tool applies to their specific context. If these decision aids are used after the oncology visit, patients might feel settled on a decision based on discussions with clinicians (and might have already scheduled the first treatment appointment). With planning and consideration, either or both types of tools (those used inside and outside the oncology visit) can facilitate SDM based on individual clinics’ structures and patients’ needs.

SDM: CHALLENGES AND RECOMMENDATIONS

Many oncologists already recognize the importance of patient-centered communication and psychosocial support during oncology visits [20, 25, 64]. Given the vast number of preference-sensitive decisions in oncology, and the principles provided

Figure 3. Screen shots from a Web-based decision aid, the Prostate Interactive Education System (PIES) [63]. Clicking on each link in the introduction brings viewers to a new page describing the background on prostate cancer, risk factors for prostate cancer, detection of prostate cancer, diagnosis of prostate cancer, tests performed, and treatment options. There are also individual decision guides for each of the treatment options (surgery, including robotic surgery and radical prostatectomy; radiation therapy, including brachytherapy; hormone therapy; cryotherapy; watchful waiting). The watchful waiting table of contents is shown in the lower screen shot.

Table 3. Sample of websites to access decision aids/decision support tools

Organization	Website	Additional information
Ottawa Hospital Research Institute	http://www.decisionaid.ohri.ca	Includes publicly available decision aids and others Describes how to order aids that require fees or permission Describes whether aids meet IPDAS criteria
Cardiff University	http://www.decisionlaboratory.com/research.php	The Decision Laboratory group develops and evaluates decision aids on a not-for-profit basis
University of Sydney	http://sydney.edu.au/medicine/public-health/shdg/resources/decision_aids.php	Includes aids developed by the Sydney Health Decision Group Three are cancer specific
Mayo Clinic	http://www.mayoclinic.com/health/DiseasesIndex/DiseasesIndex/METHOD=displayAlphaList&LISTTYPE=mcDisease&LETTER=a and http://dev.shareddecisions.mayoclinic.org/	Includes comprehensive guides on many health conditions Shared Decision Making National Resource Center also describes other SDM resources and links to other decision aid websites
NA	http://www.thedecisionaidcollection.nl/	Multilingual group of decision aids available from public sites Links to other decision aid websites
Memorial Sloan-Kettering Cancer Center	http://www.mskcc.org/mskcc/html/44.cfm	Includes an overview of the health condition, steps to receiving care (including follow-up care), and patient stories to help clarify values
Health Dialog	http://www.healthdialog.com/Main/Personalhealthcoaching/Shared-Decision-Making/Video-Decision-Aids	Maintains a collection of patient decision aids that oncologists can access or order Most aids are video based

Abbreviations: IPDAS, International Patient Decision Aids; NA, not applicable; SDM, shared decision making.

during oncology training, embracing SDM in oncology practice is logical to most oncologists. However, even advocates of SDM acknowledge some challenges to thorough and effective implementation. For example, deciding on the best timing to implement patient decision aids poses one obstacle to integrating SDM in oncology practice. In addition, there are also some unique communication challenges that can arise in oncology during SDM. Communication about cancer often occurs as a series of conversations over time, with multiple clinicians involved (including surgeons, medical oncologists, radiation oncologists, nurses, and others). These clinicians might inadvertently introduce uncertainty into the decision by recommending treatment that is in line with their specialty or expertise. For example, in prostate cancer centers, urologic surgeons often recommend surgery and radiation oncologists often recommend radiation to treat early-stage disease [65]. Proactively managing patients' uncertainty about communicating with multiple clinicians about the same decision can be difficult [66], especially when patients are facing a cancer diagnosis.

Furthermore, each clinician involved in patients' decisions must be familiar with the tradeoffs among options, including

the statistical benefits and risks, in order to start the process of SDM. This knowledge is often difficult to find and integrate into each patient's situation because not all patients conform to evidence-based guidelines for treatment [67]. Some clinician decision support tools help address some of these challenges by highlighting evidence summaries and guidelines [2, 68]. Others include summary pages for clinicians to help simplify the process of communicating about tradeoffs and statistics [2, 57, 69]. When there is information that is unknown or uncertain, acknowledging this uncertainty to patients is a key aspect of SDM and can enhance the patient-clinician relationship [67].

Many clinicians fear that engaging in SDM or using patient decision aids adds time to an already time-pressured visit [13]. There is evidence demonstrating that patient decision aids either have no effect on the consultation length or can save time [2, 41, 59, 70, 71], especially if patients gain some background about options and details of options prior to the visit when a decision must be made. However, some patients will want to schedule additional visits to finalize their decision, and in some settings the initial SDM consultation will take more time than

standard practice [72, 73]. In the long run, the benefits of SDM could outweigh the possible time burden if SDM helps achieve patient-centered care, improve the quality of oncology decisions, and improve patient adherence to these decisions [51].

Finally, many clinicians describe concerns about where to access evidenced-based patient decision aids or SDM tools [13, 74]. There are several websites that have been developed to help clinicians find such tools. Table 3 lists some of these available websites. In addition, the Ottawa Hospital Research Institute also includes an annotated bibliography of available decision aids, although it was last updated in 2002 [75]. Future research is ongoing to determine how best to evaluate patient decision aids and to develop minimum standards for good quality decision aids [33; J.N. Williams, manuscript submitted for publication]. This research will help clinicians select the most appropriate tools that meet or exceed minimum guidelines.

To engage in SDM training opportunities, oncologists might consider reviewing the Ottawa Decision Support Framework and website tutorials. In addition, reviewing the International Patient Decision Aids criteria [32, 76] and the International Patient Decision Aids instrument [33] can provide guidance on the quality of patient decision aids oncologists might select for use in practice. The SDM Wiki [77] also stores a list of abstracts, publications, presentations, and other resources for the SDM community to learn about SDM research and practice. For more intensive training in SDM, finding available multiday courses at conferences or host institutions, with opportunities for role-playing, simulated patient interaction, and feedback on one's own performance during these activities, can facilitate skill development in SDM [13]. The Foundation for Informed Medical Decision Making has a breast cancer initiative to support shared decision making

in breast cancer centers in the U.S. [78] and supports four specialty care demonstration sites [79] aiming to implement decision aids and SDM into clinical practice; these sites might be able to provide additional opportunities for SDM training.

CONCLUSION

More than half of all medical interventions involve unknown clinical effectiveness or involve complex tradeoffs between benefits and harms [80]. Oncologists are challenged with communicating this uncertainty to patients to help them make quality care decisions. Most clinicians underestimate patients' desire to be involved in the decision-making process and assume that patients prefer a more paternalistic model of care [13, 51]. Others are unsure about how to apply the SDM process to particular clinical contexts, to work with patients to weigh the tradeoffs between the benefits and risks of treatments, and to make quality decisions that are consistent with the best available evidence and patients' preferences [13]. Given recent policy movements toward incorporating SDM and translating evidence into routine clinical practice, oncologists are likely to continue expanding their use of SDM and will have to confront the challenges of incorporating SDM into their clinical workflow.

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