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Implementation of Shared Decision Making into Urological Practice

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Abstract

Introduction: Shared decision making (SDM) is a collaborative approach to care that improves the quality of medical decisions by helping patients choose options concordant with their values and the best available scientific evidence.

Methods: A literature review was performed targeting publications through January 2020 on the topic of SDM and decision aids (DA) for urologic conditions. An expert panel was convened to evaluate this information and create this paper to share with the urologic community.

Results: Practice guidelines and expert panels recommend SDM for patient counseling. Patients who have engaged in SDM have greater knowledge and decision satisfaction, as well as greater participation in care. Numerous organizations make available free resources for SDM, including DAs and tools to evaluate the quality of SDM.

Conclusions: SDM is an important component of high-quality healthcare delivery. In appropriate circumstances, urologists should adopt SDM into routine clinical practice.

Introduction

Since the American Urological Association (AUA) published the first version of this paper in 2015¹ interest in shared decision making (SDM) has surged within the urological community. At the time of this update, the original paper has been accessed thousands of times, the AUA held a Quality Improvement Summit on the subject in 2016, and the AUA Annual Meeting has offered multiple courses on SDM. The drivers of this interest are many and include the desire to help patients, greater patient advocacy and health policy efforts such as The Center for Medicare and Medicaid Services (CMS) national coverage determination requirement of SDM.² However, the single most important factor has likely been the United States Preventive Services Task Force's (USPSTF) policy reversal on prostate-specific antigen (PSA) screening. The USPSTF has shifted from recommending against routine PSA screening to advocating for a SDM approach to counseling men considering PSA screening; a position that requires all urologists and primary care doctors to be adept at SDM in their patient counseling. Yet, clinicians often have a poor understanding of SDM and how to implement it into clinical practice.³ To improve the quality of care for urological patients, an AUA workgroup empaneled by the Quality Improvement Patient Safety Committee has reviewed the literature in the field of

urologic SDM and updated its original recommendations for how to best implement SDM into clinical practice.

Shared Decision Making

SDM is a collaborative decision-making process between patients and their healthcare team relevant to medical decisions where multiple options are considered clinically acceptable. This approach is particularly relevant to clinical scenarios where the ratio of benefits to harms is uncertain, equivalent or “preference sensitive” (e.g., dependent on the value that an individual patient may place on them); or complex in terms of problem-solving or implementation.^{4,5} SDM aims to improve the quality of medical decisions by helping patients choose options, delay or forego care altogether, concordant with their values and in accordance with the best available scientific evidence. In randomized trials, patients receiving decision aids (DAs) to support SDM are more knowledgeable, have expectations that are more realistic, participate more actively in the care process and frequently arrive at decisions aligned with their personal preferences.⁶⁻⁸

The increasing focus on patient-centered care in healthcare reform has made SDM a frequent topic of discussion in recent years. In the landmark 2001 report “Crossing the Quality Chasm,” the Institute of Medicine (now called the National Academy of Medicine) articulated the provision of “care that is respectful of and responsive to individual patient preferences, needs and values, and ensuring that patient values guide all clinical decisions” as one of six central specific aims for improving quality of care.⁹ Additionally, the Affordable Care Act (ACA) established a program to develop, test and disseminate patient DAs.

One challenge of implementing SDM is the lack of a universally accepted definition of the concept. In a systematic review published in 2006, fewer than 40 percent (161 of 418, 38.5 percent) of articles examined included a conceptual definition of SDM.¹⁰ Although 31 concepts were used to describe SDM, the only categories that appeared in more than half of the 161 definitions were “patient values/preferences” (in 67.1 percent) and “options” (in 50.9 percent). The review concluded that a definition of SDM is necessary for operationalizing SDM in further research and practice, and provided the essential, ideal and general qualities of SDM.¹⁰ One widely accepted SDM model defines SDM according to its key characteristics: 1) involvement of both the clinician and the patient in the decision-making process; 2) mutual sharing of information by both parties; 3) reaching consensus about the decision; and agreement on next steps in the decision to implement it.¹¹ This paper will reflect the latter model of SDM.

Benefits of Shared Decision Making

SDM requires a partnership between the care team, the patient and, sometimes the patient’s family when appropriate and desired by the patient. Ideally, it includes a balanced presentation of options and outcomes tailored to the individual patient’s risk.¹² Equally important is active engagement with the patients to help clarify and communicate their own values and preferences.¹³ SDM benefits both the care team and patients and is considered by many to be essential in the presence of multiple appropriate options or uncertainty about the risks or benefits of a medical decision.¹⁴

The benefits of SDM result from a relationship of trust and mutual respect between patient and care team.¹⁵ Patients who perceive that they have participated in their healthcare decisions more often report feeling informed or empowered,¹³ are more likely to express higher satisfaction with their medical care and report better quality of life. They are less likely to have decisional regret and more likely to adhere to the agreed-upon medical plan.¹⁶⁻¹⁷ Such empowerment may be particularly important for long-term, anxiety-evoking decisions such as the decision to get prostate cancer surgery for early stage prostate cancer, which can have long-term effects on sexual function.

Prostate cancer screening and treatment related decisions are often preference-sensitive, and thus provide rich opportunities for SDM to be realized. Patients presented with the benefits and harms of difficult healthcare choices are capable of coming to reasonable decisions, often different from those they might have made without SDM.⁷ A balanced presentation of prostate cancer natural history, diagnosis and treatment options led to decreased interest in prostate cancer screening in six of nine studies¹⁸ and increased preference for watchful waiting for low-risk disease.¹⁹ Only one-quarter of high-risk prostate cancer patients considering surgery elect a nerve-sparing approach when participating in SDM to explain the potential risks and benefits of nerve-sparing prostatectomy.²⁰ With physician assistance, patients and families can prioritize their values and make rational choices with more realistic expectations, less decisional conflict and increased long-term satisfaction.¹⁵

Use of Shared Decision Making in Clinical Practice

Preference-sensitive conditions are prevalent in urologic practice. Although prior studies have found low rates of SDM use among urologists,²¹ emerging data from the 2019 AUA Annual Census finds that 77 percent of urologists report that they regularly incorporate SDM in at least one preference sensitive clinical scenario.²² This uptake of SDM is encouraging and may be a sign that evidence is outweighing perceived barriers to SDM.²³

The increased use of SDM among urologists may warrant a shift in education and research towards efforts to

measure and provide feedback about the quality of SDM. For example, a key aspect of SDM is eliciting patients' preferences and values; however, a 2015 study concluded that while urologists usually inform patients of risks, benefits and alternatives of treatments, they rarely discussed patient preferences.²⁴ Data from the 2019 AUA Census echoes this theme, finding that asking about patients' preferences and values is one of the least commonly incorporated parts of SDM across several preference sensitive clinical scenarios (54-71 percent as opposed to rates between 90-91 percent of regularly discussing options).²²

In addition to variation in preference elicitation, the accepted primacy of clinical judgement can influence patterns of disclosure or weighing of patient preferences, which may lead to inferior quality of decisions. For example, within preference-sensitive scenarios, physicians have been found to tailor their disclosure and description of available treatment options based on their assessment of the patient.^{25,26} This can be problematic because it may introduce bias in the decision-making process and result in poor decisional quality.²⁵⁻²⁶ When patients and physician preferences do not align, physician preferences often outweigh patients' preferences.²⁷⁻³¹ Educational modules and validated measurement tools to track and report the quality and outcomes of SDM may be beneficial.³²

Innovative methods to support quality SDM have been described for clinical use.^{28,32-38} Several institutions are committed to providing access to high quality DAs that are accessible online.³⁹ New collaboratives such as SHARE-IT (SHARing Evidence to Inform Treatment) decisions are developing platforms for rapid synthesis of online, publicly available, DAs based on quality clinical practice guidelines.⁴⁰ Clinical institutions have also modeled methods to integrate SDM and DA use into clinical workflow. For example, at Massachusetts General Hospital clinicians are provided regular training on SDM and can place a "referral for a decision aid" which prompts a central distribution of materials to patients.³⁷ The future of SDM may see the rise of novel methods to help patients understand risk, and identify and express their preferences. These include methods such as best case/worst case scenario mapping, discrete choice experiments, and conjoint analysis systems, which have been piloted in urologic research but have yet to be implemented in regular clinical use.^{28,33,36}

Limitations of Shared Decision Making

Although the merits of SDM are well described, there are some limitations to this method of supporting decisions. First, some clinical circumstances may not align well with SDM if there is one dominant option from an evidence standpoint. In addition, it can be more challenging to implement during acute clinical scenarios.⁴¹ Literature on the topic of SDM during acute clinical scenarios is rare, but what is available points to the need for more training and support for SDM to take place at these times.⁴¹ Furthermore, there is little guidance on the use of SDM during inpatient hospitalizations after acute clinical events. One qualitative study of patients with spinal cord injury found that in the acute phase of injury, participants had reduced ability to participate in decision making immediately following their injuries.⁴²

To this end, it is important to know that patients' preferences for control over their medical decisions varies, and this preference can be different at various points of time for the same patient.^{42,43} Although a large number of studies on the topic find that most patients wish to engage in SDM, they also describe a minority of patients who do not wish to participate in their own decisions.⁴³ Some studies have tried to establish the characteristics of such patients. For example, early work in this area found that younger patients were more interested in SDM.⁴⁴ However, others found that demographics play only a limited role in explaining the variations in attitudes among patients.⁴⁴ Before deciding SDM is not appropriate for a patient, the clinician should consider whether the patient is fully aware that there is more than one option for treatment, as well as the trade-offs involved with the options. It is important to involve all patients in SDM unless they explicitly say they do not want to be involved.

Another limitation of SDM is that the link between SDM and clinically meaningful outcome measures has not been clearly established in urology. In 2018 the National Quality Forum (NQF) recommended research directed towards building patient-centered outcome measures to study the quality and implementation of SDM.³² Long-term, prospective assessments of the quality of medical decision making and with links to person-centered outcomes such as survival, hospital readmission and quality of life are necessary in order to provide feedback to patients and providers about SDM.

Finally, there is a perception that the formal process of informing a patient about treatment options, eliciting preferences for outcomes and arriving at a shared decision may not be feasible in practices with limited resources.²³ However, there is no strong quantitative evidence supporting the notion that SDM requires more time than usual care; some studies demonstrate no difference, some suggest that SDM required more time than usual care (on average 2.6 minutes)⁷ and others suggest that less time was necessary.^{7,45} This heterogeneity is likely due to the variety of interventions characterized as "SDM" and the variety of clinical contexts studied. Regardless of the time necessary for the SDM process, many believe its benefits likely merit its implementation even at the cost of a small amount of additional time, especially once use of SDM becomes routine and more efficient.⁴⁶

Measuring the Quality of Shared Decision Making

A 2018 systematic review identified 40 diverse instruments for measuring SDM (16 patient questionnaires, 4 clinician questionnaires, 18 coding schemes, and 2 measures incorporating multiple perspectives).⁴⁷ In general, there are two approaches for measuring the quality of SDM: 1) measuring the *outcome* of the SDM process; and 2) measuring the *presence* of SDM in the clinical encounter.

The SDM process is often linked to the outcome of “decision quality.” Decision quality in the context of preference sensitive decisions and clinical equipoise can be difficult to define.⁴⁸ Nonetheless, SDM outcomes have been conceptualized as having adequate patient knowledge and concordance between individuals’ values and the treatment they received.⁴⁹ Other related measures include satisfaction with the decision,²⁴ evidence of desired level of participation in decision making,⁵⁰ decreased decisional conflict,⁵¹ and decreased decisional regret.⁵²

The Decisional Conflict Scale is a widely used measure of the outcome process, though it has come under some criticism.⁵³ A four-item version of this scale, is also available for routine clinical use.⁵⁴ One issue with relying on decisional conflict as a primary measure of SDM quality is that in some circumstances effective SDM can increase patients’ decisional conflict (as opposed to decreasing conflict) because patients learn that they face decisions with inherently difficult trade-offs.

Experts have also emphasized that decision-specific knowledge and concordance between preferences and treatment choices are conceptually critical.⁵⁵⁻⁵⁷ Consistent with this emphasis, “informed choice” has been formally defined as the combination of adequate patient knowledge, attitudes toward options, and behavioral intentions.⁵⁸ Recently, this approach to measuring informed choice was used as the primary outcome in a randomized controlled trial of prostate cancer screening DAs.⁵⁹

The second general approach to measuring SDM is to assess whether elements of SDM occurred in the clinical encounter. Numerous measures exist that assess subjective perceptions of SDM from the perspective of clinicians and/or patients. Dyadic measures assess SDM from the perspective of both patients and clinicians including measures such as the SDM-Q-9 and SDM-Q-Doc^{60,61} and the iSHAREpatient and iSHAREphysician questionnaires.⁶² The CollaboRATE scale offers a relatively brief measure of SDM from the patient perspective.⁶³ Research has shown that agreement between patients’ and clinicians’ perceptions of SDM tends to be low.⁶⁴

Additional approaches to measuring the presence of SDM in the clinical encounter allow a relatively more objective assessment. For example, the OPTION scale offers a coding framework that can be used to code SDM in audio or video recordings of clinical encounters.⁶⁵ The MAPPIN’SDM provides matched scales for clinicians, patients, and third-party observers to rate SDM in the encounter.⁶⁶ The Detail of Essential Elements and Participants in Shared Decision Making (DEEP-SDM) permits the identification of decision points as well as the coding of each of the essential elements involved in SDM.⁶⁷ These more objective ratings of SDM require either audio or video recordings so that the encounter can be rated. Other measures of SDM, including measures used to assess the SDM process from the patient perspective, are accessible through the National Cancer Institute’s (NCI) Grid-Enabled Measures (GEM)-SDM measures database⁶⁸ and the Ottawa Hospital Research Institute (OHRI) website.⁶⁹

Proper engagement with and implementation of SDM requires the ability to assess implementation efforts from both the provider and patient perspectives. Unfortunately, the tools for such evaluation are limited. Most studies of SDM employ direct observer methods,^{65,70,71} which are difficult to integrate into routine clinical practice.⁷² A review of instruments used to assess SDM identified 20 tools, of which 13 were patient-reported, five were observer-based, and two were employed physician self-report.⁷³ The Dyadic OPTION scale is a provider and patient self-reported modification of the observer-based OPTION scale.^{65,74} Additionally, the Decision Support Analysis Tool (DSAT-10) is a freely available resource that evaluates key elements of the SDM process in a checklist format.⁷⁵ Lastly, Observer OPTION-5 was developed as a formative measure of SDM in clinical practice and outlines five core clinician behaviors: 1) identifying a clinical problem as one that requires a decision; 2) explaining a need for the patient and clinician to deliberate together about options; 3) helping the patient understand available options; 4) eliciting the patient’s preferences about available options and their potential outcomes; and 5) integrating the patient’s preferences into the decision.⁷⁶

Providers may choose to evaluate the effectiveness of their implementation efforts by having patients self-report their own decision-making experiences. Of the patient-reported SDM instruments, most measure patient preferences for participation in SDM, self-efficacy and/or decision quality manifest as satisfaction with their decision or decision regret.⁷³ While processes to collect, collate and report these data for routine clinical use are not yet formalized, physicians can assess the effectiveness of SDM among individual patients whom they have counseled. However, research has found that there is a lack of concordance between patient evaluation of the effectiveness of SDM as well as patient involvement and observers’ validation of these factors.^{64,77}

The perspective of the stakeholder (i.e. patient, physician, researcher) evaluating decision quality is important in determining the specific measures used. Measurement of SDM outcomes can help health systems and clinicians understand whether their efforts are successful, and, if not, how to identify targets for remediation. In addition, measurement of SDM outcomes can inform federal and private compensation. Since its inclusion in the ACA, SDM is

is becoming part of federal regulation and is being mandated by some accountable care organization contracts. Such stakeholders might require a parsimonious measurement set that is feasibly implemented into routine care or can be assessed using data extracted from an electronic medical record. From the academic perspective, detailed measures will be important for research and progress in the field.

Patient Decision Aids

Engaging a patient in SDM and ensuring all of its principal components are addressed is a complex task. Evidence-based patient DAs have been developed as tools to facilitate and streamline this process. Urologists may be key facilitators in patients' decision to use DAs.⁷⁸

Benefits of Decision Aids

DAs are designed to increase knowledge about specific disease states and behavioral choices such as screening, estimate personal risk, help clarify personal values and ideally assist patients to better communicate with their clinicians. Using a DA prior to the clinical encounter often prepares patients for the subsequent SDM consultation⁷⁹ by increasing their knowledge of their disease and treatment options and promoting a sense of involvement by patient and caregiver. Although DAs cannot replace SDM,¹⁵ they clearly enhance and facilitate the SDM discussion for both clinicians and patients. DAs improve accurate risk perceptions, meaning that patients who have used a DA have a better assessment of the probabilities of various disease states after treatment.⁸⁰

DAs can help tailor the discussion to the patient's specific needs.^{15,81,82} The information collected from patients using DAs can also help clinicians tailor their consultations, facilitating clinicians' understanding of each patient's concerns.⁸³ Since they typically include values clarification exercises, DAs could help patients to identify their beliefs as well as improve concordance between patient values and the treatment received; however, the science of values clarification is still in its infancy.⁸⁴ The workgroup feels that future research could inform the optimal approach to values clarification and how it should be integrated within DAs.

When used as part of SDM for prostate cancer screening, DAs improve short-term disease-specific knowledge and intent to discuss screening.^{18,85} The effect of DA use on screening rates has varied greatly across studies.⁸⁰ Of ten studies examining PSA screening, three demonstrated reductions in screening rates, while seven did not. DAs that incorporate personal risk such as nomograms or computer-based risk calculators can further tailor the SDM conversation and are widely used for genitourinary malignancies.⁸⁶ Studies also suggest that DAs promote a perception of decreased decisional conflict and treatment satisfaction,^{7,18} as well as decreased levels of anxiety and distress, among men with newly diagnosed prostate cancer, though the relationship is uncertain for other disease conditions.^{80,87} DAs could improve the patient-clinician interaction, as well as help patients discuss their prostate cancer diagnosis with family members.⁷⁹

Decision Aid Format

Although DAs today are increasingly internet-based, the format in which DAs are delivered has evolved significantly over the last 25 years. Early versions of DAs were typically either booklets or audio recordings accompanied by booklets. Other formats have included video cassettes, DVDs, internet webpages, prompt sheets, decision boards and option grids. The Agency for Healthcare Research and Quality's (AHRQ) report on cancer decision support tools suggests that use of audio and visual tools (e.g., audiotapes, video cassettes/DVDs and CD-ROMs) has decreased over the last 25 years, with a significant accompanying increase in software or internet-based DAs.⁸⁸

DAs come in various media formats (e.g., brochures, websites, videos) and aim to provide information about the clinical condition, attributes of the options and a framework to clarify and communicate the patient's personal values. In 2016, the NQF published DA certification standards as a step toward monitoring the quality of available DAs across clinical conditions and accrediting high-quality decision

support resources.⁸⁹ The International Patient Decision Aid Standards (IPDAS) Collaboration has an established and well-regarded quality assessment framework, including 74 items qualifying, certifying and establishing the quality of DAs.⁹⁰⁻⁹² To further expedite the assessment of DAs, IPDAS has created a checklist framed around questions related to content, process and effectiveness. As more DAs are being designed for the internet, IPDAS has developed specific criteria for internet DAs (e.g., permit printing as single document, make it easy for patients to return to the DA, provide a systematic way to move through web pages).⁹⁰ In addition to the IPDAS framework, AHRQ has developed the Patient Education Materials Assessment Tool (PEMAT), which provides a systematic method for clinicians to select among the multitude of patient educational materials based on their understandability and their actionability.⁹³ The PEMAT can be used in a spreadsheet to score DAs; those having the highest scores are most appropriate for use by the practitioner evaluating them.

Although there have been numerous randomized trials comparing decision outcomes (e.g., knowledge, satisfaction, interest in SDM, treatment choice⁷) between patients receiving a DA and those not receiving a DA, there have been few studies of how delivery formats (e.g., booklet versus computer-based tool) affect these same outcomes. One review found no evidence that delivery format altered the effectiveness of the tools;⁸⁸ however, the strength of evidence on this topic was low. Others suggest that patients often prefer visual aids, particularly those demonstrating the risks and benefits of treatment options,¹¹ and patients more frequently express a preference for

printed material over video.⁹⁴⁻⁹⁷ Such media format preferences may vary based on patient age, socioeconomic status and the condition represented on the DA. Some researchers have found that older populations, such as women aged 75 years and older, almost unanimously (98 percent in one study) preferred a paper-based rather than a computer-based tool.⁹⁸ In general, however, the perceived value of DAs is highly context specific.⁹⁹

Further research is needed to test whether specific internet features (e.g., audio voiceover, interactive graphics, effects of tailoring) impact key decision outcomes, since these additions provide inconsistent or limited benefit to readers.^{88,100,101} Internet-based DAs with the capability to incorporate personal risk into an interactive presentation have been shown to facilitate discussions of colorectal cancer screening,^{101,103} yet an AHRQ review found that interactivity (e.g., personalized risk information) did not result in additional benefits compared to tools without interactivity. The workgroup believes that the field would benefit significantly by randomized controlled trials testing the effectiveness of different types of delivery formats across diseases and populations, especially in regard to internet-based tools.

Limitations of Decision Aids

In spite of all their benefits, in clinical practice, DAs may only have a limited effect on health outcomes because SDM is most appropriately used in situations in which there is no clear best option. Additionally, DAs have demonstrated a limited effect on patient satisfaction, in part because of ceiling effects where many patients report high satisfaction and the potential for regret to build over time.⁶ DAs might be less effective among patients with low health literacy or numeracy.¹⁰⁴ Because DAs are often used prior to the clinical encounter, clinicians may not be aware of any potential comprehension difficulties a patient may be having. To mitigate this important limitation, IPDAS recommends for research purposes the assessment of the health literacy of a patient population followed by selection or development of a DA written at that level.^{104,105} When formal assessment of a patient population's health literacy is not possible, using AHRQ's Health Literacy Universal Precautions can be helpful. These universal precautions include general strategies such as writing in plain language, simplifying communications, and confirming understanding through methods such as teach back.¹⁰⁶ In addition, the clinicians can use the DA in the SDM discussion, often called encounter DAs or conversation DAs,¹⁰⁷ these may also be enhanced with the real time use of Option Grids.¹⁰⁸ There remain many other unanswered questions regarding DAs including how to make them most efficient, their effects on clinical workflow, and their costs. The workgroup recommends and supports future research to address these questions critical to DAs' dissemination and implementation.

Decision Aids Relevant to Urologic Practice

DAs in various formats and languages have been published for many different urologic conditions. The OHRI "maintains the world's largest inventory of patient DAs."¹⁰⁹ To be included in the OHRI database, DAs must be freely available, include an update date that is within the past five years, provide scientific references, and include information about both the diagnosis and possible treatment options considered. The database also provides a score of each DA based on the IPDAS-quality criteria.⁹⁰ The OHRI database includes DAs in multiple languages and currently covers fourteen urologic topics ranging from pediatric diagnoses such as circumcision and undescended testes to choosing a urinary diversion following cystectomy. The OHRI database also includes multiple DAs for some urologic topics including fourteen different English language DAs covering prostate cancer screening or treatment. An additional repository for DAs is the Option Grid website, which includes DAs on treatment choice for prostate cancer of various aggressiveness as well as on PSA screening decisions.¹⁰⁸

While some diagnoses already have a variety of available DAs, new DAs are also being developed to help clinicians and patients engage in SDM. For example, a recently published DA produced through a collaboration of clinicians and patient focus groups is designed to help transgender men make decisions regarding genital gender-affirming surgery.¹¹⁰

Barriers to Implementing Shared Decision Making

Despite the benefits of SDM, its uptake and use in practice has not been universal.^{111,112} Barriers to implementation of SDM are many and varied.⁴⁵ Such barriers are categorized below as stemming from the attitudes and behaviors of both providers and patients, as well as from system-level influences.

Clinician Barriers

Clinicians may consider the clinical situation to not warrant SDM or they are not convinced of the evidence supporting SDM. However, even providers who do recognize SDM's theoretical advantages may not routinely implement SDM into their practices. Studies have found that fewer than 10 percent of providers correctly implement SDM in their practices.¹¹¹ Some providers find that SDM techniques, like having an external summary sheet or presenting unconventional treatment options, feel "artificial" or are challenging to learn and use, suggesting poor provider self-efficacy.^{113,114} Others consider it difficult either to communicate the basics of SDM, especially to patients who might not be as comfortable engaging in these discussions, or to assess how much disease-specific knowledge or decision-making involvement a patient wants.¹¹⁴ Additionally, incomplete understanding of the differences between SDM and usual care conversations can lead to an insufficient change in provider behavior.^{115,116}

The most common perceived barrier to SDM implementation is the assumption that SDM will lengthen consultation time.⁴⁵ Additionally, some clinicians perceive SDM as not attractive to patients because of characteristics such as patient age, gender, anxiety level, cultural background, personality, education or health literacy.^{45,113,114,117,118} However, patients often feel that providers underestimate their interest in participating in SDM.^{45,118} Many providers may be pre-selecting patients for SDM who they perceive as having interest in the process or having the capability of deriving benefit from SDM.⁸⁴ Such bias decreases access to SDM and may exacerbate racial and socioeconomic disparities already present in the use of SDM.^{119,120}

Other more subtle provider attitudes may create additional barriers to SDM. Some providers perceive that SDM challenges their autonomy by involving patients more closely in their own health decisions; such an attitude on the part of clinicians, unsurprisingly, results in decreased SDM engagement.¹¹⁸ Another provider barrier to implementation of SDM is the reluctance of certain clinicians to disclose uncertainty.¹²¹ This may be uncertainty regarding the likelihood of an outcome or complication, the strength of evidence on which that probability is estimated or the extrapolation of population outcomes to the individual. Providers attribute their discomfort to concern that patients might consider them to have inadequate knowledge, that they might appear foolish or that they might lose patients' trust.¹¹⁷ Although such concerns may appear to be well-founded, a recent qualitative study found that many patients endorsed the notion that "doctors are just people ... and there is a lot they don't know."¹²² Less experienced providers tend to be the most uncomfortable with disclosing uncertainty.¹²²

Providers' disagreement with currently accepted interpretations of available evidence or guidelines, disagreement with presentation of medical information or perception that available tools or DAs are not applicable to a given patient's clinical situation can also become barriers to the implementation of SDM.^{113,115,123} Paradoxically, strong clinician agreement with guideline recommendations may also be a barrier to SDM should the clinician paternalistically defer SDM in an effort to prevent the patient from making a "bad" decision.^{45,111} Such findings are not inconsistent, as clinician opinion to either extreme may undermine SDM if the opinion is so extreme as to override the clinician's respect for patient autonomy.

Related to this, providers may restrict their SDM discussions to treatments that are available to them.²⁶ For example, in a Veterans Affairs hospital setting, providers that had the robot available framed robotic prostatectomy more favorably than providers at institutions with no robot. In an environment where resources are democratized, SDM likely better balances treatment options than in areas where availability dictates treatment choice.

Patient Barriers

Although most patients want information about their condition and want to be asked about their preferences, some still want their provider to make the final decision.¹¹⁴ These control preferences could be a barrier to SDM if the patient gives up authority for the final decision. Long-term satisfaction may be lower among such patients.¹²⁴ Another important barrier to SDM is some patients' perception of their own vulnerability and their fear that being assertive might adversely impact their care.^{122,125} Reluctance to questioning their providers or even guilt at taking up their providers' time is a problem among patients, regardless of their socioeconomic status.^{120,122} Patient passivity is a significant barrier to SDM. Another potential barrier is a lack of SDM self-efficacy. Given that these diagnoses are often new and frightening and come with a lot of complicated jargon, patients may not feel they have the knowledge required to participate in SDM.¹²⁶ Additionally, patients often do not anticipate participating in SDM, as it is still uncommon to most clinical encounters.¹¹¹ Because there is no expectation of SDM, exclusion of SDM does not prompt a negative reaction from the patient. This lack of expectation becomes a subtle barrier, as physicians may feel no pressure to engage in SDM if patients do not address its absence. Finally, patient perception of provider behavior can also be a barrier to SDM. When interviewed in a qualitative study assessing barriers to SDM, patients who felt disrespected, felt that their concerns were not heard or described their clinicians as authoritarian did not wish to participate in SDM.¹²²

System-level Barriers

Most system-level barriers to implementation of SDM highlight the tension between the efficiency necessary for a large volume of patients and the time and thought necessary to tailor information for specific patients. In order for it to be effective, SDM must be integrated with institutional efforts to improve care for patients with complex diagnoses. Without careful planning, even beneficial care models, such as multidisciplinary clinics, may actually expose patients to a higher likelihood of being influenced by a single biased provider who may steer patients toward particular management options based on their personal experiences.^{114,118} Institutional efficiency targets also may create barriers to SDM, as studies suggest they lead providers into pressuring patients to make decisions quickly, which providers feel may compromise SDM.^{113,117} In an unprepared environment, SDM has the potential to produce significant workflow disruption.¹²⁷ A study of gastrointestinal clinicians found that the lack of ancillary staff time, reimbursement and relevant DAs were perceived as major barriers to SDM implementation in patients with inflammatory bowel disease.¹²⁸ Application of technology-based SDM interventions may better incorporate the tenets of SDM without disrupting clinic workflow. For example, a video presenting prostate cancer treatment options increased patient knowledge for their treatment options without affecting clinic workflow.¹²⁹

Scheduling and distribution of labor among clinician and ancillary staff are systems-level issues that must be addressed by an organization seeking to implement SDM in order to facilitate workflow and quality patient care.

Although a broad consensus of patients, healthcare providers and politicians advocate implementation of SDM, there is little discussion of where to find the resources necessary to execute it well.

Decision Coaching

Decision coaching is a structured approach used to facilitate the decision making process and help patients think through their screening and treatment options.¹³⁰ This type of coaching can be done independently or alongside a DA. Compared to usual care, decision coaching has been shown to improve knowledge.¹³¹ However, this improvement in knowledge is similar to the knowledge obtained from exposure to a DA alone.¹³¹ Accordingly, decision coaching may be a suitable strategy for situations when a DA is not available or when a social process is required in clarifying and discussing values, verifying understanding, and facilitating progress in decision making.¹³¹ More research is needed to better understand the contribution of decision coaching on decision quality, psychological outcomes, and health outcomes.^{130,131} Other gaps in the decision coaching literature include the best ways to train health professionals in decision coaching, who should deliver decision coaching (e.g., health professional or lay coach), and whether decision coaching should be conducted by one member of the healthcare team or shared among various members of the team.^{130,131}

What is a Decision Coach?

Broadly defined, a decision coach is a trained healthcare professional who is non-directive and provides decision support intended to build a patient's skills in the following areas: 1) thinking through options; 2) discussing decisions with healthcare providers during medical encounters; and 3) carrying out the decision once an option has been chosen.¹⁰⁹ Although the decision coach role is often performed by a registered nurse, other members of healthcare team can fulfill this role.¹³²⁻¹³⁴ For example, in prior studies, decision coaching has been provided by premedical students, pharmacists, health educators, psychologists, physicians, and genetic counselors.¹³² Decision coaching can be done face-to-face or by telephone. While limited research exists on the efficacy of other virtual decision coaching options (e.g., Health Insurance Portability and Accountability Act (HIPAA)-compliant mobile apps and web-based platforms), these options may become more common as novel telemedicine technologies are increasingly implemented within healthcare systems.

Models to Support Decision Coaching

Several studies have explored how to deliver components of decision coaching. Myers et al. compared a standard intervention (brochure and practice quality assessment survey) to an enhanced intervention (brochure plus a nurse-led decision counseling session) to support informed decision making about prostate cancer screening.¹³⁴ Vines et al. trained lay health advisors called "prostate cancer ambassadors" to support informed decision making about prostate cancer screening; the curriculum was based on adult learning theory and social cognitive theory.¹³⁵ The FAST model (Formulate issues, Analyze issues, Synthesize insights, Translate insights into action) has also been used to support decision coaching.¹³⁰ Compared to usual care, men with prostate cancer who received coaching based on the FAST model had higher decision self-efficacy and lower decisional regret.¹³⁶ In a different context, Sepucha et al. evaluated the use of consultation planning and consulting recording templates to help nurses support decision making for women facing breast cancer treatment decisions.¹³³ Lastly, Belkora et al. examined the use of a consultation planning intervention to help cancer patients make lists of questions before seeing their clinician.¹³⁷ In that study, employees and volunteers from rural community-based resource centers conducted the consultation planning sessions. In general, these studies found decision coaching increased knowledge and patient satisfaction, suggesting this might be an effective strategy to promote SDM in clinical practice.

To date, there are limited data on the efficacy of decision coaching in certain subgroups of the population such as older adults, those with lower socioeconomic status, underrepresented racial and/or ethnic minorities, and those with lower literacy and numeracy levels.¹³¹ There is also growing attention to the potential placement of decision coaches within healthcare teams.¹³¹ Historically, decision coaches or community health workers have performed this role as part of a research study and thus, were not fully integrated into the routine healthcare team (i.e., working *parallel* to the healthcare team versus *with* the healthcare team). The Interprofessional Shared Decision Making (IP-SDM) conceptual model clearly positions the decision coach role as an integral part of an interprofessional team.¹³⁸ Such frameworks may enhance future integration of decision coaches into routine clinical care.¹³²

Resources for Training in Decision Coaching

The OHRI website provides many helpful resources for decision coaching including scripts to help standardize how such training is provided, video demonstrations, a generic personal decision guide, and overviews of relevant frameworks. For example, the "decision coach-mediated SDM" framework expands SDM beyond the patient-clinician dyad.^{132,134} With this approach, a decision coach prepares the patient to participate in healthcare discussions with a primary clinician. The SLCT process for initiating critical reflection (slctprocess.com)¹³⁹ and SCOPED checklist for making decisions (scoped.com)¹⁴⁰ developed by Dr. Jeff Belkora also provide helpful resources for decision coaching.

Training Urologists to Use Shared Decision Making

Although SDM training initiatives are increasing in number to meet growing interest,^{141,142} data on the effectiveness of SDM training programs for health professionals⁸ and trainees¹⁴³ is limited. To evaluate these training programs, an

international and interdisciplinary working group agreed on the importance of relational competencies (e.g., listening to the patient, adapting information into plain language, and otherwise facilitating patient involvement) and risk communication competencies (e.g., discussing uncertainty and effectively communicating about risks and benefits).¹⁴⁴ Yet few studies have used these competencies to examine the effectiveness of SDM training. In those that have, role play-based training formats emphasizing practical skills might lead to more SDM proficiency compared to didactic theoretical presentations of SDM.¹⁴⁵ In graduate medical education contexts, workshop-based instruction including skills-focused resources and interactions have been shown to improve SDM performance.^{146,147} A one-day workshop, including two hours of written and oral didactic content, a 30-minute video modeling ideal behavior, four hours of role-play practice, and 30 minutes of individual feedback on audio-taped patient consultations, has also demonstrated effectiveness in improving SDM skills among oncologists.¹⁴⁸ More research is needed to determine the optimal length, format, and evaluation process of SDM training programs for urologists.

AHRQ provides SDM resources for clinicians according to a method that they call the SHARE Approach: 1) **S**eek your patient's participation; 2) **H**elp your patient explore and compare treatment options; 3) **A**ssess your patient's values and preferences; 4) **R**each a decision with your patient; and 5) **E**valuate your patient's decision.^{5,149} Table 1 displays the SHARE Approach steps as they apply to a sample urology context: clinically localized prostate cancer.

Table 1. AHRQ SHARE Approach As Applied to An Example in Urology: Decision-Making about Clinically Localized Prostate Cancer *

SHARE Steps	Sample Language
<p>1. Seek your patient's participation</p> <p><i>Summarize the health problem.</i></p> <p><i>Ask your patient to participate.</i></p> <p><i>Include family and caregivers in decisions.</i></p> <p><i>Remind your patient that his or her participation is important.</i></p>	<p>"It's time for us to think about what to do next."</p> <p>"Let's go over the options so we can find a path that works for you."</p> <p>[If patient defers to you to make the decision]: "I'm happy to share my views based on what I know about you. But first, I'd like to ask you some questions so I make sure I understand what matters most to you. There is no one best option here. Once I make sure I understand what's important to you, we can work together to make a decision that fits your needs."</p>
<p>2. Help your patient explore and compare treatment options</p> <p><i>Assess what your patient already knows about his or her options.</i></p> <p><i>Write down a list of the options and describe them in plain language.</i></p> <p><i>Clearly communicate the risks and benefits of each option.</i></p> <p><i>Offer evidence-based DA tools whenever possible.</i></p> <p><i>Use the teach-back technique to check for understanding.</i></p> <p><i>Use the teach-back technique to check for understanding.</i></p>	<p>"What have you heard about prostate cancer?"</p> <p>"Let's talk about what the research says about the benefits and risks of each treatment option."</p> <p>"I want to make sure I explained the options clearly. Would you please share with me what you'd tell a family member about your options?"</p>

<p>3. Assess your patient's values and preferences</p> <p><i>Encourage your patient to talk about what matters most to him or her.</i></p> <p><i>Ask open-ended questions.</i></p> <p><i>Listen actively, showing empathy and interest.</i></p> <p><i>Acknowledge the values and preferences that matter to your patient.</i></p>	<p>"As you think about your options, what's important to you?"</p> <p>"What concerns you the most about this choice?"</p>
<p>4. Reach a decision with your patient</p> <p><i>Ask your patient if he or she would like additional information to help make a decision.</i></p> <p><i>Check to see if your patient needs more time to consider the options or discuss them with others.</i></p> <p><i>Confirm the decision with your patient once it is made.</i></p> <p><i>Verify next steps.</i></p> <p><i>Schedule follow-up appointments.</i></p>	<p>"It is fine to take more time to think about the options. Would you like some more time, or are you ready to decide?"</p> <p>"What other questions do you have for me to help you make your decision?"</p> <p><i>[if DAs are available, hand out a DA to review]</i></p>
<p>5. Evaluate your patient's decision</p> <p><i>Make plans to review the decision in the future.</i></p> <p><i>Monitor the extent to which the treatment decision is implemented.</i></p> <p><i>Assist your patient with managing barriers to implementation.</i></p> <p><i>Revisit the decision with your patient to determine if other decisions need to be made.</i></p>	<p><i>[if the patient wants more time to decide]</i> "Here is some information you can review when you talk to your family about your choices. Let's talk again in 2 weeks to discuss how you are feeling about your choice."</p> <p><i>[if the patient chooses active surveillance]</i> "Let's plan to review this decision in about six months."</p> <p><i>[if the patient chooses surgery or radiation therapy]</i> "Let's get you on the schedule for treatment/surgery."</p>

*Adapted from AHRQ's SHARE reference guide¹⁴⁹

Incorporating Shared Decision Making Into Practice

SDM is increasingly incorporated into clinical guidelines, including in urologic contexts. For example, for clinically localized prostate cancer, current AUA/American Society for Radiation Oncology (ASTRO)/Society of Urologic Oncology (SUO) guidelines specify that “treatment selection should consider patient, tumor, and treatment-related factors...allowing patient values to drive this decision.”¹⁵⁰ Additionally, the AUA guideline for early detection of prostate cancer recommends SDM for men ages 55-69 who are considering PSA-based screening.¹⁵¹

SDM is an important component of high-quality, patient-centered health care.¹⁵² Organizations such as the Centers for Medicare & Medicaid Services (CMS) now require documentation of SDM in order to process payment for selected screening tests and procedures such as lung cancer screening, left atrial appendage closure therapy, and implantable cardioverter defibrillator placement.¹⁵³⁻¹⁵⁷ Some accountable care organizations plan to require SDM for clinically localized prostate cancer and benign prostate hyperplasia treatment decisions.^{153,154} Additionally, recent changes to the Merit-Based Incentive Payment System (MIPS) have designated SDM as a performance metric to inform clinician reimbursement.¹⁵³ SDM skills are therefore highly relevant to the urology community.

A strategy should be devised to implement SDM. OHRI outlines five steps (Figure 1).¹⁵⁸ Additionally, routine patient-facing materials should be tailored to facilitate patient participation in decision making by increasing readability through use of plain language. For example, initial study of a patient-centered prostate biopsy pathology report demonstrates its utility for improving patients’ information recall.¹⁵⁹

Decision making is a longitudinal process that cannot be achieved in one session.¹⁶⁰⁻¹⁶³ A prime example of this is localized prostate cancer under active surveillance. Engaging in SDM over time can present challenges for both clinicians and patients in the absence of explicit guidance about SDM across multiple visits; DAs might facilitate SDM by allowing patients to review information and consider their preferences that might change with new data or lifestyle adjustments.¹⁶⁰ Table 2 summarizes practical strategies to engage in SDM despite some reported barriers to the process.

Table 2. Strategies for overcoming common concerns of SDM and/or DA use

Common Concerns	Strategies
Patients do not seem to want to participate in the decision-making process. ¹⁶⁴	Provide information about treatment options before assessing patients’ interest in SDM. ^{160,165} Recommend the SDM process, ¹⁶⁶ adapting it as needed to suit patients’ interest. ²³
Urologists and urologic surgeons lack familiarity with DAs. ²¹	Access and review publicly available DAs through ¹⁶⁷ and the OHRI Decision Aid Inventory, ¹⁶⁸ and/or subscription-based DAs which may be available through urologists’ health systems.
Urologists and urologic surgeons prefer locally-derived data about treatment options, risks, and benefits over the population-level data found in DAs. ²¹	Tailor DAs to maximize their relevance to your practice, e.g., by supplementing existing content with locally-derived data and (if format allows) adding other handwritten notes.
Treatment/management decisions are often longitudinal – not standalone events. ^{160,169}	Make explicit plans to revisit the decision together with the patient at a clinically-appropriate interval. ⁶⁹ Motivational interviewing techniques, such as asking open-ended questions, reflective listening, building motivation, and providing information, can be used to address patients’ values and barriers to implementing a care plan and may improve cancer-related anxiety. ^{160,170,171}

Conclusion

SDM is a collaborative, decision-making process between patients and their healthcare providers relevant to medical decisions where multiple options are considered clinically acceptable. SDM represents the state of the art in counseling patients faced with difficult or uncertain medical decisions. Its use is encouraged by the National Academy of Medicine (NAM), the ACA and by AUA guidelines statements, yet SDM is underutilized in clinical practice. The objective of this paper is to encourage and support implementation of SDM into routine clinical practice. It outlines the components essential to SDM, the processes by which clinicians can fulfill those criteria (including listing education and evaluation resources), and the processes by which SDM can be implemented on a systems level. Numerous barriers to the implementation of SDM exist but may be overcome by adhering to these processes.

This panel strongly endorses that urologists learn about SDM and adopt it into their clinical practice.

Take-away Points

SDM is a collaborative, decision-making process between patients and their healthcare providers relevant to medical decisions when multiple options are considered clinically acceptable.

The key elements of SDM include:

Involvement of both the clinician and the patient in the decision-making process.

Sharing information by both the clinician and the patient.

Building consensus through the expression of preferences by both clinician and patient.

Agreement by both the clinician and patient on the decision to implement.

SDM represents the state of the art in counseling patients faced with difficult or uncertain medical decisions. Decision aids are tools that can facilitate, but not replace, SDM.

SDM is underutilized in clinical practice.

Implementing SDM into routine clinical practice involves key steps, such as AHRQ's 5-step SHARE Approach:

Seek your patient's participation

Help your patient explore and compare treatment options

Assess your patient's values and preferences

Reach a decision with your patient

Evaluate your patient's decision¹⁴⁹

ABBREVIATIONS

ACA	Affordable Care Act
AHRQ	Agency for Healthcare Research and Quality
ASTRO	American Society for Radiation Oncology
AUA	American Urological Association
CMS	Centers for Medicare & Medicaid
DA	Decision aid
DEEP-SDM	Detail of Essential Elements and Participants in Shared Decision Making
DSAT-10	Decision Support Analysis Tool
GEM	Grid-Enabled Measures
HIPAA	Health Insurance Portability and Accountability Act
IPDAS	International Patient Decision Aid Standards
IP-SDM	Interprofessional Shared Decision Making (IP-SDM)
MIPS	Merit-Based Incentive Payment System
NAM	National Academy of Medicine
NCI	National Cancer Institute
NQF	National Quality Forum
OHRI	Ottawa Hospital Research Institute
PEMAT	Patient Education Materials Assessment Tool
PSA	Prostate-specific antigen
SDM	Shared decision making
SHARE-IT	SHARing Evidence to Inform Treatment
SUO	Society of Urologic Oncology
USPSTF	United States Preventive Services Task Force

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