Shared Decision Making

State of the Science

Grace A. Lin, MD, MAS; Angela Fagerlin, PhD

Patients have traditionally entrusted decision making to physicians. However, during the past several decades, patients have been encouraged to become more activated and involved in their health decisions. These situations abound in cardiology, for example, therapy for stable coronary artery disease, anticoagulation for atrial fibrillation, and placement of implantable cardioverter-defibrillators. Each condition demands patient participation in the decision-making process because patients live with the consequences of medical decisions in their day-to-day lives. Unfortunately, research has also shown that patients often are misinformed about the risks and benefits associated with treatments and have little involvement in the decision-making process.1,2 Thus, 1 of the great challenges of increasing patient engagement is ensuring that patients make informed, evidence-based decisions that are consistent with their values and preferences.

Shared decision making (SDM) has come to the forefront as a way to improve clinical care for patients by encouraging the production and dissemination of accurate, balanced, understandable health information and increasing patient participation in care. SDM interventions have been shown to improve patients’ understanding of the available treatment options, increase the proportion of patients with realistic expectations of benefits and harms, stimulate patients’ involvement in decision making, and improve agreement between patients’ values and treatment choices.3 Incorporating patient preferences into the decision-making process may also lead to improved patient well-being through better adherence to treatment, fewer concerns about illness, and higher satisfaction with health outcomes.4,5

In this article, we review the state of the science in the field of SDM. We discuss models of SDM, as well as methods for providing decision support to patients, including best practices for risk communication, efficacy of decision aids (DAs) for decision support, and use of decision coaches to facilitate shared decision making.

Models of SDM

SDM was first invoked by the President’s Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research in 1982.6 One of the earliest and most commonly cited models of SDM is from Charles et al.,7,8 aptly subtitled “It Takes at Least Two to Tango.” The model lays out the basic principles of SDM (Table 1). There must be involvement of ≥2 participants, and each party takes steps to be involved in the decision-making process and freely share information with the other. The physician’s responsibility is to give accurate medical information, elicit and acknowledge patients’ preferences for participation, give the patients choices about how the decision-making process will proceed, and respect patients’ choices. Patients have the responsibility to communicate their values, goals, and preferences to the physician. Finally, when a treatment decision is made, both parties agree to the decision. Later models build on the basic principles of SDM laid out by Charles et al.7,8

A systematic review found significant variation in the definition of SDM in the literature, in both the processes documented and the roles and responsibilities of the patients and clinicians.9 Makoul and Clayman9 found that 4 models were most commonly cited,7,10–12 and they derived 9 essential process elements as follows: (1) defining and explaining the problem, (2) presenting options, (3) discussing pros and cons (benefits/risks/costs), (4) sharing patient values and preferences, (5) discussing patient ability and self-efficacy, (6) offering doctor knowledge and communication, (7) checking and clarifying understanding, (8) making or explicitly deferring a decision, and (9) arranging follow-up. Other elements of SDM such as providing unbiased information, defining roles and desire for involvement, deliberation and negotiation, partnership, and coming to a mutual agreement are also mentioned.

Although the principles underlying SDM have been clearly laid out, implementation of these principles into routine clinical care has been much less successful. Recognizing the practical barriers to implementation, more recent models have focused on how to involve patients effectively in the decision-making process. For example, Elwyn et al11 have proposed a 3-step model designed to help patients through the decision-making process as follows: (1) introducing choice through offering options and justifications for those options, (2) describing options, and (3) helping patients explore preferences and make decisions. Matthias et al14 propose a model that emphasizes the importance of physician communication skills and emphasize that SDM is important not only at the decision point, which is the focus of most SDM interventions,
Table 1. Comparison Between Types of Decision Making

<table>
<thead>
<tr>
<th>Stage of Decision Making</th>
<th>Paternalistic</th>
<th>In Between Approaches</th>
<th>Shared</th>
<th>In Between Approaches</th>
<th>Informed</th>
</tr>
</thead>
<tbody>
<tr>
<td>Information exchange</td>
<td>One way, from provider to patient; provider decides what information to share</td>
<td>Two way; both parties share all relevant information (medical and personal)</td>
<td>One way, from provider to patient; provider shares all relevant information</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Deliberation</td>
<td>Mainly provider</td>
<td>Physician and patient opinion sought/offered; patient acknowledges and agrees</td>
<td>Mainly patient</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Decision</td>
<td>Provider alone</td>
<td>Patient led and provider opinion sought/offered; patient acknowledges and agrees</td>
<td>Patient alone</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Adapted with permission from Charles et al and Makoul and Clayman. Authorization for this adaptation has been obtained both from the owner of the copyright in the original work and from the owner of copyright in the translation or adaptation.

but during the entire encounter. However, there have been few studies of interventions to train healthcare professionals and increase adoption of SDM, so consistently effective programs for training in SDM have yet to be identified.15

Although most models of SDM concentrate on the relationship between an individual clinician and patient, Légare et al have developed an approach that incorporates other actors, including family, surrogate decision makers, and an interprofessional team (physicians, nurses, health coaches, etc), and promotes collaboration among all parties to assist the patient in making a decision. The importance of such expanded models is likely to increase because care models increasingly shift toward use of interprofessional teams.

Although the emphasis varies among the models of SDM discussed above, all describe ideal elements and processes to achieve SDM in clinical care (Table 2). Implementation of SDM requires both the recognition of preference-sensitive decisions and the ability to provide decision support to patients. Several methods of providing decision support have been developed, the most common of which—DAs, health communication skills, and decision coaching—we describe below.

**Providing Decision Support**

Most models of SDM are applicable to preference-sensitive decisions, in which there is >1 medically reasonable choice available, and the risk–benefit ratio depends on how the patient values certain outcomes (eg, Class IIa and IIb recommendations in clinical practice guidelines). For example, in patients with atrial fibrillation who qualify for anticoagulation therapy, the benefit of stroke prevention must be balanced against the risk of bleeding and the inconveniences associated with anticoagulant medications. In such situations, the information the patient provides about his or her preferences is critical to making the right decision. Unfortunately, physicians can often misdiagnose patient preferences if preferences are not explicitly discussed.17

However, SDM is also a continuum.18 Although most patients would like to be informed about a decision, their preferences for participation in the decision-making process may vary depending on the situation. For example, older patients tend to want to be informed of their choices but prefer to rely on physician recommendations.19 Women, more educated patients, and patients deciding whether to undergo an invasive procedure tend toward wanting to be partners in the decision-making process with the physician.20,21 On the contrary, patients facing uncertain or unfamiliar situations may need assistance from their physicians or other providers, decision coaches, or family members to form their preferences for participation and for treatment.21

Assessing the patient’s preference for style of decision making is a critical initial step toward identifying whether a shared decision-making process is appropriate for the situation. A common measure of preference for SDM is the Control Preference Scale, which asks people whether they prefer (1) to make the final treatment decision, (2) to make the final selection of their treatment after considering their doctor’s opinion, (3) that their doctor share responsibility, (4) that their doctor make the final decision after considering their opinion, or (5) to leave all treatment decisions to their doctor. This question could easily be asked in clinic visits, although it is only currently asked in research settings.22

Although many advocate SDM in theory, there are challenges for practicing SDM in the clinical setting. Physicians may feel that they do not have the time or skills to communicate patient-specific information about treatment options and outcomes, although studies show that engaging patients in SDM does not seem to lengthen the encounter.23,24 In the next section, we discuss evidence-based tools to help facilitate SDM.

**Best Practices for Risk Communication**

A key piece of the SDM process is ensuring that patients are well informed about the risks, benefits, and alternatives of the treatment(s) available. Unfortunately, patients face numerous challenges in understanding the medical information they need to make informed decisions. Many of the available decision support materials are written at higher literacy levels than the average patient is able to read.25 The average American reads at about the eighth-grade reading level,26 yet DAs have been found to be written at a 12th-grade or higher level—meaning that the information is incomprehensible to many patients.

Inadequate numeracy may also harm patients’ ability to make informed decisions. People who have difficulty understanding or using numeric information (eg, risk and benefit statistics) may have a reduced ability to make accurate comparisons between the risks and benefits of treatment (or no
Innumeracy is pervasive, with approximately half of the adults in the United States unable to accurately calculate a tip and 20% of college-educated adults not knowing which of the following risks is higher: 1%, 5%, or 10%. To put the issues of low numeracy into clinical perspective, when a cardiologist tells a patient that 64% of patients with angina will have symptom relief with medical therapy in the first year or that the risk of heart attack during percutaneous coronary intervention is 2% to 5%, many patients will not understand such statistics well enough to use them as part of making an informed decision. Thus, patients may make decisions not reflective of their preferences.

Finally, in part, because of patients’ difficulty with health literacy and numeracy, physicians often use verbal qualifiers (eg, you have a high risk of a heart attack) rather than using numeric or graphical formats. Although patients may prefer qualitative explanations of risk, studies have demonstrated that interpretation of these imprecise terms is highly variable. For example, high risk to a physician may mean 5%, but to a patient, it may mean 25% (or vice versa). Thus, numeric and graphical representations of risk are preferred for clear risk communication. Below, we present 3 evidence-based tips on how to more clearly communicate risk to patients. Other tips, although geared toward oncologists, can be found elsewhere.

### Tip 1: Present Statistical Information Using Absolute Risk

When trying to educate patients about the risks associated with their treatment options, one must decide whether to present that information using absolute or relative risk presentation. For example, a cardiologist could tell patients that taking a statin will decrease their risk of heart attack by 30% (relative risk) or that their risk of heart attack decreases from 10% to 7% (absolute risk). Research has consistently shown that changes in risk seem larger when presented using relative risk than when using an absolute risk and that medical treatments were viewed more favorably when presented in relative risk. Thus, the use of relative risk information can have negative consequences for patients in that it could cause patients to...
inaccurately perceive that a treatment is more effective than what has been empirically proven.

Even physicians are unduly influenced by relative risk presentation. Chao et al.33 had oncologists indicate their hypothetical prescribing behavior after reading a journal article describing a clinical trial of chemotherapy. Oncologists either had the benefits of chemotherapy presented using a relative risk or an absolute risk presentation. Oncologists were significantly more likely to prescribe the chemotherapy when the data were presented using relative risk information.

An even more difficult risk presentation strategy for patients to understand is number needed to treat. Sheridan et al.33a tested patients’ understanding of data presented using absolute risk, relative risk, and number needed to treat and found that number needed to treat was the most difficult risk communication method for patients to understand and recommend that it never be the only way risk information be communicated to patients.

**Tip 2: Highlight the Incremental Risks Associated With Treatment Distinctly From Baseline Risks**

Patients may not be able to differentiate their total risk of a side effect from the risk associated with treatment. For example, all adults have a baseline risk of stomach bleeding. However, that risk increases with taking aspirin. If patients just see the total risk of having stomach bleeding by those who take aspirin, they may perceive the risk of taking aspirin to be greater than what it is (ie, they may think that the entire risk is because of the drug because they are not accounting for baseline risks). Using an incremental risk approach can help differentiate these risks.34,35 For example, as seen in the Figure, the incremental risk approach draws attention to the change in risk. The risk of severe bleeding with aspirin (0.5 patients of 100) and the additional risk incurred if choosing warfarin (3.5 patients of 100) are depicted in the same pictograph. This makes it clear how a person’s risk changes as a function of the treatment chosen.

In a study of women at high risk of breast cancer who were considering chemoprevention, women who received risk information in a DA using the incremental risk approach were less worried about the side effects of treatment and perceived less risk of experiencing a side effect than those patients who received the same data but presented using a total risk presentation.34,35 This may be because of the fact that patients who only see the total risk may inaccurately think that all the risk is because of treatment and may not understand that some of the risk is baseline risk. The incremental risk approach addresses this inaccuracy and reduces this misperception. An important caveat is that the incremental risk approach was only beneficial when the data were also presented within a pictograph.

**Tip 3: Use Pictographs to Communicate Risk and Benefit Information**

A growing body of research has revealed that pictographs help all patients (regardless of numeracy) better comprehend risk information.36–38 Pictographs have been found to be more effective than bar graphs and tables and equally effective to pie graphs when communicating gist-level information (ie, the main point of the communication rather than the specific statistical information).36 Similarly, when the goal of communication is to convey exact statistical information, pictographs were again one of the top graphic formats as they were equally effective as bar graphs and tables but more effective than pie graphs.36 Thus, for communicating gist or verbatim information, pictographs were among the most effective graphical formats. However, recent articles suggest that when numbers are presented within graphs, bar graphs and pictographs have produced similar knowledge.39 Finally,
Decision coaching that is used to support decision making aims to provide patients with education resources (eg, DAs), help patients formulate questions related to the decision, and encourage patients to consider their values and goals of treatment.51,52 For example, Belkora et al52 have successfully used a decision coaching program to improve decision making in breast cancer patients by having patients review a DA and then participate in a structured interview with a trained coach. Topics covered during the consultation planning included the following: (1) questions or concerns about their diagnosis, (2) treatment options available, (3) objectives and goals for consultation and treatment, (4) key people involved in decision, and (5) the kind of information patients want or need to make the decision. The coach recorded the patients’ questions, concerns, and values into a document that was given to the

### Table 3. Useful Websites for Decision Aids

<table>
<thead>
<tr>
<th>Organization</th>
<th>Website</th>
<th>Description</th>
<th>Cardiology-Focused Decision Aids</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ottawa Hospital Research Institute</td>
<td><a href="http://www.decisionaid.ohri.ca">http://www.decisionaid.ohri.ca</a></td>
<td>Comprehensive list of available decision aids, toolkits for implementing decision support</td>
<td>Angina, AF, CAD, hyperlipidemia, stroke, valvular diseases</td>
</tr>
<tr>
<td>Mayo Clinic Knowledge and Evaluation Unit</td>
<td><a href="http://shareddecisions.mayoclinic.org">http://shareddecisions.mayoclinic.org</a></td>
<td>Paper and electronic decision aids for in-visit use</td>
<td>Statin for hyperlipidemia</td>
</tr>
<tr>
<td>Option Grids</td>
<td><a href="http://www.optiongrid.org">www.optiongrid.org</a></td>
<td>Paper decision aids for in-visit use</td>
<td>Angina, AF</td>
</tr>
<tr>
<td>Health Dialog/Informed Medical Decisions Foundation</td>
<td><a href="http://imdfoundation.org">http://imdfoundation.org</a></td>
<td>Video-based decision aids</td>
<td>CAD, CHF</td>
</tr>
<tr>
<td>Heathwise</td>
<td><a href="http://www.healthwise.org">http://www.healthwise.org</a></td>
<td>Online interactive decision aids</td>
<td>AF, pacemaker, implantable cardioverter-defibrillator, supraventricular tachycardia, hyperlipidemia, coronary artery bypass surgery, angioplasty, CHF, aortic stenosis, valve replacement, hypertension</td>
</tr>
</tbody>
</table>

**AF** indicates atrial fibrillation; **CAD**, coronary artery disease; and **CHF**, congestive heart failure.
patients and clinicians. Finally, the decision coach also accompanied patients to the clinic visit to take notes for the patients.

This process has been tested in several studies with positive results.\textsuperscript{51,53} Patients who participated in coaching had higher decision quality, and there was a greater match between patient and physician perceptions of the quality of the decision-making process. In addition, patients reported greater satisfaction with the appointment. The note taking also had significant benefits because patients did not have to worry about remembering the entire discussion, and thus the quality of the consultation improved.

There were also benefits for the physicians.\textsuperscript{53} Significantly, neither the length of appointments nor the number of follow-up appointments differed between those who received or did not receive coaching. In fact, patients and physicians were able to accomplish more in the same amount of time, and, anecdotally, physicians felt that the intervention helped them achieve a more effective, higher-level conversation that was focused on the critical issues. Note taking by the decision coach also led to physicians having greater confidence that patients had accurate recollections of the discussion.\textsuperscript{51}

Other researchers have developed different decision coaching programs that provide patients with a list of suggested questions to ask. Studies have found that these lists increased the number and quality of questions asked at medical appointments.\textsuperscript{55} Furthermore, some have suggested that 1 of the best methods for improving chronic disease care is to improve patient–physician communication by helping patients better prepare for their clinical encounter. Patients who feel that their physician understands their concerns, for example, feel more in control of their medication regimen, which could significantly improve patient health.\textsuperscript{56} Finally, decision coaching that incorporates the use of DAs improves decision quality, increases patient satisfaction, and is cost effective.\textsuperscript{57}

Trials of decision coaching for cardiovascular conditions, testing either individual coaching or group coaching led by primarily trained nurse coaches, have demonstrated that decision coaching seems to improve patients’ knowledge, level of anxiety, ability to participate in SDM with providers, and satisfaction with communication.\textsuperscript{56,57} However, as with DAs, evidence that such interventions affect health outcomes has not yet been established.

SDM Now and in the Future

SDM is 1 method of meeting the Institute of Medicine’s goal of providing patient-centered care. Practicing SDM with patients, particularly using DAs, clear risk communication, and decision coaching, can lead to improvements in patient knowledge, more accurate perceptions of risk and benefit, as well as increasing patient participation in the decision-making process and increasing the concordance between patient values and the treatment decision. The push to include SDM in clinical care and indeed make it standard of care is increasing, with both state and federal legislation recognizing that patient participation in healthcare decisions is critical to building a high-quality healthcare delivery system. Physicians can and should lead the way of incorporating SDM into their practice, and future installments of this series will provide guidance for successful implementation.

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References


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