Shared Decision Making

Measuring Shared Decision Making
A Review of Constructs, Measures, and Opportunities for Cardiovascular Care

Karen R. Sepucha, PhD; Isabelle Scholl, PhD

Shared Decision Making: Definition, Framework, and Key Constructs

In the past few decades, patient-centeredness has gained in importance,1,2 and policies to promote patient-centered care have been increasing.3 Several different models of patient-centered care have been described. Although these models vary on their specific definitions and dimensions, they all emphasize the importance of facilitating the engagement of patients in their own healthcare decisions.1,4,5

In some cases, facilitating patient engagement in decisions focuses on ensuring patients receive proven, effective care and do not receive proven, ineffective care. In cardiology, these situations often correspond to American College of Cardiology/American Heart Association class I or III recommendations with strong evidence, and the quality of decisions can be measured by the percentage of eligible patients who receive care that is consistent with the guidelines. Several quality measures endorsed by the National Quality Forum for cardiovascular care fall into these situations, such as the percentage of patients who receive \( \beta \)-blockers at discharge from cardiac surgery or persistence of \( \beta \)-blocker usage after a heart attack except for those patients at low risk.

However, even in situations with class I recommendations, some questions arise in implementing these recommendations into clinical care. For example, the high nonadherence rates for \( \beta \)-blocker therapy (or statin therapy) suggest that patients think differently about the tradeoffs between the potentially modest survival gain and the side effects of the therapy.6,7 In these cases, is it acceptable for patients to decline therapy, and if so, what if any documentation might we need to be confident that the decision was informed and high quality?

As Brindis and Walsh8 highlight in their presidential address, decisions, such as the use of statins for primary prevention, treatment of atrial fibrillation, valve replacement (eg, the use of tissue or mechanical valves), and use of implantable cardiac defibrillators, are all common for which there is not a clear attack except for those patients at low risk.

One approach that supports increased patient engagement in medical decision making is the model of shared decision making (SDM). The concept of SDM was first described in the 1980s9,10 and is an interactive process between patients (and family members) and the healthcare team to ensure that decisions are evidence based and patient centered. The key elements of SDM in the visit include defining and explaining the problem, helping patients (and providers) to recognize that a decision needs to be made, presenting options, discussing the pros and cons (ie, the outcomes in terms of benefits and risks and costs) of each option, eliciting patients’ goals and concerns (ie, finding out what matters most to them), discussing the ability and self-efficacy of patients in implementing the options under consideration, checking and clarifying the understanding, selecting a best option (or deferring decision pending test results, second opinion, etc), and arranging follow-up.11

The goal of SDM is to ensure high-quality decisions. Decision quality has been defined as the extent to which patients are informed, meaningfully involved in the decision-making process, and receive tests and treatments that reflect their goals and concerns.12-14 The Figure was adapted from Sepucha and Mulley15 and presents a simplified model of the medical decision-making process. The circles highlight the key stakeholders, patients and families, providers, and the healthcare organization within which they interact to make decisions. The squares indicate the main activities: consultation(s), care being delivered (this may be predominantly through the healthcare system or through the patient and family in case of lifestyle changes), and then outcomes that are experienced.

After the outcomes are experienced, 2 feedback loops describe how information about outcomes and experiences of patients is ideally used to improve quality of future decisions. The top loop represents the incorporation of evidence (such as the likelihood of different health outcomes for different patient populations), and the bottom loop represents the incorporation of goals and subjective experiences of patients (such as how good or bad the different outcomes are to live with). Patient decision aids, risk calculators, or other tools may be helpful to translate information from these feedback loops in ways that are accessible in routine care. Both streams of information are needed to ensure informed, patient-centered decisions.

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The Importance of Measurement of SDM

It is important to have a means of measuring SDM to understand the effect of interventions, such as patient decision aids, and the quality of decisions. Across the continuum outlined in the Figure, different constructs can be measured to provide insight into the decision-making process. These constructs are divided into 3 broad categories:

1. Decision antecedents or features of the patient, provider, or organization that may influence the decision-making process, such as the preference of patients for participation in decision making, health literacy of patients, competencies of a healthcare provider or skills in risk communication, or the availability of decision aids within a healthcare system.

2. Decision-making process focuses on the features or behaviors in the consultations (such as level of patient involvement or engagement, type of topics covered in the consultation, and use of decision support tools or methods), the amount and type of deliberation on the part of patients and providers, and

3. Decision outcomes, such as decision quality, that include knowledge and the extent to which patients receive treatments that match their goals, decision regret, and experience of patients with care.

The work of the International Patient Decision Aids Standards group has established consensus around the importance of measuring the involvement of patients in the decision-making process and decision quality to evaluate the effect of patient decision aids. For any given study, the most appropriate measures will be determined by the purpose of the study. Those interested in conducting research, for example, will tend to have more detailed assessments, possibly at multiple time points, to understand the effect of interventions or explore relationships between different constructs. There have been several randomized studies of patient decision aids in heart disease. For instance, the 2011 Cochrane Collaborative systematic review of patient decision aids included 8 trials of decision aids for cardiovascular disease. Three studies were about treatment of atrial fibrillation,21–23 2 about coronary revascularization,21,22 and 3 about prevention of heart disease.23–25 Other than patient demographics, few of these studies measured any decision antecedents. Three used some measure of preference of a patient for participation in decision making. About half of the studies included some measure of the decision-making process, 4 used the Decisional Conflict Scale (DCS), and 1 used an unnamed survey of the decision-making process. Most included an assessment of ≥1 decision outcomes. None had a

Figure. A model of medical decision making that highlights different measurement constructs. SDM indicates shared decision making. Reprinted from Sepucha and Mulley. Authorization for this adaptation has been obtained from the owners of the copyright in the original work and the translation or adaptation.
comprehensive assessment of decision quality, but many (7 of 8 studies) assessed 1 aspect of decision quality, knowledge of patients. Three also measured realistic expectations (or quantitative understanding of the risks and benefits of patients), and 3 assessed satisfaction with the decision-making process. As this subset of studies from the Cochrane review illustrate, there is wide variation in the measures used for evaluating patient decision aids.

Those interested in incorporating SDM in clinical care and conducting quality improvement studies often prefer shorter instruments that only include actionable information that can be easily integrated into routine care. One example of this type of use is described in Stacey et al for chronic pain caused by osteoarthritis. Patients are surveyed shortly after watching a decision aid and before heading to the specialist on a series of health-related outcomes (functional status, pain, and quality of life) and decision-making areas (knowledge, goals, decisional conflict, and treatment preferences). The data are then summarized in a report that provides an assessment of appropriateness of surgery for knee or hip osteoarthritis. Clinicians can use the report to address any knowledge gaps and ensure that treatments are tailored to patients’ goals and preferences. An example of such a patient report is shown in Figure 1 of Stacey et al.

SDM is now mentioned in regulations for patient-centered medical homes and accountable care organizations, which has resulted in increasing interest from healthcare administrators for reliable and valid means to document whether it has happened. For example, an administrator may be interested in understanding whether the rates of percutaneous coronary interventions for stable angina are appropriate at their center. A process measure of SDM for this situation might be the percentage of patients who received a decision aid before having the procedure. An outcome measure might be the percentage of patients who reported high decision quality (eg, the percentage of patients who met an established knowledge threshold and stated a clear preference for percutaneous coronary intervention over medical management or bypass surgery before undergoing percutaneous coronary intervention). Another approach that administrators might take is to use the SDM component of the Consumer Assessment of Healthcare Providers and Systems (CAHPS) survey, which includes items that assess whether patients were meaningfully involved in selecting treatments, the Patient-Centered Medical Home version, the Accountable Care Organization version, and the Surgical version of CAHPS include items relating to the decision-making process.

Criteria for Evaluating the Quality of Measures

Several different organizations have developed frameworks for evaluating survey instruments. One framework is the Consensus-Based Standards for the Selection of Health Measurement Instruments Checklist for assessing the methodological quality of studies on measurement properties, which was developed by an international, multidisciplinary expert group. The Consolidated Standards of Reporting Trials (CONSORT) group has also done considerable work to develop standards for reporting on patient-reported outcome measures, many of which are applicable to measures of SDM.

Table 1 gives a brief overview of important criteria from these frameworks that are relevant to SDM measurement that researchers can use to evaluate the quality of an instrument. In the literature on health measurement scales, many different criteria and definitions exist. Interested readers can find more details in the books of Streiner and Norman or Fowler.

Review of Key Measurement Instruments

There are many measures to assess the different aspects of SDM. In a recent review, Scholl et al identified 28 instruments that have undergone psychometric testing and that assess decision antecedents, the decision-making process, or decision outcomes. This review concluded that most of the existing scales showed good results on reliability and factorial structure of the measures. However, they also found that many measures need to be tested further, especially on aspects of validity. Other studies have found limited reporting on measures used in SDM studies, which renders an appraisal of the available measures difficult. An analysis of the measures used in the 86 randomized controlled trials that are included in the 2011 Cochrane review of patient decision aids found that for many measures there is a lack of reporting on the performance of measurement instruments used in the studies.

For investigators who plan to conduct research on SDM or to incorporate SDM into clinical practice, several helpful resources on measures of SDM are listed in Table 2. In the remainder of this section, we highlight several examples of published measures that assess decision antecedents, decision-making process, and decision outcomes and discuss some strengths and weaknesses.

For decision antecedents, 1 widely used instrument is the Control Preference Scale that assesses the preferred role of a patient in decision making. It was developed by Degner and Sloan and it has undergone psychometric testing in different settings and samples.

In the category of measures that assess the decision-making process, we highlight 4 measures. The Observing Patient Involvement (OPTION) Scale assesses the decision-making process from a perspective of external observer, by rating either a directly observed consultation or audio- or video-recorded consultations. Although several studies found good reliability of the instrument, for example, in a study on primary care visits on cardiovascular prevention, it could benefit from further testing about validity. One of the main advantages of the OPTION Scale instead of other observer scales is that it has been widely used in the research context for the past years also in studies on SDM in cardiology. Another benefit is that the original English version has been translated into 7 different languages (Chinese, Dutch, French, German, Italian, Spanish, and Swedish) and thus allows cross-country comparisons of research results.

Another instrument is the 9-item SDM Questionnaire. It has 2 versions: 1 that assesses the perspective of a patient (SDM-Q-9) and another that assesses the perspective of a healthcare provider (SDM-Q-Doc). Both versions have shown...
to be acceptable, reliable, and have factorial validity. A US-based study found indicators of convergent validity. The patient version has been tested in a subsample of patients with cardiovascular disease, showing appropriate psychometric properties. One of the main advantages is that they are brief tools with 9 items only. A further benefit is that the original German version has been translated into 9 other languages (Dutch, English, French, Hebrew, Italian, Japanese, Korean, Persian, and Spanish) and thus also offers a possibility to compare research results across countries or to pool data.

A third instrument to measure aspects of decision process is the DCS. The DCS is 1 of the most widely used measures in studies evaluating patient decision aids. There are several versions of the scale available, and the original includes 16 items in 5 subscales: uncertainty, informed, values clarity, support, and effective decision. The instrument has demonstrated strong psychometric properties in varied treatment contexts and patient samples and has undergone psychometric testing in a subsample of patients with cardiovascular disease. The DCS has also been translated into several languages (Chinese, Danish, French, German, and Spanish).

A final instrument worth mentioning is a supplemental set of SDM items now included in several versions of the CAHPS surveys. A screener item identifies respondents who report making a decision about starting or stopping a medication or having a procedure. The items were adapted from the Decision Quality Instruments (DQI; described in more detail in the next paragraph) and are fairly generic (eg, “Did any of your healthcare providers discuss the reasons not to have the medication/procedure?”) and often require respondents to

Table 2. Resources for Finding Measures of Shared Decision Making

<table>
<thead>
<tr>
<th>Resource</th>
<th>Description</th>
<th>Link/Reference</th>
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<tbody>
<tr>
<td>NCI GEM-Shared Decision Making measures database</td>
<td>A project initiated by the NCI that aims to harmonize measures of SDM. Key constructs and measures along with formal and informal ratings are available on the site.</td>
<td><a href="http://www.gem-beta.org">www.gem-beta.org</a></td>
</tr>
<tr>
<td>OHRI website</td>
<td>The OHRI website has a section on evaluation that includes access to instruments and scoring guides.</td>
<td><a href="https://decisionaid.ohri.ca/eval.html">https://decisionaid.ohri.ca/eval.html</a></td>
</tr>
<tr>
<td>Massachusetts General Hospital HDSC website</td>
<td>The HDSC website provides access to the decision quality instruments and scoring guides.</td>
<td><a href="http://www.massgeneral.org/decisionsciences/">http://www.massgeneral.org/decisionsciences/</a></td>
</tr>
<tr>
<td>CAHPS</td>
<td>CAHPS clinician and group surveys include items related to shared decision making for medication decisions.</td>
<td><a href="http://cahps.ahrq.gov/clinician_group/">http://cahps.ahrq.gov/clinician_group/</a></td>
</tr>
</tbody>
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CAHPS indicates Consumer Assessment of Healthcare Providers and Systems; GEM, grid enabled measures; HDSC, Health Decision Sciences Center; OHRI, Ottawa Health Research Institute; NCI, National Cancer Institute; and SDM, shared decision making.
reflect back over a period of time (“In the last 6 months, how often did your healthcare providers...”). CAHPS is the most widely used patient experience survey, and incorporation of an assessment of SDM, even if fairly general, will provide an opportunity to gather evidence on SDM practices in primary care and specialty providers in different settings. Some of the challenges of the CAHPS survey is the retrospective sampling and the lack of any clinical information on the actual decision.

Finally, we highlight 2 different measures that assess decision outcomes, one measuring decision quality and another measuring decision regret. DQIs have been developed for a range of common healthcare decisions, and they measure knowledge and the extent to which patients receive treatments that match their goals. The DQIs are decision specific and include multiple-choice knowledge items that are used to create a knowledge score and items to assess goals of patients and treatment received, which are then used to create a concordance score (reflecting percentage of patients who receive treatments that match their goals). Fourteen different DQIs are available for download (http://www.massgeneral.org/decisionsciences/). The DQIs for surgical treatment of breast cancer, herniated disc, and knee and hip osteoarthritis have demonstrated strong content and discriminant validity, as well as adequate retest reliability, and are acceptable to patients and feasible to implement.

A final outcome measure is the Decision Regret Scale, a 5-item scale used to assess the level of distress or remorse of patients about a decision that has been made. It has demonstrated strong internal consistency and has been shown to correlate with decision satisfaction, decisional conflict, and quality of life.

This section provides a brief summary of some of the common measures. For those interested in more details, please see the resources in Table 2 (eg, the Ottawa website has detailed documents on the DCS and the Decision Regret Scale). Furthermore, readers may be interested in the review by Scholl et al, who examined measures of SDM, or the review by Kryworuchko et al, who examined common primary outcome measures used in randomized trials of decision aids, including the DCS and the Control Preference Scale.

### Current Opportunities

The field of research on SDM in general and measurement of SDM in particular has grown considerably for the past few decades. Recently, it has received a lot of attention at the health policy level, and as a result, the call to measure its content and discriminant validity, as well as adequate retest reliability, and are acceptable to patients and feasible to implement.

The hip and knee osteoarthritis DQIs formed the basis for the quality improvement project referenced earlier in Ontario where patients are routinely screened for their knowledge and goals in advance of a specialist visit. One advantage of these instruments is the rigorous development process and strong psychometric properties; however, a disadvantage is the decision-specific nature of the surveys, which limits their feasibility and generalizability across topics.

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and providers also need to document that the patient is well informed and has clear preference for the procedure. There is an important role to be played by investigators and clinicians in cardiovascular disease to advance the field of SDM. Cardiology has been at the forefront of collecting and reporting of outcomes. However, the major cardiology registries do not include any patient-reported outcomes. There is an opportunity to build on the strong commitment to capturing outcomes to include patient-reported outcomes (eg, angina and quality of life) and aspects of decision-making process and decision outcomes (eg, decision quality and decision-making process) in registries. Doing so will help provide a clearer picture of the appropriateness of procedures and would enable assessment that the patients are not only clinically appropriate for a particular procedure but also provide some assurance that it reflects informed preferences of patients.

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References


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