Evidence-Based Medicine in Otolaryngology Part 7: Introduction to Shared Decision Making

Allison K. Ikeda1, Paul Hong, MD, MSc2, Stacey L. Ishman, MD, MPH3, Stephanie A. Joe, MD4, Gregory W. Randolph, MD5, and Jennifer J. Shin, MD, SM5

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Abstract

Shared decision making (SDM) is a collaborative process in which patients, families, and clinicians develop a mutually agreed upon treatment plan when more than one reasonable treatment option exists. This cooperative engagement fosters improvements in patient satisfaction, disease management, and outcomes and also has the capacity to promote evidence-based care. Thus, this seventh installment of our Evidence-Based Medicine in Otolaryngology series focuses on SDM. We introduce SDM, including its potential to reduce decisional conflict and decisional regret, when it should be used, its potential benefits, barriers to implementation, and its role in the management of chronic disease and otolaryngological conditions.

Keywords

shared decision making, decisional conflict, decisional regret, option grids, decision aids, evidence-based medicine, otolaryngology, pediatric otolaryngology, patient expectations, patient-centered care, health care utilization

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What Is SDM?

SDM is a process in which physicians and patients collaborate to mutually agree on individualized health care plans for treatment and diagnostic testing. The key components of SDM include (1) physician elucidation of clinical data; (2) accurate patient communication about personal values, preferences, and goals of treatment; and (3) cooperative conversation between physicians and patients to facilitate decisions that align clinical evidence and patient preferences in an individually tailored way. SDM thus involves a synergistic meeting of those with medical expertise (clinicians) and those with expertise in the relevant personal values (patients). Herein, we discuss multiple facets of SDM, including the related concepts of decisional conflict, decisional regret, option grids, and decision aids, as well as when SDM should be used, how it facilitates evidence-based practice, and its benefits and barriers.

What Are Decisional Conflict and Decisional Regret?

Decisional conflict and decisional regret are undesirable states that could result from decision-making process in medicine, and both may be alleviated through the practice of SDM. Decisional conflict is a state of uncertainty that

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shared decision making (SDM) occurs when clinicians and patients work in concert to develop management plans on the basis of current evidence and individual patient values and preferences. This process can facilitate improvements in health status, through better disease control and enhanced preventive measures. Accordingly, the Institute of Medicine has defined SDM as a key component of good quality care, and it has been incorporated into broad-scale initiatives on the international stage. SDM is typically applied in patient situations where the evidence has not delineated a single optimal management plan (eg, elective procedures). In the United States, SDM has received increased attention due to recent emphasis on patient-centered outcomes and reduction of wasteful spending and may also serve as the basis for Medicare/Medicaid payment innovation, as proposed by the Patient Protection and Affordable Care Act.

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What Are Decisional Conflict and Decisional Regret?

Decisional conflict and decisional regret are undesirable states that could result from decision-making process in medicine, and both may be alleviated through the practice of SDM. Decisional conflict is a state of uncertainty that
develops in the presence of inadequate knowledge, unclear values, insufficient support, and/or inaccurate perceptions; such conflict can lead patients and families to delay health care decisions and cause heightened emotional stress. Decisional regret is defined as distress or remorse that occurs after a health care choice has been made, when the patient and family are living with the results of their commitment. Decisional regret has been reported to be as high as 1 in 7 self-reported surgical patients and can be attributed to both patient- and procedure-related factors. SDM has been shown to significantly decrease both decisional conflict and decisional regret. Prospective data obtained from consecutive families whose children underwent consultation for pediatric otoplasty, adenotonsillectomy, or tympanostomy tube insertion demonstrated that parents who felt more included in the decision-making process reported less decisional conflict and decisional regret.

**When Should SDM Be Used?**

SDM may be applied in a range of clinical scenarios but is of greatest value in settings where there is no reflexively preferred choice. In these situations, decisions are often termed preference sensitive because in the absence of data delineating a single “best” option, the decision is influenced by patient preferences, as well as physician expertise and available resources. SDM may also be effective when managing chronic diseases, where patient preferences may evolve over time, and when considering screening measures that are potentially contentious (e.g., prostate-specific antigen for prostate cancer screening in healthy men). Decision support tools such as decision aids and option grids may help support this process; these tools are also typically developed to support health care decisions for which there is no clear-cut or obvious ideal choice.

**How Do Option Grids and Decision Aids Relate to SDM?**

SDM may be supported by option grids and decision aids, tools whose components have been detailed further in an earlier installment of this series. To review in brief, an option grid provides facts in a table that facilitates comparisons of management possibilities; option grids have been developed for otitis media with effusion, language options for deaf children, sore throat, and tonsillitis. A grid designed to support decision making from the recent Clinical Practice Guideline on Otitis Media with Effusion is shown as an example (Table 1). Decision aids have more facets than option grids and typically incorporate both published data and a determination of individual values and patient preferences. Their availability in otolaryngology is more limited. A decision aid example is provided in Figure 1. It contains not only a brief description of pediatric obstructive sleep apnea, management options, and the associated risks and benefits but also a section to help clarify family values. Employing option grids and decision aids before, during, and/or after appointments has demonstrated tangible improvements in informed consent, health-related quality of life, patient knowledge, and decisional conflict. Nonetheless, option grids and decision aids are not themselves the principal components of SDM; they are tools designed to support the SDM process. It is the interactive collaboration between clinicians and patients that is the indispensable core of SDM.

**How Does SDM Facilitate Implementation of Evidence-Based Practice?**

Evidence-based medicine has been said to stand on 3 pillars: clinical data, clinician expertise, and individual patient preferences. Shared decision making can be the culmination of this practice when multiple feasible management options exist. First, data from robust clinical studies form the foundation for discussion, and key study results are the springboard for the collaborative discussion. Second, clinician expertise is used to help explain the anticipated risks and benefits of each potential choice, as well as to provide insight into which might be best suited for the presenting patient. Furthermore, even when decision support tools such as decision aids and other supplementary materials are used, in many instances, it is the clinician who must describe study data and how they apply to specific circumstances. Third, patients and families express their preferences for care, based on their health status values, either through discussion or with the assistance of decision aids.

**What Is the Potential Role of SDM in Otolaryngology Conditions?**

Multiple otolaryngological conditions involve complex decision making, including chronic otitis media, mild obstructive sleep apnea in children, vestibular schwannoma, profound bilateral sensorineural hearing loss, chronic rhinosinusitis, laryngeal carcinoma, and thyroid nodule with indeterminate cytopathology. Each of these conditions may be appropriately managed with a range of approaches, and understanding patient values and preferences may help during the selection of a treatment plan. For example, children older than 4 years who are symptomatic with otitis media with effusion may be managed in multiple ways, including watchful waiting, tube placement, adenoectomy, or both tube placement and adenoectomy. The related multidisciplinary clinical practice guideline for otitis media with effusion describes the range of appropriate options and the rationale for each. It also provides a table that families can use to help their decision-making process, as well as material that is friendly to the layperson. Once consulting otolaryngologists help families understand the potential choices, they can work together to determine the best option match for individual children.

Also, we often see patients who have been referred by a primary care physician or pediatrician. Patients may arrive with an expectation for symptom relief and not initially understand that the plan is for a surgical consultation. This scenario can predispose to a patient-physician disconnect, and a point-by-point review of potential options for management (e.g., observation, medications, or surgery) may help alleviate it.
What Considerations Are Important for Pediatric Otolaryngology?

Managing the pediatric population has unique challenges. Many common conditions (eg, recurrent acute otitis media) tend to improve over time without any major intervention, and more than 1 treatment option or procedure may be considered simultaneously (eg, tympanostomy tubes and adenoidectomy). Further complicating the issue is that more than 1 parent or caregiver is often involved in the proxy decision-making process for young children, and the developmental level for the provision of assent must be appropriately addressed in adolescent patients.

### Table 1. Grid Describing Management Options for Children with Otitis Media with Effusion.

<table>
<thead>
<tr>
<th>Frequently Asked Questions</th>
<th>Watchful Waiting (Surveillance)</th>
<th>Ear (Tympanostomy) Tube Placement</th>
<th>Adenoidectomy</th>
</tr>
</thead>
<tbody>
<tr>
<td>Are there any age restrictions?</td>
<td>Watchful waiting can be done at any age.</td>
<td>Ear tubes can be done at any age.</td>
<td>Adenoidectomy is not recommended for age &lt;4 y for treating ear fluid that persists for at least 3 mo.</td>
</tr>
<tr>
<td>What does it involve?</td>
<td>Checking the eardrum every 3 to 6 mo in your doctor's office. Periodic hearing tests may also be performed.</td>
<td>Placing a tiny tube in the eardrum to reduce fluid buildup that causes hearing loss, then checking the tube in your doctor's office until it falls out.</td>
<td>Removing most of the adenoids, a clump of tissue in the back of the nose that stores germs, then checking the ears in your doctor's office to be sure the ear fluid is gone.</td>
</tr>
<tr>
<td>How long does the treatment take?</td>
<td>Regular checkups until the fluid in the middle ear goes away (months to years).</td>
<td>The operation takes about 10 to 20 min and usually requires general anesthesia.</td>
<td>The operation takes about 30 min and requires general anesthesia.</td>
</tr>
<tr>
<td>How long does it take to recover?</td>
<td>Does not apply.</td>
<td>A few hours.</td>
<td>About 1 or 2 d.</td>
</tr>
<tr>
<td>What are the benefits?</td>
<td>Gives your child a chance to recover on his or her own.</td>
<td>Relieves fluid and hearing loss promptly and prevents relapse of fluid while the tube is in place and stays open.</td>
<td>Reduces time with fluid in the future, reduces the need for future ear surgery. Relieves nasal blockage and infections (if applicable).</td>
</tr>
<tr>
<td>What are the potential risks and side effects?</td>
<td>Persistent fluid can reduce hearing, bother your child, and can rarely damage the eardrum and cause it to collapse. If the fluid does not eventually go away on its own, then watchful waiting could delay more effective treatments.</td>
<td>About 1 in 4 children get an ear infection (drainage) that is treated with eardrops. About 2 or 3 in 100 children have a tiny hole in the eardrum that does not close after the tube falls out and may need surgery. There is a very small risk of serious problems from the anesthesia.</td>
<td>There is a small chance of bleeding (that could require a visit to the office or hospital), infection (that is treated with antibiotics), or delayed recovery. There is a very small risk of abnormal voice (too much air through the nose) or serious problems from the anesthesia.</td>
</tr>
<tr>
<td>What usually happens in the long term?</td>
<td>The fluid and hearing loss eventually go away, or another treatment is tried.</td>
<td>Most tubes fall out in about 12 to 18 mo. About 1 in every 4 children may need to have them replaced.</td>
<td>The chance that your child may need future ear tubes is reduced by about 50% after adenoidectomy.</td>
</tr>
<tr>
<td>Are there any special precautions?</td>
<td>Baths and swimming are fine. Air travel can result in ear pain or damage to the eardrum depending on how much fluid is present.</td>
<td>Baths, swimming, and air travel are fine. Some children need earplugs if water bothers their ears in the bathtub (with head dunking), when diving (more than 6 ft underwater), or when swimming in lakes or dirty water.</td>
<td>Baths and swimming are fine. Air travel can result in ear pain or damage to the eardrum depending on how much fluid is present.</td>
</tr>
</tbody>
</table>

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Several studies assessing elective surgeries in pediatric otolaryngology have shown high levels of parental decisional conflict. For instance, 21 of 65 parents (33%) considering otoplasty for their children and 10 of 23 parents (44%) being consulted for a bone conduction device for children with unilateral aural atresia reported significant decisional conflict. Fortunately, parents who thought they were more involved in the decision-making process (as measured through SDM questionnaires) had significantly reduced levels of decisional conflict. Hence, there could

**Figure 1.** A decision aid for pediatric adenotonsillectomy. Reproduced with permissions from Paul Hong and Jill Chorney.
be real benefits of implementing SDM in pediatric otolaryngology.

Interestingly, perceptions of SDM may not always match what is actually occurring during the surgical consultation visit in pediatric otolaryngology. When consultation visits were recorded and analyzed using a validated coding measure, there was great variability in the degree to which parents participated, and parent perceptions of SDM were not correlated with actual observed involvement during the visit. This was despite the finding that both parents and surgeons reported similar perceptions of the degree of SDM. More work is needed to understand the complexities of SDM in pediatric otolaryngology.

**What Are the Benefits of SDM?**

SDM has been shown to improve health care–related decision-making quality, and some have even referred to it as “the pinnacle of patient-centered care.” In otolaryngology, data from parents considering adenotonsillectomy, tympanostomy tube placement, or otoplasty for their children demonstrated that parents who perceived themselves to be more involved in the decision-making process had significantly less decisional conflict and decisional regret. Overall, these studies suggest that otolaryngology conditions are well suited for SDM, and further research is needed in our field.

Outside of our specialty, in addition to reducing decisional regret and decisional conflict, SDM minimizes delays in finalizing decisions. SDM has also been successfully used to manage chronic diseases, with the goal of improving patient adherence to beneficial treatments. Recommended actions to ensure effective collaboration with patients include the Partner, Arrange, Resolve, Track, Navigate, Educate/Engage, and Relay (PARTNER) Framework for Care Management, and implementation of this framework has led to more rapid control of hypertension. Similarly, SDM-based programs have also proven effective in diabetes management. The patient-centered Empowerment, Motivation, and Medical Adherence (EMMA) consultation program focused on increasing medication adherence and blood glucose control in patients with type 2 diabetes. Each physician-patient interaction employed set objectives, dialogue tools, and specific opportunities for patients to reflect upon and express their preferences. After reviewing patients’ current condition and the potential impact of their choices, goals were set and the patients’ own motivation, values, and feelings formed the basis for behavioral changes. Prior to the EMMA intervention, 45% of patients had discrepancies between the medications taken and what had been prescribed. Afterward, 68% of patients achieved glycemic control and 21% reported weight loss. In addition, 59% reported that they followed the treatment plan to a “high” or “very high extent.” In addition, Lee et al. reported that empowered patients with encouraged health literacy, self-efficacy, and self-care behaviors could improve HbA1c levels. This emerging literature suggests that medical care may be optimized through SDM.

**What Are the Barriers and Limitations of SDM?**

Although the literature regarding SDM in otolaryngology is still emerging, potential barriers to effective SDM have been examined in other fields. These may occur at multiple levels, including patient factors (eg, health literacy, trust, family experiences, uncertainty about whether they should be engaged in the process), clinician factors (eg, information sharing, health concerns, interpersonal skills), and patient-clinician interaction factors (eg, perceived power imbalance, systems deficiencies). Common system-level barriers include medical organizations that have not recognized or promoted SDM and emphasized volume over patient-centered care. Clinician attitudes toward SDM can be dismissive (ie, SDM is not needed, SDM is already being practiced) or paternalistic (ie, SDM results in information overload for patients, patients want their provider to make decisions for them). In addition, even when clinicians believe that they are providing SDM, the reality may not match the perception. For example, an observational study of pediatric clinicians found limited use of SDM when discussing treatment decisions for children with chronic inflammatory conditions. Specifically, providers rarely elicited information about their goals or preferences, and the information exchange was mostly unidirectional (from provider to parent and child). This was despite the fact that some clinicians reported that SDM was part of their usual care. Similar results were found in a study of pediatric otolaryngologists when discussing elective surgical procedures. Coding analysis of video recordings of surgical consultations for adenotonsillectomy and tympanostomy tube placement demonstrated that minimal SDM was observed.

One key barrier reported by many health care providers is the perceived time constraint. It may be difficult to complete a patient-centered encounter within the typically scheduled clinic time. However, studies have shown that SDM does not necessarily take more time when routinely practiced. In addition, SDM could potentially save time in the long term if patients and family members are more engaged in their own health care, thereby enhancing treatment adherence and reducing unnecessary visits to their providers.

Further potential barriers to implementing SDM include patient factors. Some patients may not realize that there are benefits to engaging in their medical decision making. This seems more common in vulnerable populations (eg, low socioeconomic status, ethnic minorities, adolescents) who may have less ability or inclination to manage their health. In addition, patients and families may not have ideal comprehension of their medical conditions. A 2010 national survey found that fewer than half of the responding patients were able to answer more than 1 knowledge-based question correctly for the 9 most common medical conditions. Two studies of families of patients in the intensive care unit (ICU) showed that just 29% to 54%
understood all 3 components of the diagnosis, prognosis, and treatment, with associated deficits in comprehension, failure to understand information provided by the physician, failure to recall information, and/or failure to receive information.\textsuperscript{51, 52} In addition, physicians may not recognize when poor family comprehension is present, and increased time spent with ICU staff is not necessarily associated with better family understanding.\textsuperscript{53} Rodriguez et al\textsuperscript{53} reported that 47% of primary surrogate decision makers who spent less than or equal to 30 minutes had poor knowledge, compared to 49% of those who spent over 30 minutes in discussion. SDM barriers may be addressed through efforts to advance health literacy and better physician-patient communication.\textsuperscript{54}

**Practicalities of SDM**

A 2008 systematic review of SDM in clinical practice found that the facilitators cited most frequently were significant provider motivation and the perception that SDM has a positive impact on patient outcomes and the clinical process.\textsuperscript{42} The most frequently reported barriers were time constraints and lack of applicability due to either patient or clinical factors.\textsuperscript{42} Nonetheless, 2 studies have assessed if SDM increases encounter time and found no differences; these studies both had average encounter times of greater than 15 minutes.\textsuperscript{46, 47} Studies evaluating these factors, especially the time required for SDM for surgical conditions and practice sites, are necessary to determine the true impact SDM has on clinical practice and whether the perceived burdens of SDM are accurate.

While there are no investigations of these factors in otolaryngology, SDM has been used to assist families in making decisions regarding the treatment of obstructive sleep apnea (OSA) in a multidisciplinary clinic focused on the treatment of children with OSA without tonsillar hypertrophy.\textsuperscript{55} In this randomized controlled trial, the SDM tool was compared to traditional counseling; the authors found that decisional conflict was lower for the group using the tool and that there was no difference in the time required to counsel patients.\textsuperscript{55} When prompted, all providers felt that the tool provided an easy framework for discussion with the families. Despite these findings, the use of the actual SDM tool in subsequent clinical encounters is closer to 50% (written communication, K. Tiemeyer to S. Ishman, July 2017). When queried, providers in this clinic noted that it was most helpful to them when decision making was not straightforward and they felt that the families should consider multiple options (eg, continuous positive airway pressure vs soft tissue surgery). However, providers also reported that they frequently forgot to use the tool; in light of this, the SDM tool is now being given to the faculty for all patient encounters in this site's upper airway clinic.

**Conclusions**

SDM arises from cooperative collaboration between patients, families, and clinicians working together to make optimal medical choices. This process relies on clinical data, clinician expertise, and individual patient values and has been shown to decrease decisional conflict and regret, as well as to increase adherence to treatment plans and health care savings. Barriers to SDM exist, although initial reports suggest that the practicalities of implementation are feasible in our field.

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**Author Contributions**

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**References**


