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A Patient-Centered Approach to Clinical Practice Guidelines in Otolaryngology

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Abstract

Patient education is used to engage patients in their own health care and is relevant in most clinical situations. Shared decision making (SDM) is used to engage patients when a choice needs to be made about a diagnostic or therapeutic procedure and the medical evidence does not indicate which choice is best. American Academy of Otolaryngology-Head and Neck Surgery (AAO-HNS) clinical practice guidelines (CPGs) include multiple action statements that may benefit from patient education or SDM. In this Commentary we discuss patient education and SDM using examples from AAO-HNS CPGs. We believe that use of patient education and decision support materials for SDM will enhance the effectiveness of SDM and improve the uptake of CPG. We issue a call to action for all stakeholders to consider how to put these materials into the hands of our patients.

Keywords

Decision Making; Physician-patient relations; Practice guidelines

Introduction

Shared decision making (SDM) is "an approach where clinicians and patients share the best available evidence when faced with the task of making decisions, and where patients are supported to consider options, to achieve informed preferences".[1] SDM may be used when the patient and physician need to make a health care decision but there is no "best" option. When the evidence does not indicate a superior option, patient preferences may heavily influence the decision. SDM includes three principle components. First, the patient is made aware that a choice exists and options are presented. Second, the patient is given information about risks and benefits of the options. Third, the patient is encouraged to consider the options in light of their personal values and preferences. Value consideration may entail further dialogue with the clinician or consultation with family members. Because the process of SDM encourages patients and providers to consider health care options from the patient's

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perspective, it has been referred to as the "pinnacle of patient-centered care".[2] Despite broad support for SDM it is largely an unrealized ideal and issues must be addressed before SDM can be routinely implemented.[3] One obstacle is that we lack patient education resources of sufficient quality to educate and inform patients to a degree that would allow them to compare options in an informed manner.

Thinking beyond SDM, which has limited applicability, patient education is nearly always relevant and necessary to engage patients in their own health care. Education is provided verbally by health care providers and is also provided through print brochures, posters, informed consent documents, and electronic media.[4,5]

Patient education and SDM are related and overlapping concepts, each with important roles for implementing American Academy of Otolaryngology-Head and Neck surgery (AAO-HNS) clinical practice guidelines (CPGs). CPGs "include recommendations intended to optimize patient care" based on clinical evidence but they are not intended to be rigid directives and do not replace clinical judgment.[6] As health care providers, if we are to implement CPGs and be patient-centered, we need to be prepared to educate patients about their condition in context of the CPG recommendations, and when there is more than one valid health care option, we need to be prepared to share decision making with them.

This commentary will discuss patient education and SDM as well as how SDM expands beyond patient education to encompass patient preferences and values. We will describe opportunities for patient education and SDM using the AAO-HNS CPGs.

Opportunities for Shared Decision Making in AAO-HNS Clinical Practice Guidelines

Each CPG contains several "action statements," each written as a *strong recommendation, recommendation, option*, or *no recommendation*, based on the evidence and the balance of risks and benefits. *Strong recommendations* indicate a clear best option, in which case there is likely little variation in clinical practice. In contrast, *options* or *no recommendations* indicate there is no best option, and there is likely more variation in clinical practice. CPG statements written as *options* or *no recommendations* may be appropriate for SDM (Table). While not all of these statements may be appropriate for SDM, the list provides a topical overview.

For an example of an opportunity for SDM in practice, consider this scenario. A 7-year old child presents for consideration of tonsillectomy following 7 documented episodes of sore throat last year and a positive group A beta-hemolytic strep test. The patient's brother also had recurrent sore throat and developed rheumatic fever. The parents are concerned that if they do not proceed with tonsillectomy their child may be at risk of rheumatic fever. On the other hand, they are also concerned about the risk of bleeding, particularly because they are devout Jehovah's Witnesses and are opposed to blood transfusions for their children.

According to the CPG: Tonsillectomy in children"[7] tonsillectomy is an *option* for children with "recurrent throat infection with documentation". However, there is a "large role for

shared decision making in severely affected patients, given the favorable natural history of recurrent throat infections and modest improvement associated with surgery… .” In other words, tonsillectomy and observation are both valid options, and the physician and the parents may use SDM to consider the parents’ values and preferences and make a decision. In the scenario presented, dialogue between the physician and parents may help the parents balance their concerns about bleeding and infection. Discussion and time to consult with family members may allow them to make a decision that fits with their religious values and personal concerns.

There are multiple challenges to implementing SDM in practice and experts have acknowledged the lack of clear direction on practical implementation of SDM. One model for using SDM in practice includes “a) introducing choice, b) describing options, often by integrating the use of patient decision support, and c) helping patients explore preferences and make decisions.[8] This model rests on supporting a process of deliberation and on understanding that decisions should be influenced by exploring and respecting “what matters most” to patients as individuals… ”. In the tonsillectomy scenario “introducing choice” entails explaining to the parents that they will need to choose between tonsillectomy and observation. “Describing options” entails providing the parents with sufficient information about tonsillectomy and observation, including risk, benefits, and perhaps the provider’s experience and complications rates, so that the parents can make an informed choice. “Helping patients explore preferences and make decisions” involves supporting parents as they consider the risks of hemorrhage requiring transfusion and infectious complications from streptococcal infections.

Even as it is broken down into the components of introducing choice, describing options, and exploring preferences, SDM is still a formidable task in part because of limitations of physicians’ time and limitations of patients’ health literacy, reading abilities, and numeracy skills. Decision support tools, such as decision aids (DAs) may facilitate SDM.[3,9] DAs may be in print or electronic form and are used to explain options to patients using text, pictures, and figures to convey health and statistical information that is easily understood. With DAs to explain treatment options, patients choose fewer invasive procedures, have greater knowledge about health care risks, less decision conflict, and less uncertainty.[8-10] DAs exist for a variety of health care conditions, but there are few in otolaryngology.[11]

Educating Patients About AAO-HNS Clinical Practice Guidelines

A CPG statement written as a *recommendation* or a *strong recommendation* indicates there is sufficient evidence to support a preferred treatment option. CPG statements that are written as *recommendations* or *strong recommendations* are not typically appropriate for SDM because the evidence indicates which option is best. Patient education may help patients understand their health condition and the evidence behind the CPG statement, but SDM is probably not applicable for a *recommendation* or a *strong recommendation*.

Patient information is widely available, but the quality may be insufficient. Recent studies found that patient information posted online by professional societies and academic departments substantially exceeds recommended reading levels.[12,13] Some consider

informed consent to be a form of health education. Indeed, the process of informed consent was conceived to ensure that we inform our patients of treatment options. However, as currently implemented, it has serious limitations as an educational process.[14-16] For example, Braddock and colleagues analyzed informed consent discussions in 1100 audiotaped patient encounters.[15] Although surgeons performed better than other physicians, the discussions did not reliably describe the planned procedure and physicians rarely assessed a patient's comprehension of the information. The authors concluded that greater efforts are needed to educate and inform patients in clinical practice.

Implementing an AAO-HNS CPG is likely to be more successful if there are patient education materials to accompany key action statements, particularly if the action statement advises care that differs from established clinical practice or from patient expectations. Notwithstanding the limitations of existing patient health information, this information has great value for some of our patients. However, materials developed in the future will need to take into account the limited reading, numeracy, and health literacy skills of many patients.

For an example of an opportunity for patient education regarding CPG, consider this scenario.

A 2-year old child is referred to an otolaryngologist after 8 episodes of acute otitis media (AOM) over the last year. The child has met all of his developmental milestones. On physical examination, there is no middle ear fluid and the audiogram and tympanometry are normal. The parents report they were told by their pediatrician, "Your child needs tubes."

According to the CPG: "Tympanostomy tubes in children" "clinicians should not perform tympanostomy tube insertion in children with recurrent AOM who do not have middle ear effusion in either ear at the time of assessment for tube candidacy." [17] In the scenario presented there is no middle ear fluid and there are no mitigating circumstances, factors such as developmental delay, severe AOM, or multiple antibiotic allergies, that would support a need for tympanostomy tube surgery. According to the CPG, the best treatment is watchful waiting. However, the parents may resist this recommendation if they had expected that tympanostomy tube surgery would be recommended. Their expectations may be based on: a) the pediatrician's comment, "Your child needs tubes", b) personal experience such as with an older child who received surgery in this clinical scenario, or c) the domestic and personal stress that develops from lack of sleep and missed workdays while caring for a sick child. In the face of these parental expectations, a recommendation not to perform surgery is not only unexpected but may be unwelcome and difficult for parents to understand. The otolaryngologist may need to provide a considerable amount of explanation for the rationale not to operate. Patient education materials will be useful to explain this recommendation to patients and gain their acceptance. Without such materials, it can be a very difficult task for a physician to recommend treatment that goes against the patient's expectations.

Conclusion

Regardless of whether our patients need to make a health care decision or only want to understand their health condition, basic educational materials may be invaluable in helping

them to understand their health care treatment and options. As physicians, we need guidance about how to educate our patients. We need educational materials to help us convey reasons for specific treatment recommendations—particularly when those recommendations may go against patient expectations. We issue a call to action for physicians, health systems, and CPG developers to consider means of distributing appropriate patient education materials and decision support tools. Just as we have experts capable of developing robust CPG, we need complementary expertise to develop patient education and decision support materials in order to engage patients in their own health care and to facilitate SDM. We believe that such information—information developed with patients' needs in mind—may make the difference between a CPG being adopted or ignored.

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Table

“Option” or “No Recommendation” Action Statements from AAO-HNS CPG

Adult sinusitis[18]	Symptomatic relief for viral sinusitis
	Symptomatic relief for acute bacterial sinusitis
	Watchful waiting for acute bacterial sinusitis
	Nasal endoscopy for chronic sinusitis
	Allergy testing for chronic sinusitis
Cerumen impaction[19]	Observation instead of removal
	Need for removal in special populations
	Cerumenolytic agents for removal
	Irrigation as a method of removal
	Manual removal other than irrigation
	Prevention
Benign paroxysmal positional vertigo[20]	Audiometric testing
	Vestibular rehabilitation as initial therapy
	Observation as initial therapy
Hoarseness (dysphonia) [21]	Laryngoscopy and hoarseness
	Anti-reflux medication for treatment
	Prevention
Tonsillectomy guideline.[7]	Tonsillectomy for recurrent throat infection
Sudden hearing loss[22]	Corticosteroids as initial therapy
	Hyperbaric oxygen therapy
Improving voice outcomes after thyroid surgery[23]	Intraoperative electromyography (EMG) monitoring Intraoperative corticosteroids
Bells Palsy[24]	Combination antiviral therapy
	Electrodiagnostic testing with complete paralysis
	Surgical decompression
	Acupuncture
	Physical therapy
Tympanostomy tubes[17]	Chronic OME with symptoms
	Tympanostomy tubes in at-risk children