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Physician perspectives on decision-making for treatment of pediatric sleep-disordered breathing

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Abstract

Sleep-disordered breathing (SDB) is prevalent in children and most commonly treated by surgery with adenotonsillectomy. We aimed to learn physician perspectives of social and communication factors that influence decision-making for treatment of pediatric SDB. Purposive sampling identified 10 physician key informants across disciplines and practice settings, who participated in semi-structured interviews regarding SDB care experiences and communication with parents. Interviews were analyzed using directed qualitative content analysis. Physicians provided a variety of perspectives on decision-making for treatment which fell into three over-arching themes: approach to surgery and alternatives, communication and decision-making with families, and sociocultural factors/barriers to care. Perspectives were moderately heterogeneous, suggesting that individual social and relational elements may significantly influence how physicians refer patients and recommend treatment, and how parents choose surgery for this prevalent condition. These findings will inform development of culturally-competent communication strategies and support tools to enhance shared decision-making for physicians treating children with SDB.

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Contributors' Statements:

Emily F. Boss, MD, MPH: Dr. Boss conceptualized and designed the study, conducted qualitative interviews, contributed to analysis, drafted the initial manuscript, revised the manuscript, and approved the final manuscript as submitted.

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Keywords

Shared Decision-making; Communication; Sleep-disordered Breathing; Pediatric Otolaryngology; Adenotonsillectomy

Introduction

Sleep-disordered breathing (SDB), a spectrum of obstructive breathing disorders ranging from snoring to obstructive sleep apnea¹, is a prevalent condition² affecting 6–20% of children under the age of 18 in the United States^{3–5}. SDB left untreated may have moderate physical, behavioral, and neurocognitive effects on children^{2, 3, 6, 7}. Surgical removal of the adenoids and tonsils (adenotonsillectomy, AT)⁸ is the most common treatment for pediatric SDB, with over 500,000 cases performed annually^{2, 6}. Despite its potential impact on resolution of SDB and its sequelae, prior research depicts unnecessary variation of AT utilization and quality of perioperative care^{9–11}. This variation persists despite development of clinical practice guidelines for diagnostic strategies for SDB (polysomnography) and pediatric tonsillectomy.^{9, 12–14} There is also suggestion of clinical equipoise as to long-term benefits of surgery for children with milder SDB. A recent multi-institutional randomized clinical trial comparing early surgery with AT to watchful waiting showed improvement or resolution of sleep symptoms after 6 months in nearly half of children who did not undergo surgery^{15, 16}.

Given that some children with SDB may benefit equally from surgery or watchful waiting, there is increasing emphasis on improving the decision-making process for parents through shared decision-making (SDM), where physicians present evidence-based treatment alternatives, with risks and benefits, which are also congruent with family needs and values^{1, 15, 17}. Moreover, there is increased interest in family-physician communication and patient-centered outcomes research for elective surgeries in children such as appendectomy and tonsillectomy^{18, 19}.

We have previously reported results of interviews with parent stakeholders detailing their perspectives on experience of care, communication and decision-making in pediatric SDB²⁰. To address more circumferentially the context of decision-making for pediatric SDB treatment, in the current study we sought to examine perspectives of SDB treatment from a group of physician stakeholders. In particular, we address physician perspectives on social and communication factors that influence care experiences and decision-making for pediatric SDB.

Methods

This study was approved by the Johns Hopkins School of Medicine Institutional Review Board (IRB:47806). Participants were recruited by e-mail for participation through purposive and snowball sampling. Physician experts in SDB clinical research and practice were identified and selected based on field of study and practice setting in order to attain heterogeneous perspectives from physicians who treat children with SDB. Physicians were

recruited from community and academic settings. Interested parties reviewed and signed a written consent form prior to participating.

Data collection.

Physicians engaged in individual, audio-recorded, in-depth, semi-structured interviews led by a facilitator trained in qualitative research. Interview questions were developed with regards to experiences specific to evaluation and treatment of children with SDB (e.g., “What barriers do you feel parents experience?”) and experiences in communicating about SDB and treatment alternatives to patients and families (e.g., “What risks/limitations do you discuss with families?”). Physicians were asked open-ended questions to explore their decision-making processes and communication style with families about SDB and AT, to gain a variety of clinician perspectives about SDB treatment and decision-making with parents. To limit the scope to experience of care and decision-making, we did not aim to establish practice patterns, baseline knowledge, or training algorithms. Interviews lasted approximately 20 minutes for each participant.

Analysis.

All audio-recorded interviews were transcribed and analyzed using directed qualitative content analysis^{21, 22}, by using previous research to “identify key concepts or variables as initial coding categories” prior to beginning analysis (p. 1281)²². Analysis consisted of 1) use of key concepts to identify over-arching themes or domains and sub-theme clusters, 2) coding responses to correspond to identified sub-themes, and 3) creating summaries of each theme. Two researchers reviewed all transcripts and developed emergent themes by line-by-line coding of two initial transcripts, and applied those codes to a third transcript as a means of source triangulation. Data was thematically coded using ATLAS.ti qualitative analysis software²³. Analysis was complete when investigators reached consensus on all three steps.

Results

10 physicians were interviewed. Professional fields included general pediatrics (n = 4), pediatric otolaryngology (n = 2), general otolaryngology (n = 2), sleep medicine/pulmonary (n = 1), and pediatric anesthesiology (n = 1). Demographic characteristics are shown in Table 1. Three overarching themes related to SDB treatment and decision-making were identified to capture the heterogeneous attitudes: Physician perspectives of SDB surgery and alternatives; communication and decision-making between physicians and families; and social, cultural, and personal factors.

Physician perspectives of SDB treatment

Perspectives based on perceived parental concerns.—Physicians described how treatment strategy was impacted by family preferences and prior experience (“*a lot of people are resistant to surgery because [the information they previously got is] not concrete*”) and parental concerns and objectives (“*I’d like to know what parents want out of a conversation....what are their concerns...?*”). Some physicians reported modifying their approach based on these perceptions (“*I sort of get a feel for the parents and you work within that feeling to decide what they seem to want*”). They also identified concerns parents

wanted addressed routinely, including bleeding, effectiveness of surgery (*“does it work?”*), complications (*“they always have concerns about complications of surgery”*), pain management (*“most parents are worried about pain after surgery”*) and anesthesia (*“[A parent’s concern is] the anesthesia....It’s always anesthesia”*). One physician attributed parental concerns to media-driven reports of tonsillectomy (*“since the...case in Oakland, we’ve gotten a lot of questions about that case”*). There was not a predominant approach to treatment decisions among physicians, as some seemed to stress shared decisions and others stressed disease severity as overriding factors.

Overall position on SDB treatment.—In addition to relaying parental concerns, physicians indicated their own views on the most important aspects of treating SDB. Some saw surgery as curative (*“tonsillectomy is...helpful in most cases and curative in many cases,”*) or as having significant value due to improvement in symptoms such as child behavior and bed wetting. Others viewed tonsillectomy as a final option (*“Surgery to me is a last resort. When you come in and you need an operation it’s because you’re at your wit’s end where you’ve run out of other options ...”*). Tonsillectomy’s potential overuse in the current climate was referenced (*“any kid who snores, they take their tonsils out”*), as were severe morbidities, including death. However, many physicians viewed tonsillectomy as predominantly positive (*“the mom...said ‘you saved my child’s life.’ That’s pretty empowering...I think it does help a lot of people”*). Overall, physicians’ personal views of AT varied, with some more moderate (*“be as conservative as possible”*), and others liberal (*“people are uniformly happy”*), with one emphasizing responsible utilization (*“I could care less if I do an extra tonsillectomy, I want to make sure I’m doing it for a good reason”*). Dimensions and expanded quotes on the theme of physician approach to treatment are further presented in Table 2.

Communication and decision-making between physicians and families.

Information-sharing.—Physicians discussed how they communicate risks and benefits of AT surgery to parents on a number of levels. Some said they begin with the pros and cons of treatments with parents (*“I think it’s good to break [treatment options] into those tiers”*). Others elaborated on specific risks of treatment options to their patients, particularly tonsillectomy (*“there’s a risk of bad things happening”*), including pain, discomfort, and risks associated with anesthesia. Physicians emphasized reassuring parents about the overall risk (*“it’s very safe”*) or leaving out information about rare and serious sequelae. One otolaryngologist stated:

I don’t think I would necessarily say [there’s a risk of death] to every parent... I think it impairs their ability to make a decision, to some degree...it’s an unrealistic and unlikely outcome, but I think it makes it hard for them to make a decision.

Overall, the majority indicated the importance of discussing risks and benefits with parents, whether treatment options (*“it’s a more complex situation than just to say no treatment, medication, or tonsillectomy”*), pros and cons (*“let’s talk about all the pros and cons of these approaches”*), or postoperative expectations (*“It hurts.”*).

Decision-making and parent engagement.—Multiple physicians identified information-sharing and engagement as an important aspect of decision-making (*“I just want them to be in charge of the decision”*). Some stressed the importance of information-gathering overall for parental engagement (*“The more informed a parent is, the easier you are to arrive at a shared decision”*), indicating that asking informed questions showed greater interactivity. Accordingly, to engage parents, physicians provide information and take part in strategies such as educating parents on specific aspects of SDB (*“to understand pathological sleep problems versus normal sleep”*).

Physicians also spoke of decision-making styles. Some viewed SDM favorably and spoke of establishing the parent as the sole decision-maker. One otolaryngologist stated:

I’m not here to tell you ‘you should have surgery’ My job is to give you information and to answer as many questions as I possibly can and to empower you with as much information as possible.... Nobody, under non-emergent circumstances should have medical decisions made for them.

Others spoke about implementing a more traditional informed approach that involved information-sharing to collaborate with the parent, including the importance of providing options and treatment-specific information¹⁸ (*“I tell them... about what the other [treatment] options are so that [they] understand what all of [their] options are”*). Two pediatricians felt SDM in consideration of tonsillectomy was not their role (*“I imagine shared decision-making comes in much more when they are seeing [the] surgeon”*), or viewed SDM cautiously (*“It’s not clear that [SDM is] what is preferred by the parents.”*) Dimensions and expanded quotations on communication and decision-making perspectives are further presented in Table 3.

Social, Cultural, and Personal Factors.

Several physicians commented on how decision-making and treatment approach may vary depending on social or cultural factors such as parent education level, insurance, or race/ethnicity. Some physicians commented on potential care barriers imposed by effects of lower socioeconomic status and access to resources (*“unfunded and underfunded patients... simply cannot get access to the care that they need”*). Another elaborated on the manner in which insurance or socioeconomic status might influence aspects of communication and information-sharing:

In the Medicaid population, most of the questions have to do with how much time off work will I need? What would be the day-to-day care of the child?...in the more affluent patient populations you hear much more about schooling and behavior and achievement...and less so about the recovery.

Care considerations due to patient ethnicity were noted as a prominent theme. Four physicians who were interviewed had high distribution of Hispanic children in their patient population and discussed cultural perceptions of decision-making (*“In certain Spanish-speaking cultures there is a pervasive ...belief that tonsillectomy sterilizes your child and prevents them from having children one day. There are a lot of these cultural barriers to overcome”*). Another otolaryngologist considered Hispanic parents to be more reliant on the

physician's expertise (*"in general Latino families are pretty compliant"*). Two pediatricians who worked primarily with Hispanic children discussed potential harm of overwhelming parents with too much information (*"you lose things when you add in superfluous conversations that they don't want"*).

Three physicians indicated that their own experiences as parents impacted their care and communication strategies, including birth of a child giving new insight (*"I can understand now how incredibly stressful this can be for a family"*), being more attentive to sleep-related concerns after having a child with SDB who had undergone tonsillectomy (*"it wouldn't have been this real to me"*), and basing treatment recommendations on their own children's health (*"they get better. I know...a lot of it is based on my experience with my own kids"*).

Otolaryngologists addressed how relationships between surgeons and pediatricians impact care recommendations. Two otolaryngologists spoke of some prevailing underestimation of the effects of SDB (*"There are still pediatricians who ask the question, does sleep apnea even occur in children?"*), resistance to referrals (*"pediatricians don't want to refer them."*), and variation in management (*"why does that pediatrician do that and this pediatrician does this?"*). One pediatrician commented on a strong working referral relationship (*"we have a great relationship with ENT"*). Physician perspectives on social and personal factors are further presented in Table 4.

Discussion

This study is the first to qualitatively report physician key informant perspectives on treatment, communication, and decision-making for pediatric sleep-disordered breathing and adenotonsillectomy. The study was intended to understand representative views of physician key informants, rather than be inclusive of all physician attitudes and practice patterns. Findings contribute a new dimension to patient-centered outcomes research in pediatric SDB, as understanding stakeholder perspectives for this prevalent condition is integral to developing future communication strategies for clinical practice and research. Our findings reveal extensive variability in how physicians across and within specialties view and discuss the risks and benefits of adenotonsillectomy for treatment of SDB with families. The baseline heterogeneity observed in this small sample is significant as it suggests physician factors toward unexplained variation in adenotonsillectomy, which is among the most common surgical procedures performed in U.S. children. This variability begs a need for standardized, culturally-competent educational materials or decision aids for this prevalent condition, as well as greater dissemination of evidence-based guidelines.

The large variation in perspectives and communication approaches demonstrated by physicians has significant implications, as it underscores the potential impact of practice and knowledge variation on surgical utilization. Wide geographic variation in AT rates in the U.S., independent of factors including insurance or race, has been previously demonstrated⁹. Despite recent development of clinical practice guidelines that provide direction on appropriate use of diagnostic polysomnography²⁴ and tonsillectomy^{25, 26} for pediatric SDB, there are still many decisions left to the individual practitioner and family that depend on child health factors, practice setting, and physician and family preferences and values^{27, 28}.

While the current analysis was not performed to identify practice patterns and application of evidence-based care, it may be difficult to distinguish physician perspectives on SDB treatment from their views on appropriate clinical practice.

One prevalent theme observed was the perception of communication being directed by factors related to socioeconomic status, ethnicity, and culture. Some physicians discussed how families with lower education or income may pursue more practical and information about recovery and logistics, and less about long-term sequelae of surgery or observation. Four physicians referred to Hispanic ethnicity when they spoke of culture-specific concerns, such as sterility with surgery, and propensity to engage in decision-making. Three physicians commented on their personal family experiences impacting care and treatment recommendations. These perspectives suggest that there may be a profound impact of social influences on physician recommendations and/or parent choice for surgery. Prior studies have identified certain populations of children who may be at higher risk for SDB, including children who are African-American, or who are from lower-income neighborhoods^{29, 30}. Likewise, there is a heightened prevalence of risk factors for SDB, most specifically obesity²⁷, in particular ethnic groups such as African-American and Latino children³¹. Discrepancies in the kind of information shared with or elicited by parents and pediatric patients of different backgrounds are important to consider when evaluating communication strategies that could influence decisions for referral or treatment, and also surgical utilization of AT.

Indeed, physicians working with patients from diverse backgrounds acknowledged the importance of cultural awareness. Some physicians emphasized the importance of thorough disclosure on risks and benefits of treatment, while others thought some parents preferred less information and less of a role in decision-making. Prior research has shown a disparity in physician disclosure of procedural risks, where some withheld detailed risk information for risk profile between 1:200 to 1:10,000, though this withholding was not necessarily due to perceived cultural preferences³². While physicians in this study acknowledged the importance of relating to family perspectives to facilitate understanding, it was not possible to know how and to what degree this occurred. Some physicians made generalizations about racial, ethnic and socioeconomic groups that could potentially be perceived as stereotyping and might influence information disclosure, decision-making and patient treatment and outcomes. Further observational studies of clinician-patient interactions are needed to evaluate physician communication across patient and family demographics. These findings suggest the need for continued training in cultural competence and respect, techniques for shared decision-making and complete information disclosure.

There were some limitations in this study that should be noted. The sample size was relatively small, and physician roles and perspectives were diverse. Although the diversity in perspectives is considered indicative of the context of variability in healthcare as opposed to a misrepresentative sample, it is noted that data saturation or consensus within each theme was not attained. We purposively selected a range of physician specialists who engage with pediatric SDB patients. However, additional interviews would be helpful to determine if the results presented here resonate with clinicians more broadly. Role distribution of the current sample was somewhat limited. There is also the possibility of biased responses, as

physicians were not assessed for social desirability. Finally, it is noted that as a qualitative study, analysis of these interviews were subject to the perspectives of the three coders, and data may not be generalizable to the overall population.

However, the great variation noted across these interviews strongly highlights the need for further research into the relationship of clinical practice variation, patient and family background, and physician characteristics with SDB treatment recommendations and ultimate utilization of tonsillectomy. Our prior analysis of parent perspectives²⁰ suggested a potentially more prominent role of the pediatrician in decision-making for surgical evaluation and treatment, which is consistent with other research suggesting that shared decision-making is more impactful in continuous or chronic care settings^{20, 33, 34}. As such, interventions to disseminate and implement evidence-based guidelines and referral indications to pediatricians, as well as finesse systems of patient access to diagnostic and subspecialty care, will be pivotal.

Conclusion

This research demonstrates a variety of physician perspectives on decision-making for treatment of pediatric SDB. The diverse perspectives presented highlight factors that influence both physician and parent decision-making for AT surgery. Findings suggest that despite the best available evidence, social and relational elements influence how physicians recommend and parents choose surgical treatment. This study also suggests a need for further research into implicit racial bias in clinical encounters, and culturally-competent communication styles. Findings from this study will be used to inform communication strategies and development of training and decision support tools to encourage application of shared decision-making for physicians treating children with SDB.

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Abbreviations:

SDB	Sleep-disordered breathing
AT	Adenotonsillectomy
SDM	Shared decision-making

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Table 1.

Participant Characteristics, overview (N = 10)

Characteristic	n (%)
Gender	
Male	7 (70%)
Female	3 (30%)
Age [M (SD)]	45.7 (9.6)
Ethnicity	
Caucasian	8 (80 %)
Indian	1 (10%)
Asian	1 (10%)
Specialty	
Pediatric Otolaryngology	2 (20%)
Otolaryngology	2 (20%)
General Pediatrics	4 (40%)
Pediatric Sleep Medicine/Pulmonary	1 (10%)
Pediatric Anesthesiology	1 (10%)
Practice Setting	
Academic	5 (50%)
Community/Academic	2 (20%)
Community/Private	3 (30%)
Years in Practice [M (SD)]	13.9 (9.2)

Table 2.
Physician perspectives on the approach to treatment and alternatives for pediatric SDB

Theme	Sample quotations
Approach to treatment based on perceived parental concerns	<ul style="list-style-type: none"> • "It's the <i>anesthesia</i>. Yes, it's the anesthesia, yeah. It's like, who's giving it, who's doing it, where's it going to be done, what's their experience? It's always anesthesia." -- <i>Otolaryngologist</i> • "That's an important thing for me is what are the parents hoping to accomplish during that office visit? What is it that they want to discuss and what are their concerns?" -- <i>Pediatric otolaryngologist</i> • "If I think the child needs surgery and they sort of lead me in that direction, I'll be more aggressive that way. If they're unsure, I'm definitely more conservative medically....I first talk about issues related to Sleep-disordered Breathing." -- <i>Otolaryngologist</i> • "I try to be sensitive in a way that I can be comfortable managing. Values-wise I think that comes with their relationships with families." -- <i>Pediatrician</i>
Overall position on SDB treatment	<ul style="list-style-type: none"> • "I would say a lot of these kids do a lot better...I had a parent come up to me in a restaurant...it was probably like six months after I'd taken her tonsils out, and the mom came up to me in a restaurant and hugged me and said, 'You changed my child's life.' That's pretty dramatic and empowering." • "It's not obvious. There may be a benefit. There may not." -- <i>Otolaryngologist</i> • "I know that surgery will cure things as well in most cases, but surgery also has tremendous risks and should be utilized, in my opinion, as the last resort when all other treatment modalities have been exhausted." -- <i>Pediatric otolaryngologist</i> • "I could care less if I do an extra tonsillectomy or not. I really definitely want to make sure that I'm doing it in a good way...that I'm doing it for a good reason. I know doctors who any kid who snores they take their tonsils out." -- <i>Otolaryngologist</i> • "More than most surgeries that I refer for, I almost never hear anybody complain about a tonsillectomy. There's almost no regret." -- <i>Pediatrician</i>

Physician perspectives on communication and decision-making between physicians and families

Table 3.

Theme	Sample quotations
Information-sharing	<ul style="list-style-type: none"> • "I always tell people...surgery is very effective. It's quick. It gives you very immediate results but surgery has its problems and I list the morbidity of surgery. What I normally say to them is, what we're here to do is decide whether the problems your child has justify putting him through a surgery which is common but does have problems associated with it." -- <i>Pediatric otolaryngologist</i> • "I always warn parents that it's terrible...I'm like, 'It's really painful. You're not going to eat for a couple of days.' If they're going through with it, I'd rather them expect the worst and then be like, 'Oh it wasn't so bad,' than to be shocked at how horrible this is." -- <i>Pediatrician</i> • "The kid's got sleep apnea but your child has a one in 30 thousand risk of death. You can't synthesize that information." -- <i>Otolaryngologist</i>
Decision-making and parent engagement	<ul style="list-style-type: none"> • "In our patient population they're like, 'Whatever you say, doctor, that's what I'm going to do.'" -- <i>Pediatrician</i> • "The less informed the parent is, the more you are likely to make the decision for them." -- <i>Pediatric otolaryngologist</i> • "The patients who start asking a lot of questions are engaged in the process...the number one thing I look for is somebody who is asking a lot of questions." -- <i>Pediatric otolaryngologist</i> • "The first thing is who is showing up to the visit? Typically more engaged parents, both parents are there. And not only there, when I say there, I mean engaged in the conversation and the questions and so on." -- <i>Pediatric otolaryngologist</i> • "It's hard to tell because it could just be the way they deal with stress, talk don't talk about it, but there are some where you know, like the dad sleeping in the chair when the kid is sitting there ready for surgery and the kid is nervous, but the dad doesn't care." -- <i>Anesthesiologist</i> • "Sometimes it's just getting them to actually engage at a time when they wouldn't otherwise. It's also making sure they understand." -- <i>Pediatrician</i>

Table 4.

Physician perspectives on sociocultural factors and barriers to care

Theme	Sample quotations
Demographic and Social Groups	<ul style="list-style-type: none"> • "We have a very large Hispanic population and they ask questions which the rest of the patients don't. Like, is my child going to become sterile as a result of this? Is it safe to take the tonsils out and will taking the tonsils out make my child sick for the rest of his life?" -- <i>Pediatric otolaryngologist</i> • "What are the cultural elements, what are the values that go into that decision-making?" -- <i>Pediatric otolaryngologist</i> • "I think there can be sometimes cultural differences, and it's hard because you're going through interpreters but I think they are more concerned about the surgery than others." -- <i>Sleep medicine/Pulmonologist</i> • "In the Medicaid population, most of the questions are to do with how much time off work will I need? What would be the day-to-day care of the child?" -- <i>Pediatric otolaryngologist</i>
Barriers to care	<ul style="list-style-type: none"> • "That set of barriers has a lot to do with demographics, socioeconomic status, things like that. We have educational barriers, we have patients who are simply not educated about their child's care, about healthcare in general. There are language barriers." -- <i>Pediatric otolaryngologist</i> • "In certain cultures...the term 'tonsillectomy' literally as it's translated in Spanish, somewhere along the way in grandparents' generation has become manipulated to make them think that you're sterilizing their children and will be unable to have children one day...because you're removing two balls." -- <i>Pediatric otolaryngologist</i> • "We have a lot of very difficult social situations where the children are in the care of the grandparents or the care of foster parents, or just the parents are no longer in the picture. They may bounce from home to home on a frequent basis, have in-complete follow-ups." -- <i>Pediatric otolaryngologist</i> • "[Racial minorities or low-income families] mostly come from places where they have very little access to medical care." -- <i>Pediatrician</i>
Other social influences to care	<ul style="list-style-type: none"> • "It's funny because I have a kid, when she was four, five, six her tonsils were so big and she was tiny, and we thought about it a lot...And her tonsils are smaller now...Ninety-five percent of what I do in my office on a regular basis I didn't learn in residency...a lot of it is based on my experience with my own kids, and then just being in practice." -- <i>Pediatrician</i> • "Sometimes there are barriers to obtaining the care even when they feel that they need the care, so their pediatricians don't want to refer them, they don't think it's necessary, they think there are too many unnecessary surgeries being performed." -- <i>Pediatric otolaryngologist</i>