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An Expanded Framework to Define and Measure Shared Decision-Making in Dialogue: A ‘Top-down’ and ‘Bottom-up’ Approach

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Abstract

Objectives: We aimed to develop a comprehensive, descriptive framework to measure shared decision making (SDM) between parents and clinicians during clinical encounters for children undergoing evaluation for pediatric tonsillectomy.

Methods: We combined a top-down (theoretical) approach with a bottom-up approach based on audio-recorded dialogue to identify all communication processes related to parental decision-making about pediatric tonsillectomy for their child. Pediatric tonsillectomy was used as the demonstrative elective surgical procedure. We coded 55 pediatric consultations using the framework and report interrater reliability.

Results: We identified 14 clinician behaviors and 5 patient behaviors that have not been previously described, and developed a new SDM framework that is descriptive (what does happen) rather than normative (what should happen). Through the bottom-up approach we identified three broad domains not present in other SDM frameworks: socioemotional support, understandability of clinician dialogue, and recommendation-giving. We also specify the ways in which decision-making roles are assumed implicitly rather than discussed explicitly. Interrater reliability was >75% for 92% of the coded behaviors.

Conclusion/ Practice Implications: This SDM framework allows for a more expansive understanding and analysis of how parental decision-making about surgery for their child takes place during clinical encounters. The framework is descriptive, not normative, and includes domains and behaviors not present in existing measures. Ideally this framework will bring attention to a broader conception of SDM across clinical scenarios and allow researchers to further explore these newly identified domains and behaviors.

Keywords

tonsillectomy; shared decision-making; pediatrics; SDM framework; conversation analysis

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1. Introduction

Shared decision making (SDM) between clinicians and patients is thought to be an ideal component of medical encounters, particularly in contexts in which there is clinical equipoise or uncertainty regarding the benefits and risks of options. These situations are often preference-sensitive: patients may weigh the risks and benefits of a treatment option differently based on their individual goals and values²⁻⁴. Models of SDM have been described^{5,6}, and tools have been developed to measure SDM in medical dialogues.⁷⁻⁹ While they use different language and categorize competencies differently, nearly all frameworks encompass the same core components of SDM: discussion of the patient's role in decision-making, description of the problem requiring a decision, available options, risks, benefits and uncertainties, assessment of patient understanding and of patient preference, and making a decision or follow-up.

Almost all studies that have measured SDM in clinician-patient encounters, both in adult and pediatric settings¹⁰⁻¹⁵, have found that clinicians rarely fulfill all of the criteria set forth by the frameworks. This may result from the fact that commonly-used SDM frameworks were developed in a 'top-down' manner - using a theoretical framework for what ought to happen - rather than in a 'bottom-up' manner based on observation of real-life patient-clinician dialogue. As a consequence, there are required elements in these frameworks that are rarely, if ever, performed in practice. For example, most measurement frameworks ask clinicians to discuss with patients their preferred level of involvement, check a patient's preferred information-delivery format, and explicitly state that there is more than one option. In reality, the clinician often does not spend time asking the patient (who may not know) the first two questions, and the task of informing the patient that there is more than one option may not be explicit (instead the patient will intuit from the clinician's listing of options that there is more than one option).

Furthermore, SDM during pediatric consultations for elective surgery, where the parent usually is the decision-maker for the child, may pose particular challenges for parents given perceived risks of surgery and anesthesia, and the possible equipoise of a non-invasive treatment alternative^{16,17}. To our knowledge, no existing framework accounts for parental decision-making specifically. Because existing SDM measurement frameworks are theoretically derived, they might miss other important elements of the dialogue that have not been considered.

Entwistle and colleagues have argued for a broader conception of SDM than what is presented by existing SDM frameworks. This conception reconceives the doctor-patient relationship as one more akin to a friendship – one in which the doctor's role is not just to provide factual information in a detached way, but to emotionally support the patient in her decision¹⁸⁻²⁰. Our framework aims to draw attention to the aspects of the dialogue that may contribute positively or negatively to the patient's perception of emotional support. We believe that this plays an important role in a patient's ability to engage in the decision-making process.

In an effort to measure and identify how to quantify and ultimately improve SDM, we underwent a rigorous process of developing a new measurement framework using both a top-down (theoretical) and bottom-up (based on what we find in the dialogue) approach for parents making surgical decisions for their children. In doing so, we also propose some clarification to the common problems in measuring SDM more generally and expand the range of communication behaviors related to SDM based on our observations of dialogue. Finally, we operationalize the measurement framework and include some preliminary reliability data. Although parental decisions about elective tonsillectomy in children is the index scenario studied, our intention is for this framework to be relevant for adaptation across a broad range of clinical encounters.

2. Methods

2.1 Study Subjects and Setting

The data used in development of this code were collected as part of a parent study evaluating communication, decision-making, and parent-reported outcomes for pediatric sleep disordered breathing (K08HS022932, PI Boss). Sleep-disordered breathing represents a spectrum of breathing patterns at night ranging from primary snoring to obstructive sleep apnea that may result in impaired behavior or neurocognitive function. Surgical removal of the adenoids and tonsils is the most common treatment for pediatric sleep-disordered breathing and, with more than 600,000 cases annually, is also the most common major surgery performed in children²¹. Despite the effectiveness of surgery at reducing symptoms of SDB and improving or eliminating sleep apnea, there is evidence that symptoms may resolve in up to half of children over time without surgery²². Moreover, there is documented regional variation in tonsillectomy utilization, with concern for overuse in some children and underuse in some populations²³. These findings imply that shared decision-making may improve the quality of decisions and reduce unexplained surgical variation^{24,25}. Therefore, this particular clinical setting is apt for the development of an SDM measurement framework because the decisions made here are uniform, elective, and typically take place in a single visit so that we could capture most of what was discussed in that encounter. Moreover, while baseline disease severity and comorbid symptoms would theoretically impact complexity of decision-making for tonsillectomy, prior research has shown that decision conflict remains high regardless even for simple elective surgical procedures¹⁶.

Participants were recruited from three otolaryngology clinic sites in Maryland, USA. Eligible clinicians were surgeons or surgical nurse practitioners who treated children at one of the sites. Patients and their caregivers were eligible if the child was referred for evaluation of sleep-disordered breathing, and the parent/caregiver was English-speaking. Visits between clinicians and families were audio-recorded and transcribed by a professional service. Written informed consent was obtained from all clinicians and caregivers. The study received IRB approval from Johns Hopkins.

2.2 Development of Measurement Framework

2.2.1. Top-Down Approach—Our study team compared three widely-used SDM coding systems (OPTION12, MAPPIN'SDM, and Braddock et al.)^{7,9,26} with each other,

and with conceptual SDM models developed by Makoul et al.⁶, Elwyn et al.⁵, and the SHARE model from the Agency for Healthcare Research and Quality [16], in order to explore similarities and nuanced differences between the existing models. We included in our final framework all clinician communication behaviors that were mentioned in any of the three SDM coding systems, regardless of how often we expected them to occur or whether we considered that they were required in some way (morally or otherwise) of clinicians.

The OPTION and Braddock coding systems include only elements of clinician talk while the MAPPIN'SDM system includes elements of both clinician and patient talk (it requires that *both* the patient and the physician should complete each of the 15 elements in the MAPPIN'SDM coding system). However, our team concurred that this created a false or unrealistic equivalence between the roles of the clinician and the parent (e.g. coding not just for the clinician checking the parents' understanding, but also the parent checking the clinician's understanding or coding not just for the physician's listing of the available treatment options but also the parents' listing of the available treatment options). Therefore, we did not include all MAPPIN-SDM parent behaviors but instead narrowed our focus to the parents' involvement in terms that our study team deemed made the most sense for their role in the process (2 of parent behaviors in MAPPIN'SDM were included in our framework: parent describes his/her fears related to the options and the parent asks clarifying questions).

2.2.2. Bottom-up Approach—Three members of the study team (WC, EB, MCB) independently read three transcripts, made notations about the dialogue that exhibited importance in decision making, and met to discuss their observations. We compiled detailed notes about the dialogue in relation to all potential domains identified by the top-down approach, and of any additional aspects of the dialogue that were broadly relevant to the decision making process. One member of the research team (WC) subsequently reviewed 10 additional dialogues, made detailed notes about all aspects of decision-making, and then met with the rest of the team to discuss her observations.

Through this process, we identified 10 specific communication behaviors relevant to the emotional environment of the encounter (8 clinician and 2 parent). We also included one additional clinician behavior (any clinician rapport-building talk directly to child) within this domain because of its high importance to parents discovered in our earlier work²⁸. We also identified 3 clinician behaviors related to the domain of understandability, 2 behaviors (one each for parent and clinician) related to recommendation talk, and 2 behaviors (one each for parent and clinician) related to disagreement talk. Finally, we identified one additional behavior each for parent and clinician that were related to how previously described clinician behaviors occurred in the natural setting.

2.2.3 Coding Response Options—For each specific clinician or parent communication behavior, our team agreed as to whether it was fully captured by coding it as present or absent (dichotomous) or whether additional important information could be gained by coding how many times it occurred. Our team agreed that dichotomous coding was appropriate for most behaviors, but did allow for numerical coding of some behaviors. We then developed a form in RedCAP for data entry²⁹.

2.3 Key Distinctions/ Decisions

2.3.1 Normative vs. Descriptive—Early in the course of development, we identified as a key tenet in our discussions the issues of what *does* (descriptive) vs. what *should* (normative) happen. We found that when our focus shifted to the normative frame of reference, it inevitably led to deletion of codes, bias about the clinician, and narrowing of the scope of our understanding of SDM. We found that while what *does* happen sometimes corresponds within the theoretically-derived normative frameworks, in many cases it does not. Thus, focusing only on the normative leaves out a broad swath of the observed decision-making process.

2.3.2 Shared Decision-Making vs. The Appearance of Shared Decision-Making—Another distinction discussed by our team is whether we were measuring shared decision-making *itself*, or the *appearance* of shared decision-making. It remains possible that a patient (or parent) could truly feel as though they are participating in a decision without an observer being able to detect behaviors related to SDM. Any observation-based coding system is inherently limited: the behaviors we code are external markers of SDM as exhibited by clinicians or parents.

2.4 Reliability of the Measurement Framework as a Coding System

Upon finalization of the measurement framework, 2 coders (WC and CW) began coding sets of 2 dialogues, with the entire research team meeting to review the dialogue and how it was coded, and discuss any further specifications to the categories. As each set of two dialogues were coded and discussed, we calculated overall reliability as the percent of codes agreed upon by the two coders. When overall interrater reliability consistently reached >80% (after three sets of two dialogues), the coders transitioned to coding independently, starting over with the dialogue, and double-coding a 25% random sample. CW and WC coded 5 dialogues per week and met to discuss the one double-coded transcript. Any disagreements were mutually agreed upon. When consensus was not reached between WC and CW, questions were brought to the rest of the study team for discussion and group consensus.

2.5 Statistical Analysis

After all 55 dialogues were coded, we calculated the interrater reliability for the 14 double-coded visits with percent coder agreement (for the dichotomous codes) and with Pearson's correlation (for the continuous codes). In the results below, we present the reliability data for the 14 double-coded transcripts along with the code frequencies for the 55 transcripts in order to give context to the reliability data.

3. Results

3.1 Participants

There were 8 participating clinicians (5 otolaryngologist surgeons, 2 surgical fellows, 1 nurse practitioner), 5 of whom were male. Mean clinician age was 35.5 years (SD 7.7). Clinicians had variable levels of experience (3 had <5 years in practice, 2 had 5–10 years, 2 had 10–20 years, 1 had >20 years).

Of the 103 patient-families with whom we discussed the study, 55 (53%) agreed to participate. All encounters were recorded during the child's initial consultation with the otolaryngology surgeon. Of the 55 children, 30 were male (55%). The mean child age was 5.9 years (SD = 2.6) and the mean parent age was 33.2 (SD=6.2). The majority of parents attending the child's consultation were mothers (n = 48, 87%). Twenty-six (47%) children had undergone testing for obstructive sleep apnea with polysomnography prior to the surgical consultation. Of these, obstructive sleep apnea was present in 21 (81%), with disease severity based on respiratory disturbance index (mild apnea=1–5, moderate apnea=6–10, severe apnea > 10). Eight children (15%) belonged to a clinically more high-risk population, such as very young age (< 3 years; n = 4) or obese weight (n = 4).

3.2 Organizational Schema for Shared Decision Making

Table 1 shows the organization of our coding system divided by those behaviors derived from the top-down method (theoretical) and those derived from the bottom-up method described above. The table is organized into 4 goals of shared decision making as we have come to understand them through this process. Three of these align closely with Elwyn's Model for Clinical Practice: our 'Clinical Information Exchange' aligns with 'Choice Talk,' our 'Decision/Role Talk' aligns with 'Option Talk,' and our 'Opinion/Preference Talk' aligns with 'Decision Talk'.⁵ One of our specific goals – the 'Emotional Environment Supportive of Collaboration' of the encounter – is new. Tables 2–5 correspond to each of the 4 goals, list our final set of codes, and illustrate examples of each.

3.3 Identification of New Behaviors and Domains

Our bottom-up approach led to the inclusion of three umbrella domains that had previously not been emphasized in coding systems: the understandability of what the clinician explains to the patient, talk related to giving recommendations, and the emotional environment of the visit (that supports collaboration).

3.3.1 Understandability of Clinician Communication—We noticed that while some clinicians would fulfill many of the elements of SDM found in previously developed frameworks (such as explaining the risks and benefits of different treatment options), they at times would use a large amount of jargon, statistics, or give information in long monologues without stopping to check for understanding. As shared decision making would require that the parent understand the information being provided in order to be a part of the process, we included the use of jargon, statistics, and the presence of monologues (defined as > 150 words) as a rough means of describing the understandability of clinician dialogue. This domain (with the 3 specific codes) fell under the goal of clinical information exchange (Table 2). We also discovered, related to the effective acquisition of clinical knowledge, that clinicians sometimes encouraged (to varying degrees) patients/families to ask questions, and that parents sometimes demonstrated their understanding in the comments that they made.

3.3.2 Recommendation Types—Clinicians gave one or more recommendations in all but one of the visits. While recommendation-giving is not part of any previously developed frameworks, we consensed through this analysis that it played a large role in the decision making process and included four types of recommendations as part of our framework:

direct, soft, neutral, and relating to patient/family values. These recommendation codes fell into the umbrella goal of having the parent and clinician exchange opinions, and examples of each are shown in Table 4. We also noted that parents sometimes asked for a recommendation, and that parents and clinicians sometimes disagreed on a plan of action.

3.3.3 Socio-Emotional Talk—We included codes aimed to describe the emotional environment of the conversation within the goal of creating an environment supportive of collaboration. The most frequent socioemotional expression regarded offering ongoing support to parents. Clinicians also occasionally praised parents for their actions, and included children in the conversation. Notably, no clinician directly assessed parents' concerns or fears regarding surgery. Although socioemotional talk did not occur as consistently as discussion of treatment options or recommendations, we found it important to evaluate based on previous research of the importance of trust and interpersonal communication between parents and clinicians.²⁸

3.4 Clarification of Existing Domains

3.4.1 Extent of Options Talk—Within discussions of available options, our study team has noticed in previous studies^{15,30} that it is not always clear that all options are discussed, and that this involves some clinical judgement about what the range of possible options are. If a clinician gives 2 options but in fact there are 3, does that 'count' as giving options? To our knowledge, existing coding systems do not make this distinction. Because we were working in a discrete clinical area in which all of the possible treatment options are known (although may be more or less reasonable depending on the patient's presentation), we decided to list all of the available options as well as the specific risks and benefits of each option. This provided the opportunity to code for inclusion of each individual option.

3.4.2 Active vs. Passive Clinician Talk—Through our bottom-up approach we identified the need for a distinction between perfunctory or rhetorical statements made by the clinician and more intentional attempts to involve the patient. Thus, we distinguished between passive and active accomplishment of 'clinician checks for patient understanding' and 'clinician checks for patient preference'. For example, passive checks were rhetorical or closed-ended questions such as "Okay?" while active open-ended questions required more than a one-word patient response: e.g. "What do you think?" Notably, we found no examples of a clinician actively checking for parent understanding. However, an example of this would be using teach-back: "just so I make sure that I explained that clearly, could you tell me what you understood?". Similarly, we divided 'clinician checks for questions' to include two subtypes: open-ended ("what questions do you have?" and closed-ended ("do you have any questions?").

3.5 Preliminary Data: Communication Behavior Frequency and Reliability

The frequencies of the specific communication behaviors across 55 visits and reliabilities across the double-coded 14 visits are shown in Tables 2–5. The interrater reliability was 89% overall across all categories, with consistent improvement from the first week (79%) to the final week (94%). Percent coder agreement for binary codes (present/absent) ranged from a low of 50% to a high of 100%. Reliability assessed by Pearson's correlation for numerical

codes ranged from a low of 0.53 to a high of 1, with one outlier of -0.08 . This outlier occurred because while “clinician reassures/dismisses” is a numerical variable, the sample we double coded had by chance only 0s and 1s and the Pearson correlation does not provide accurate information for binary variables. Indeed, the percent reliability for this category was 86%.

While the majority of codes had high interrater reliability, the following codes had low reliability. In all cases we became more reliable with time and by adding additional clarifications to our codebook.

Uncertainties: Clinical uncertainties (e.g., clinician’s lack of certainty of the best treatment option) were coded. Initially one coder was counting uncertainties related to the clinical issue as well as the available options while the second coder was counting only the latter. We changed our code to reflect that of the second coder.

Jargon: As one coder was medical and the other non-medical, there were discrepancies in what the two coders considered to be medical jargon. Overtime, we created a dictionary of terms that we agreed on which improved reliability.

Monologues: Initially there were discrepancies in how monologues were counted if they were “broken up” only by back channeling (e.g. “mhm”). We agreed to count monologues broken up only by back-channeling as a single monologue.

Family asks questions: There were initially discrepancies in what the two coders considered to be “substantive” questions. Reliability improved with additional clarification of the criteria; we did not count any logistical questions (e.g., scheduling, parking, clinic location).

Offers ongoing support: One coder counted all mentions of making a follow-up appointment or giving a phone number whereas the other coder counted only more substantive offers of support. We decided to err on the side of leniency and include follow-up appointments and phone numbers to count as ongoing support.

Passive assessment of family preference: Because “okay?” was a common way of passively assessing both family preference and understanding, coders sometimes missed the “okay?” or instead counted it as passive assessment of understanding.

Family offers opinion unprompted: The coders sometimes disagreed on what counted as parent opinion (one coder counted preferences about logistics while the other did not). We decided to only count opinions specifically regarding the treatment options.

Soft recommendation: There were discrepancies between the two coders regarding what was “direct” vs. “soft”. Examples of such discrepancies include: “The standard of treatment is surgery” and “I would probably recommend surgery”. It was agreed upon that general statements like the first example and statements that were qualified with words like “probably” in the second example would be coded as soft recommendations.

4. Discussion and Conclusion

4.1 Discussion

This SDM framework was developed in order to allow for a more comprehensive and expansive understanding and analysis of how decisions are shared in clinical practice, particularly for parents making decisions about elective surgery for their children. We combined a top-down approach in which we compared widely used SDM coding frameworks with a bottom-up approach in which we identified additional elements of dialogue that were relevant to the decision making process. Our intention, with the bottom-up approach, was to identify the elements related to decision-making that occur in real-world settings so that they could be further measured and considered by the communication research and medical communities. We included in our framework all clinician communication behaviors in the three existing coding systems, regardless of how often we expected them to occur or whether we reasoned that they were required of clinicians. In addition, we clarified the ways in which previously-identified domains are operationalized in encounters and identified three domains that are not incorporated in previously-developed SDM frameworks: socioemotional factors, the understandability of explanations, and recommendation-giving.

Through inclusion of these additional domains, we hope to surpass a type of thinking where SDM is either present or absent, or even SDM as present to some degrees as evidenced by specific occurrences in the dialogue. Rather we are hoping to elucidate the process of how clinicians and patients might go about making decisions together, and expand the types of communication behaviors that might be related to these partnerships. For example, understandable dialogue and emotional support are categories of communication behaviors that we would always view as helpful, but might be more or less ‘necessary’ for decision-making depending on the clinical situation. Likewise, recommendations might be viewed as either helpful or harmful, depending on the individual parent, child, or clinical background.

In order for the patient or family to be fully incorporated into the decision making process, it is also necessary for the information given to be presented in a comprehensible manner. We found that on the whole providers use language that is likely far more complex than the average patient can comprehend. Moreover, clinicians rarely (if ever) actively assess patient understanding (e.g. through teach-back), meaning that the clinician herself has a poor understanding of how much the patient comprehends. Thus, while we were not always able to discern from the dialogue how much the patient understood, we included a number of elements in this framework that aim to provide at least an overall picture of information complexity. We are conducting a concurrent analysis on clinician language and understandability as it relates to parent knowledge and satisfaction.

One might wonder why recommendation-giving has not been incorporated into previous SDM frameworks. As discussed by Entwistle and colleagues, many SDM frameworks have first and foremost an anti-paternalistic agenda^{18–20} and it is possible that clinician recommendation-giving was considered too paternalistic. However, a broader conception of SDM requires us to allow for collaboration that permits clinicians to express their opinions and preferences without deeming this inappropriately paternalistic. In our view,

recommendations should possibly be considered negatively only in situations of complete clinical equipoise and those that are extremely value-laden. Even in those situations, we might not consider a recommendation negatively if the patient asks for it, or would prefer to defer to the clinician or simply understand his/her true clinical advice.

As this is a descriptive framework, it does not create an overall ‘score’ upon which to base judgments. This is a strength of the framework, as well as a limitation. This coding framework could be more nimble, such that it allows the normative judgments to occur after the coding is done, and be finely-adapted to each situation. In some scenarios, such as when there is clinical equipoise or when the decisions relate highly to personal values, there might be uniform agreement that recommendations, if given, should reflect neutrality or equipoise. In those situations, the presence of a strong direct recommendation might count negatively towards the goal of SDM. In other situations or under other circumstances, we might endorse a recommendation as the morally ‘right’ thing to do; in those circumstances, we do not want to be constrained by a coding system that counts it ‘against’ the clinician. In addition, future research can attempt to correlate elements of this framework with patient outcomes, which would allow for an understanding of which elements are beneficial to patients. This could create an evidence-base for the normative judgements we make about what should and should not occur in SDM.

While this framework was developed in the setting of pediatric surgical care, we believe that it could be applicable to many settings, both surgical and non-surgical, adult and child, with modifications as necessary for that setting. The specific options and risks/benefits, as well as the jargon encountered would be different in different settings. In addition, for use in adults, the “child talk” code would be removed and all codes would be in reference to the patient herself rather than the parent. However, the remaining elements of the code remain applicable. A future analysis is underway to support the validity of this additional bottom up approach, relating the presence of communication behaviors and domains with both clinical and patient-centered outcomes.

Of course our framework has limitations, some of which (its development within a particular context and its descriptive rather than normative nature) have already been mentioned. It is possible measuring decision-making in a consultation where the parent is making the decision on behalf of the child may limit generalizability of the framework. We view this effort as part of a series of steps towards a more complete understanding of how decisions are shared between patients and clinicians. We have tried to come closer to measuring relevant details related to decision-making, but realize that some of our important constructs (such as our attempt to measure understandability through only three codes, or the particular selection of items measuring emotional support) may fall short of achieving its goal. Furthermore, studies which evaluate whether addition of the bottom up approach is superior to a top down only approach, as it relates to outcomes, are still needed. Despite these limitations, we believe that recognition of these elements adds substantively to coding efforts.

4.2 Conclusion

In this paper we presented a comprehensive, descriptive framework to measure SDM in elective pediatric surgical care. With our approach, we identified new communication behaviors and domains not present in previously-developed SDM frameworks. The addition of these domains allows for a more comprehensive and expansive understanding and analysis of the decision making process. We hope that this framework will bring attention to a broader conception of SDM and allow researchers to further explore the communication behaviors that occur between clinicians and patients.

4.3 Practice Implications

From a research perspective, we believe that this SDM coding system provides a more holistic view of the elements involved in the decision making process. We hope that this allows researchers to explore the additional elements we identified such as recommendation giving and socioemotional dialogue. From a clinical perspective, we hope that an increased focus on these new elements by the research community will facilitate awareness among clinicians of their communication during decision-making, including how they express their opinion or make recommendations to parents/patients.

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“It can scarcely be denied that the supreme goal of all theory is to make the irreducible basic elements as simple and as few as possible without having to surrender the adequate representation of a single datum of experience”¹.

Table 1:
Organizational Schema for Dialectical Evidence of SDM with Top-Down and Bottom-Up Contributions

GOAL	Top-Down Behaviors	Bottom-Up Behaviors
Goal: Patient/family acquires relevant clinical information (Clinical Information Exchange)	<ul style="list-style-type: none"> • Clinician defines clinical issue • Clinician lists options • Clinician reviews benefits and risks associated with each option • Clinician acknowledges uncertainties • Clinician explicitly states that 'no action' is a choice • Clinician checks for patient/family understanding • Patient/family asks substantive questions 	<ul style="list-style-type: none"> • Clinician explains information in manner that patient/family can understand • Clinician allows/encourages patient to ask questions • Patient/family offers evidence of understanding
Goal: Patient/family understands that a decision is required and that they have the choice to have a role in decision making (Decision/Role Talk)	<ul style="list-style-type: none"> • Clinician explicitly articulates need for decision • Clinician explicitly states that there is >1 option • Clinician asks patient what they already know before providing options • Clinician checks with patient to see if they are ready to hear options • Clinician explicitly provides option to defer • Clinician explicitly states that patient/family has a role in decision making • Clinician emphasizes the importance of respecting patient preferences • Clinician explicitly assess patient/family's desired decision making role 	<ul style="list-style-type: none"> • Clinician implies that patient/family has role in decision making (refers to patient decision or deliberation)
Goal: Clinician and patient exchange opinions (Opinion/Preference Talk)	<ul style="list-style-type: none"> • Clinician assesses patient/ family opinion or preference • Clinician assesses patient/family values related to decision • Clinician declines to give recommendation • Patient/family offers their own opinion or preference 	<ul style="list-style-type: none"> • Patient/family asks for recommendation • Clinician gives recommendation • Patient/family disagrees with the doctor recommendation • Clinician disagrees with the patient/family choice

GOAL	Top-Down Behaviors	Bottom-Up Behaviors
Goal: Patient/family collaboration is supported by a holistic and respectful interpersonal environment (Emotional Environment)		<ul style="list-style-type: none">• Clinician assesses patient/family concerns/fears• Clinician talks to child• Clinician praises parent• Clinician offers ongoing support• Clinician acknowledges visit-specific issues (e.g. wait time, office staff, EMR)• Clinician is judgmental or admonishing to patient/family• Clinician dismisses patient/family concern• Parent expresses concerns/fears (empathic opportunity)• Parent expresses guilt or responsibility (empathic opportunity)• Clinician misses empathic opportunity• Clinician expresses empathy

Table 2:

Patient-Family Acquisition of Relevant Clinical Knowledge

Coded Behaviors	Examples	Response Options	Frequency n (%) ⁺	Reliability [^]
Clinician defines clinical issue	All right. She does have mild sleep apnea on her sleep study; not terrible. She has really big tonsils.	Present or absent	55 (100%)	100%
Clinician lists options	So, you can watch him, continue the medicine, or you can do surgery. We can also repeat the sleep study, because it was done a year ago, but I don't know if it's going to be different.	Present or absent		
	<i>Surgery</i>		53 (96)	93%
	<i>Watchful waiting</i>		29 (54)	93%
	<i>Medication</i>		31 (57)	100%
	<i>Sleep study</i>		29 (53)	100%
	<i>Pulmonologist</i>		3 (5)	100%
	<i>Other</i>		20 (36)	100%
Clinician reviews benefits associated with each option	<ul style="list-style-type: none"> - <i>Benefit of surgery</i>: Taking out her tonsils and adenoids will help with the breathing problems at nighttime. - <i>Benefit of sleep study</i>: The sleep study not only tells us if it's very severe, it also predicts the likelihood of curing somebody by taking the tonsils out. 	Present or absent		
	<i>Surgery</i>			
	Less snoring/sleep disruption		17 (31)	100%
	Improved learning/ behavior		5 (9)	93%
	Decreased bedwetting		1 (2)	100%
	Fewer strep infections/antibiotics		8 (15)	86%
	<i>Watchful waiting</i>		6 (11)	100%
	<i>Other</i>		25 (45)	86%
Clinician reviews risks associated with each option	<ul style="list-style-type: none"> - <i>Risks of surgery</i>: It's a 2 week recovery. She'll have a really sore throat.... You have to watch her carefully for any bleeding. That can happen in 2-5% of kids and you have to bring her back to the hospital if that happens. - <i>Risks of waiting</i>: We don't want to ignore his breathing issues. Long term, breathing issues probably could be a strain on the heart and lungs. Short term, memory and learning issues and things like that because they don't sleep very well. 	Present or absent		
	<i>Surgery</i>			
	Bleeding		35 (65)	100%
	Anesthesia		13 (24)	79%
	Pain		35 (64)	100%

Coded Behaviors	Examples	Response Options	Frequency n (%) ⁺	Reliability [^]
	Dehydration		9 (17)	93%
	Recovery time		36 (65)	79%
	Surgery duration		23 (42)	93%
	Nasal voice/ VPI		4 (7)	100%
	Injury to teeth/mouth		9 (16)	86%
	Persistent sleep apnea		10 (18)	100%
	Tonsil regrowth		9 (16)	100%
	Weight gain		3 (5)	100%
	Immediate respiratory problems		15 (27)	79%
	Bad breath		2 (4)	100%
	<i>Watchful waiting</i>			
	Effect of SDB on heart/lungs		14 (25)	100%
	Worsening SDB		1 (2)	100%
	Adverse impact on learning/behavior		17 (31)	93%
	<i>Other</i>		10 (18)	86%
Clinician acknowledges uncertainties with any option	He's not overweight, but he's got asthma so that would put him at a little higher risk of his symptoms not 100% resolving with surgery	Present or absent	30 (55)	50%
Clinician explicitly states that 'no action' is an option	That being said, if he's doing great, no behavior concerns, doesn't seem too tired during the day, potty trained well, I think it's a really good option to do nothing	Present or absent	24 (44)	93%
Patient/family offers evidence of understanding	So you're thinking that if she gets the Flonase it could break it up where she'd be able to breathe and it might stop the snoring?	Present or absent	16 (29)	79%
			Mean (SD)	Reliability[*]
Clinician jargon/ complex language	E.g. sleep apnea, adenoids, pulmonary, bronchoscopy, malignant hyperthermia, von Willebrand's disease, etc.	Number of occurrences	3.7 (3)	0.80 (p=0.006)
Clinician monologues	Any non-interrupted clinician speech of >150 words	Number of occurrences	2 (2)	0.37 (p=0.200)
Clinician use of statistics	- In otherwise healthy kids, about 85 to 90% will have improvement with surgery - There's a 2-5% risk of bleeding for 2 weeks after surgery	Number of occurrences	0.9 (1)	0.97 (p<0.001)
Clinician checks for understanding				
<i>Passive</i>	- Okay? - You know what I mean?	Number of occurrences	12 (22)	0.29 (p=0.309)
<i>Active</i>	(no examples)	Number of occurrences	0	

Coded Behaviors	Examples	Response Options	Frequency n (%) ⁺	Reliability [^]
Clinician encourages parent/ family questions				
<i>Closed</i>	Do you have any questions?	Number of occurrences	1 (1)	0.78 (p=0.001)
<i>Open</i>	What questions do you have?	Number of occurrences	0.31 (0)	1.00 (p<0.001)
Patient/family asks substantive questions	- Is that why tonsils are there? - And the surgery is dangerous? - Are the tonsils the things in the middle or the things on the sides?	Number of questions	1.9 (3)	0.93 (p<0.001)

[^] reliability assessed with percent coder agreement;
^{*} reliability assessed by Pearson's correlation coefficient

Table 3.

Patient Understanding of Decision and Their Role

Coded Behaviors	Examples	Response Options	Frequency n (%) ⁺	Reliability [^]
Clinician explicitly articulates need for decision	So we have to do something about this.	Present or Absent	1 (2)	100%
Clinician explicitly states that there is >1 option	- Now, there's several approaches we can take with this. - There's a few options here and we can talk them over.	Present or Absent	19 (35)	93%
Clinician explicitly provides option to defer	You don't have to make any decisions right now. Go home and think about it.	Present or Absent	12 (22)	100%
Clinician explicitly states that patient/family has a role in decision making	- Most importantly, I want you to be prepared and feel like you're making a very informed decision.	Present or Absent	9 (16)	100%
Clinician explicitly assess patient/family's desired decision making role	(no examples)	Present or Absent	0	100%
Clinician implies that patient/family has role in decision making (refers to patient decision or deliberation)	- When it's in the grey area a lot of it goes to how you feel. - If you're not sure what to do, and want to check in on another sleep study, that's fine, too. - Make sure mom is on the same page and make sure she doesn't have any questions, but I think that's fine to do. If you change your mind, we can always do surgery, but I think I would probably just watch him.	Present or Absent	21 (38)	86%
Clinician asks patient what they already know before providing options	(no examples)	Present or Absent	0	100%
Clinicians asks if patient/family is ready to hear options	(no examples)	Present or Absent	0	100%
Clinician emphasizes importance of respecting patient/family preferences	(no examples)	Present or Absent	0	100%

Table 4.

Descriptive Characteristics Related to Opinion/Preference Talk

Coded Behaviors	Examples	Response Options	Frequency n (%) ^a	Reliability ^b
Clinician assesses patient/family values related to decision	So can I ask you a question that's going to sound funny, is that if his sleep study was normal, would you believe it?	Present or absent	1 (2)	93%
Clinician assesses patient/family opinion/preference				
<i>Passive</i>	<i>After suggesting plan:</i> Okay? Does that sound good?	Present or absent	23 (42)	71%
<i>Active</i>	What do you think?	Present or absent	9 (15)	86%
Patient/family offers opinion/preference				
<i>Prompted</i>	D: So I think that most people decide that they want the tonsils and adenoids out. P: Yeah, that's kind of we were leaning towards.	Present or absent	6 (11)	93%
<i>Unprompted</i>	<i>Patient explaining reason for appointment.</i> I finally said to his pediatrician, like, "Can we, you know, talk about getting his tonsils out?"	Present or absent	22 (40)	64%
Parent provides reasoning for preference	[Watching] is great. We were just concerned about somebody else noticing the snoring, but you know honestly it didn't bother me before so it's not going to bother me from now on. He doesn't have the apnea and there is a high possibility that he's going to outgrow it so that's all that I care about.	Present or absent	11 (20)	86%
Patient/family asks for recommendation	I don't know what to do. Would you recommend doing the surgery? Would you recommend waiting?	Present or absent	5 (9)	93%
Clinician declines to give recommendation if asked	(no examples)	Present or absent	0	100%
Clinician gives recommendation				
<i>Direct</i>	- I want you to see the pulmonologist - He needs surgery	Present or absent	40 (73)	93%
<i>Soft</i>	- I think it would be reasonable to do surgery - It doesn't hurt to wait - I think we probably should do a sleep study - The standard of treatment is surgery	Present or absent	41 (75)	57%
<i>Neutral (equipoise)</i>	- There isn't a correct answer – there are pros and cons to both waiting and doing surgery - So, I think he would do fine with either....	Present or absent	11 (20)	100%
<i>Related to patient/family values</i>	<i>After parent mentioned problems in school as a big concern multiple times</i> D: Let's start with the Flonase. But if she's still having difficulty at school paying attention, then you can call and reschedule	Present or absent	2 (3.64)	93%
Patient/family disagrees with the doctor recommendation	D: Surgery is the standard of treatment... you don't want to allow his breathing to continue that way. P: Can we watch?	Present or absent	1 (2)	100%

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100%	(2)	Present or absent	<i>After parent expresses preference for no surgery (waiting), doctor does not explicitly disagree, but it is clear that he does not think this is a good option.</i> D: He breathes pretty bad when he's awake so I'm sure he breathes pretty terribly while he's asleep. You hear the noise that he makes while he breathes? I'm not sure if medicine is going to work but it's fine to try	Doctor disagrees with the patient/family choice
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Table 5.

Emotional Environment Supportive of Collaboration

Coded Behaviors	Examples	Response Options	Frequency n (%) ⁺	Reliability [^]
Clinician assesses family concerns/fears	(no examples)	Present or Absent	0	100%
Clinician praises parent	It sounds like you're doing all the right stuff.	Present or Absent	5 (9)	100%
Clinician offers ongoing support	If anything else comes up, make sure you let us know, give us a call.	Present or Absent	35 (66)	71%
Clinician is judgmental toward patient/family	Why didn't you come back when we told you to?	Present or Absent	3 (5)	100%
Parent expresses concerns/fears (empathic opportunity)	- I think we get worried when they get so large that they touch, because we're worried about her breathing. - I'm a little concerned with having his tonsils removed. He's only four. And, um, having him put under and so forth.	Present or Absent	20 (36)	79%
Parent expresses guilt or responsibility (empathic opportunity)	I had taken him for his well visit, this has been going on for a while. I was having insurance issues.	Present or Absent	3 (5)	93%
			Mean (SD)	Reliability[*]
Clinician acknowledges visit-specific issues (e.g. wait, office staff, EMR)	- Sorry for all the typing - Is it okay if I talk and type with you guys at the same time? - I apologize for the delay again.	Number of occurrences	.29 (1)	0.69 (p=0.006)
Clinician reassures/ dismisses patient/family concern	P: I hear surgery is very dangerous... My pediatrician was trying to tell me, that it's extremely dangerous for his age, is that true or? D: Um, no. It's not dangerous	Number of occurrences	0.53 (1)	-0.08 (0.794)
Clinician misses empathic opportunity	P: She scares me a lot when she stops breathing. D: How are they treating her asthma? P: Huh?	Number of occurrences	0.38 (1)	0.53 (p=0.051)
Clinician expresses empathy	D: I think he'll do very well with surgery but I understand they're scared about it. That's totally fine.	Number of occurrences	0.29 (1)	1.00 (p<0.001)
Clinician talks to child	- I like your shirt! - What grade are you in?	Number of occurrences	15.5 (11)	0.95 (p<0.001)

[^] reliability assessed with percent coder agreement;^{*} reliability assessed by Pearson's correlation coefficient⁺ frequencies reflect all 55 transcripts