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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) in clinical encounters.

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 decision making. We coded 55 pediatric otolaryngology visits 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 decision making takes place in clinical encounters, including new domains and behaviors not present in existing measures. We hope that this new framework will bring attention to a broader conception of SDM and allow researchers to further explore the new domains and behaviors identified.

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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].

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 values [2–4]. 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 settings [10–15], 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).

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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 decision [18–20]. 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 children [21]. 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 surgery [22]. Moreover, there is documented regional variation in tonsillectomy utilization, with concern for overuse in some children and underuse in some populations [23]. 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 procedures [16].

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 [27], 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 work [28]. 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

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